NATIONAL ANKYLOSING SPONDYLITIS SOCIETY



Report and Accounts For the year ended 31 December 2015

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Chairman's Report



When I took the role of Chair, my aim was to understand as much as I could about the condition, how it effects individuals and their families, what governments are doing to help people with AS and also more generally to raise awareness of the condition at every opportunity I had. This has made my first full calendar year as NASS Chair interesting, educational, exhilarating, challenging and ultimately extremely satisfying.

This year I had the pleasure of celebrating two branches' 25th Anniversaries. NASS Orpington held their spectacular event at the medieval manor house Ightham Mote in Kent, where a special performance of 'The Magpie' followed by a 'Puddings Evening' and speeches. Yes, it was as good as it sounds - nobody even blinked when I helped myself to one of each of the puddings on offer! I also had the pleasure of meeting the physiotherapists that had set up the branch at the outset and were still very much part of it. NASS Portsmouth put on an equally splendid event at the Mary Rose Museum, where guests were given a guided tour of the museum and then treated to fine food and great speeches. Both events highlighted to me the amazing sense of community that surrounds these long lasting branches, both being truly family affairs.

The Capital Challenge and Jurassic Trek also afforded me the opportunity to spend some time with supporters of NASS chatting over a few hours. In the case of the Jurassic Trek this extended over dinner, breakfast, a long walk and then dinner and breakfast - again, highly recommended! The very personal journey that people with AS have taken, first to diagnosis and then to long term management of their condition highlighted to me the numerous challenges that are faced when dealing with AS.



This year I have also started to get involved with various umbrella organisations connected with the treatment of rheumatic conditions. The European League Against Rheumatism (EULAR) held its annual conference in Rome in June. I had the honour of representing both NASS and the Ankylosing Spondylitis International Federation (ASIF) at this event. It became clear to me over the course of the four days that NASS's global reach puts it in a special position. Whilst not being a global charity, its influence is worldwide. Through this I have now also become involved in EULAR's own patient group, People with Arthritis and Rheumatism (PARE). As part of this role, in October I joined representatives from patient organisations relating to other rheumatic conditions in Amsterdam to discuss mutual challenges and ways in which we, as patients, can help each other.



In November, I was invited to sit on a panel at the International Society For Pharmacoeconomics and Outcomes Research annual conference in Milan to discuss social media. I thank all those out there who contributed to my last minute research before the conference when I asked (on social media) for people with AS to give me five words or phrases that come to mind when you think about your AS. Over 400 of you contributed in less than 20 hours!

Some of you may know Gerry Dance, our morph suit wearing, ultra-running mascot! This year he was invited back to Cyprus to have a second attempt at the Two Castles Lionheart 80km Ultra. He dropped

into the conversation with the race organisers that he was not the only person involved with NASS who has AS and likes to run long distances. So in May, I found myself lined up at his side ready to tackle the Lionheart Ultra myself. That day we both finished, raising valuable funds for NASS whilst "painting the hills of Cyprus orange" with so many runners opting to wear NASS's colours to show their solidarity for those of us with the condition. We made many new friends that weekend all of whom were keen to understand AS better.



Members' Day in York was fabulous! Being further north meant that we had a number of people who couldn't make it down to our London Members' Day in 2014. The absolute highlight for me (and I hasten to add for many others) was Bollywood dancing.

In September, it was with great pleasure that I chaired our first Scottish Patient Conference in Edinburgh and later in the day addressed some Members of the Scottish Parliament. Then in October, I chaired both our first Northern Ireland Patient Conference and a specialist course for physiotherapists organised alongside AStretch. At both events I was moved to meet so many individuals with AS who had never met anyone else with the condition, and therefore never met anyone else who could truly understand what they were going through. Quite a few tears were shed at both events showing the power of having someone to talk to who really knows everything about living with the condition. NASS goes beyond empathy to true understanding.

NASS is a national organisation and our commitment is to ensure that all people with AS, wherever they are in the UK, are supported and represented. We look forward to hosting future events and growing that sense of community that is so clearly needed not only locally, but nationwide and internationally. A strong national organisation is central to this.

Raj Mahapatra, NASS Chairman

2015

Chief Executive's Report



NASS – Highlights of 2015

- 5220 Helpline enquiries dealt with in 2015 (5.5% increase on 2014)
- 8400 'likes' on Facebook
- Two new guides produced Managing Your AS Flare & Guide to anti TNF Therapy
- 150 people attend Members' Day in York
- AS and You evenings for those newly diagnosed continues with events in Portsmouth, Sunderland, Chester and Cardiff
- First ever Scottish Patient Conference nearly 100 people attend
- First ever Northern Ireland Patient Conference nearly 80 people attend
- Scottish Parliamentary event NASS campaigns for access to hydrotherapy
- NASS Northern Ireland branches evolve
- NASS campaigns hard NICE publishes, much-needed new guidance on access to ant TNF therapy
- NASS praised by NICE for the quality of evidence submitted to the anti TNF therapy Multiple Technology Appraisal committee

Campaigning

<u>AS It Is</u>

We continued our AS It Is campaign with our first ever reception at the Scottish Parliament in September. We were very grateful to Margaret McCulloch MSP for hosting the event and addressing the audience on the issues faced by people with AS including:

- Access to physiotherapy
- Access to hydrotherapy
- The importance of work for someone with AS
- The delay in diagnosis



Mrs McCulloch also spoke about the work that NASS do and pledged her support for our campaign. I followed, speaking about the day to day lives of people with AS, Dr Stefan Siebert gave a clinical perspective and Murray Brown of NASS West Lothian gave a wonderful patient perspective, focussing on hydrotherapy and the threats to pools in Scotland. Throughout the event, NASS and our supporters were delivering the messages from the evening via Twitter, using #AS_it_is and #Splash4hydro. We also held a Scottish Patient Conference during the day which was very well attended; this is featured later in the report.

World AS Day

For World AS Day on 3 May we asked our supporters: 'What pledge will you make for World AS Day?' 122 people took part and here are the results:

- I pledge to move more, play more and laugh more 46%
- I pledge to know my limits, fight the fatigue and fingers crossed for fewer flare ups 26%
- I pledge to prioritise, prepare and pace myself the three P's 16%
- I pledge to learn more about my AS to help me accept I have it and to move forwards 7%
- I pledge to keep a good posture and actively involve my family and friends in my exercise efforts 6%

World Arthritis Day

World Arthritis Day is on 12 October every year. In 2015 NASS launched 'My plan for life with...'. NASS has been pushing for everyone with AS to have a Care Plan and accordingly we negotiated with our corporate partners for external funding to be provided by them for the project, to allow it to be undertaken. We worked with other patient organisations to produce such a plan for people with a musculoskeletal condition. Response to the document, which can be downloaded from our website, has been really positive and we continue to work with partners to further develop the project.

Influencing Local Health

Following an initial mail-out to contact all Clinical Commissioning Groups (CCGs) in 2014, NASS has maintained contact with many, particularly those who are working on a pathway for people with musculoskeletal conditions. This has allowed NASS to feed information on ankylosing spondylitis and axial spondyloarthritis and the specific needs of patients into these pathways as well as nominating several patient representatives to work with their local CCGs. We will be continuing with this work in 2016.

Information and Support

<u>Helpline</u>

Over the past few years NASS Helpline enquiries have steadily increased.

	Helpline enquiries	
2011	1000+	5,220 helpline enquiries
2012	3,792	
2013	4,308	5.5% increase on 2014
2014	4,950	
2015	5,220	

From November 2014, the Helpline has been run jointly by Sally and Amardeep, with Amardeep taking benefits and work queries and Sally taking all other queries. This meant we have been able to answer queries of all kinds much more quickly and efficiently. Both Sally and Amardeep spent around half their time each working week (17.5 hours) running the Helpline during 2015.

In October 2015, Amardeep moved across to a full time role as the Supporter Engagement Manager and Matthew Briggs joined NASS and has taken over his role on the Helpline. Matthew has received Helpline Training from The Helplines Partnership and training in Employment Support Allowance (ESA) and is awaiting his training for Personal Independence Payment (PIP).

In 2014 we estimated that around 40% of our Helpline enquiries were via telephone calls and most of the remainder were emails. In terms of medical queries, we are now seeing a clear shift away from phone calls. We estimate that around 60% of medical Helpline contacts are via email, 25% are by phone and 15% are via social media, especially our Facebook page. People either post publically on the page or send us a private message. The public messages are sometimes asking 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.

NASS actioned 530 queries regarding benefits and work in 2015. Each request for support with benefits and work usually requires lengthier, more detailed support than other Helpline enquiries, with calls aimed at gathering in-depth information about the impact of AS on daily life. Detailed support letters

are then drafted. In 2015, we provided a total of 110 letters to support people claiming benefits, a Blue Badge, appealing benefit decisions or requesting more support from their employer.

<u>Website</u>

Visitors to the NASS website have steadily increased over the past few years. However, in 2015 we have seen a slight dip in users and sessions.

	Sessions	Users
2012	146,720	94,534
2013	223,085	148,145
2014	261,408	176,626
2015	253,456	164,755

This represents a 3% drop in sessions and a 7% drop in users but those who were using the website spent longer on the site and looked at more pages than in 2014. We believe that this dip is likely due to the office move in March when we were less active. This also coincided with a period of 3 months where I was inactive after my surgery, thus not directing people to the NASS website from my Twitter feed; a possible other explanation for the dip. I am delighted however, that at the time of writing this report, in 2016 we have already seen an increase in website hits when compared to the same period in previous years.

The NASS website was redeveloped and re-launched in late 2010 and since then has not been upgraded, although it is updated on a daily basis. In the intervening 5 years, there has been a strong trend away from the use of desktop and laptop computers to access the internet and towards smart phones and tablets. Ofcom's 2015 Communications Market Report found that a third (33%) of internet users see their smart phone as the most important device for going online, compared to 30% who are still sticking with their laptop. The rise in smart phone surfing marks a clear shift since 2014, when just 22% turned to their phone first, and 40% preferred their laptop. Two thirds of people now own a smart phone, using it for nearly two hours every day to browse the internet, access social media, bank and shop online. The NASS website was not mobile optimised and this could be another key reason for the reduction in visitors to the website. Research shows that 57% of smart phone users will abandon a website if it takes more than 3 seconds to load and 30% will abandon a purchase if the shop is not optimised for mobile devices. As a high proportion of NASS memberships and donations are made via the shop on the website this could have major implications for our income.

Members' Forum

The Members' forum on our website continues to be a popular member benefit. After the update to the Forum, undertaken in 2014, usage has continued to rise especially following the new user-friendly design.

The Forum continues to be an important outlet for members to share their experiences with AS in confidence, helping others to understand their condition and provide a support network.

We continue to work with one of our forum users (Wonky Donkey) as a volunteer administrator on the forum, overseeing how the forum is run. With extra voluntary administrative support from another user (Susan) they both continue to work hard on the Forum for which we are very grateful. Their hard work ensures the Forum meets the needs of other users in both function and look.

Social Media

In order to optimise our target audience NASS has continued to engage with the AS community through social media. Social media platforms have enabled NASS to reach a wider audience and ensure that the active, vibrant organisation we are is communicated to others, both in a timely manner and through various channels.

The number of followers on our Facebook page (National Ankylosing Spondylitis Society) has shown a steady increase over the past few years.

	Followers (Likes)
2013	3,000
2014	5,500
2015	8,400

We try to post at least once a day, every day of the week. 64% of our Facebook followers are female and 36% male. In terms of age, 20% are under 34 and 76% are aged between 35 and 54.

We have two Twitter accounts; @NASSchiefexec and @NASSexercise. Followers for both these accounts rose steadily throughout 2015. The @NASSchiefexec account had 2,693 followers at the end of December 2015, a year on year increase of just under 500 followers and @NASSexercise had 2,250 followers, a year on year increase of 750 from 2014.

Our followers include people with AS, rheumatologists, rheumatology organisations, charities, hospitals and CCGs to name but a few. This means we can target groups of influential people when necessary. We set up a Pinterest page in autumn 2014. This is a very visual image-based way of communicating. It is like an online notice board with photographs and images forming links to further information. Interest in this has been much more limited. We currently have 90 followers.



Printed materials

As a consequence of the office move in March 2015, all of the NASS printed materials needed to be reprinted with the new address and telephone number. Prior to the move we deliberately allowed stocks of NASS guidebooks and leaflets to run down, thus ensuring there was little or no wastage.

This gave us the opportunity to start using the new terminology on our materials, currently being used within rheumatology. All our printed materials now read: Ankylosing Spondylitis (Axial Spondyloarthritis) (AS). This is important as people diagnosed using the new terminology of axial spondyloarthritis were unclear as to whether the NASS materials were relevant to them, which of course, they are. This has ensured that NASS information continues to remain up to date and relevant.

NASS Patient Guidebook

The NASS guidebook for patients continues to be recognised as one of the most valued NASS publications. It is distributed free of charge to rheumatology departments and given to patients newly diagnosed with AS. A guidebook is also sent to every new NASS member. We encourage long-standing NASS members to ensure that they have an up to date copy of the guidebook.

In autumn 2014 funding was obtained to allow us to replace the old exercise illustrations with full colour photographs. This ensured the most up to date exercises are included, that the exercises are clearly depicted and also means that the guidebook looks more modern and refreshed. Claire Harris, NASS trustee and Chair of AStretch, supervised the photo shoot and ensured the most appropriate exercises were included. The new guidebooks were delivered to the new NASS office in March 2015 and have been distributed thereafter.

Other Guidebooks

NASS produced two new guides in March 2015; Managing your AS flares and A guide to anti TNF therapy. We produced both in response to a perceived need from NASS members. Both guides have been extremely popular with both rheumatology departments and people with AS.

In autumn 2013, NASS produced a guide to 'Managing your AS at Work.' This 16 page guide was aimed at helping people remain in employment. The guide covers how AS can affect work, talks about AS at work, staying well at work and your rights at work. It includes an Employer's guide to AS. The guide has proved very popular and many people have downloaded the guide from our website. It is a very good starting point for people having problems at work. In 2015, we decided to take the opportunity to amend the work guide as a reprint was required and we extensively updated the information. The new version was completed in August 2015.

Factsheets

The NASS factsheets covering uveitis, fatigue and driving continue to be very popular. In early 2014 a new factsheet explaining more about the new terminology in AS was introduced. Called, 'Axial Page **10** of **46**

spondyloarthritis', it explained what axial spondyloarthritis is and how it fits together with AS. Much of this information has now been included within the NASS guidebook and accordingly we are no longer printing this factsheet, although it remains available on the NASS website.

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 2015 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 MAB is integral to all the information produced by NASS. The members are:

- Colin Beevor, Senior Clinical Nurse Specialist for Rheumatology Services
- Dr Karl Gaffney, Consultant Rheumatologist
- Claire Harris, Senior Physiotherapist
- Dr Andrew Keat, Consultant Rheumatologist
- Dr Helena Marzo-Ortega, Consultant Rheumatologist
- Dr. Athimalaipet Ramanan, Consultant Paediatric Rheumatologist
- Dr Raj Sengupta, 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

The NASS Members' Day 2015 (formerly the Patient Conference) was held on Saturday 20 June at York University. The event continued with the change in format from the previous year with a greater emphasis on fun, interactive sessions and practical ways to manage the symptoms of AS. There was a fantastic turnout of 150 people that included members, guests, trustees and health professionals. Guests were treated to fascinating presentations on a wide range of topics from our fantastic health professionals who gave up their time to be there. Dr Amanda Isdale started the day off with her talk on managing your AS followed by an update on AS research by Dr Gareth Jones. Dr Simon Smale then spoke about NSAIDs and Dr Margaret Wong gave a great presentation about AS and the eye.

The practical and mindfulness sessions were supported by an educational grant from MSD, and NASS member Sophie Matthew gave a brilliant talk on how mindfulness has helped her manage her AS. The last talk of the day was given by inspirational endurance athlete Helgi Olafson who spoke about his 1,000 mile cycle challenge, Pedal to the Medal and his battle with AS.

In true Yorkshire fashion the weather couldn't dampen the spirits of our members as they got stuck into Bollywood Dancing with Susi Gaikwad and NASS Grimsby, Essential Daily Stretches with Heather Harrison, Mindful Movements with Sophie Matthew and Nordic Walking with Jason Feavers.



NASS AGM

The Council of Management underwent a re-shuffle at the 2015 annual general meeting with John Boyle standing down after six fantastic years of service. I would like to take this opportunity to formally thank John and acknowledge all the hard work he undertook for NASS. Hedley Hamilton and Richard Jacoby became Vice Presidents and Roger Stevens became an elected member.

We were also delighted to welcome four new trustees onto the NASS Council of Management; Gillian Eames, Jean Morton, Tim Warburton and Pete Townsend who were co-opted onto the Council of Management. These four new trustees have long supported NASS and have already shown great commitment in campaigning and fighting for the AS community as a whole.

We are very grateful to all the speakers and volunteers who helped make the day a success. The trustees have decided that Bath, the birth-place of NASS, will be the destination for the 2016 Members' Day.

<u>AS & You</u>

AS & You, a series of events for people who have been diagnosed with AS within the last 18 months, continued in 2015 with evenings in Portsmouth, Sunderland, Cardiff and Chester. The events are designed to be informal and relaxed but with strong content from a rheumatologist, physiotherapist and a NASS member of staff to make sure that attendees get as much as they can from the 3 hour session. Attendees found the events to be very informative: "The right balance, presented with a sense of humour, and it felt like questions were allowed so there was a nice exchange of expert advice and honest feedback/experiences from AS patients."

Scotland

Tuesday 1 September saw a fantastic turn out in Edinburgh for the first ever NASS Patient Conference in Scotland. We were delighted to welcome nearly 100 people along for an afternoon of presentations. Raj Mahapatra, NASS Chairman, opened the day and I followed with a presentation updating the audience on how NASS can help, what we had been working on and what was coming up in the next 12 months. Dr Stefan Siebert (University of Glasgow) gave an overview of AS,





Dr Gareth Jones (University of Aberdeen) gave an update on the latest research and Lorraine Friel (Glasgow Royal Infirmary) gave a talk on the importance of exercise. The afternoon finished with a panel discussion led by questions from the audience. All in all, it was an excellent, well attended event and I was delighted that we were able to secure the funding to deliver it. Huge thanks to our wonderful speakers for giving up their time for the event, we appreciated it very much.

Northern Ireland

We were delighted to welcome and meet more than 80 people with AS to our first patient conference in Belfast on 17 October.

Our attendees heard two great talks on AS given by Dr Philip Gardiner, consultant rheumatologist from



Altnagelvin Area Hospital in Derry. They also heard talks and took part in practical demonstrations on

exercise from Claire Jeffries and Sue Gurden of AStretch, and Rhona Galway and Caroline Clarke, Senior Physiotherapists from Musgrave Park Hospital in Belfast. Janice Carlisle, a rheumatology nurse from Altnagelvin Area Hospital also helped out as part of our friends and family session.

A conference guest wrote on our Facebook page, "Thank you all so much for coming to Northern Ireland. I have left today with a positive mind. Your team has worked so hard to get where you are today! You all have inspired me so much! Let's hope we can get a much needed branch opened in Northern Ireland".



I was delighted that we were (eventually) able to secure the funding to deliver such an event, something we had wanted to do since I joined NASS in 2011. I look forward to continuing to develop a NASS presence and new initiatives and activities in Northern Ireland. Once again I would like to thank all of our speakers who gave their time to support the event.

My plan for life with...

From April 2015 every person with a long term condition was entitled to a care plan. NASS worked collaboratively with Incisive Health and other patient organisations to produce 'My plan for life with...', a document which can be used as a care plan. The resource was launched on World Arthritis Day and was downloaded 250 times in 24 hours from our website. On writing this report the plan had been downloaded from our website 850 times overall by our supporters.

Working with other organisations

NASS works on a number of initiatives with colleagues at organisations such as Arthritis Research UK, the National Rheumatoid Arthritis Society, the British Society for Rheumatology, the Chartered Society of Physiotherapists and Arthritis Care. I continue to serve as a Trustee of the Arthritis and Musculoskeletal Alliance. I am a member of the Fit for Work Coalition that works hard to support people with musculoskeletal conditions particularly in the workplace. I also serve as a member of the British Society for Rheumatology's Anti TNF Guidelines Committee and the BSR-BR Ankylosing Spondylitis Register Committee.

National Institute for Health and Care Excellence (NICE)

NASS worked with NICE on the appraisal for the anti TNF drugs back in 2008. This gave people with AS access to adalimumab (Humira) and etanercept (Enbrel). We worked with NICE again in 2011 when another anti TNF golimumab (Simponi) was approved for AS.

In 2014 the decision was taken to carry out a multiple technology appraisal (MTA) of anti TNF therapy for AS and non radiographic axial spondyloarthritis. NASS was asked to get involved as a patient organisation, so we asked for Members' views.

More than 600 took part in our research and we made our submission to NICE at the end of August 2014. NASS Trustee Roger Stevens (Portsmouth Branch) and I gave evidence at a meeting in February 2015. The Appraisal Committee then considered the evidence and produced what is called an appraisal consultation document which set out the draft recommendations made by the Committee.

Although there was good news in the appraisal consultation document we were concerned that there still wasn't an option to move to a second anti TNF if the first one doesn't work after 12 weeks or if it wears off over time. We wanted to fight this recommendation and so we carried out another survey. This time more than 800 responded.

In the survey 92% of people with AS said they were dissatisfied with this decision. Many started their anti TNF when NSAIDs either no longer helped with the pain or stiffness or caused side effects such as stomach bleeds or kidney problems. There was huge concern that if an anti TNF has stopped working effectively and you were not allowed to try a second, there would simply be no other treatments available. Those currently taking an anti TNF highlighted the beneficial effect it had on their lives, noting that effective treatment meant they were able to continue working and making a positive contribution to society. They also noted that the cost of a 12 week trial of a second anti TNF for a patient would be relatively small compared with the potential benefit.

NASS submitted the survey findings to NICE and the Appraisal Committee met again to consider the evidence on 30 June 2015. Roger Stevens and I attended again to give the patient view and Dr Karl Gaffney and Dr Raj Sengupta once again gave the clinical expert view. All four of us argued very strongly in favour of being able to switch and try another anti TNF.

NICE published the Final Appraisal Determination (FAD) in September 2015 but there was a delay in the publication of the Technology Appraisal Guidance. This was due to the pharmaceutical company, MSD, appealing against the guidance. MSD subsequently withdrew their appeal and NICE published the Technology Appraisal Determination on 1 February 2016. Within the new NICE guidance:

All the available anti TNF therapies are recommended as options for treating AS.

This means you and your rheumatologist can choose any of the anti TNF therapies on the market, including infliximab (cheapest version). Previously infliximab was not available to people with AS on the grounds of cost. NICE recommend the choice of treatment should be made after discussion between the rheumatologist and the patient about the advantages and disadvantages of the treatments available. Page **15** of **46** Adalimumab (Humira), certolizumab pegol (Cimzia) and etanercept (Enbrel) are recommended, as options for treating severe non-radiographic axial spondyloarthritis.

This means that anti TNF therapy can now be used earlier. The previous guidelines specified that people needed a diagnosis of AS, where changes to the sacroilliac joints and /or the spine could be seen on x-ray. This left some people living in pain as they had all the symptoms of AS, but they did not have changes on x-ray.

Now the guidance includes people with non-radiographic axial spondyloarthritis which is where x-ray changes are *not* present but inflammation can be seen on MRI. If you have previously been told that your x-ray or MRI results don't meet the criteria for you to go onto anti TNF therapy, it may be time to ask again.

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.

Until now, NICE guidance only allowed people to try one anti TNF, unless they had side effects in the first 12 weeks. If the first anti TNF didn't work or if effectiveness wore off over time, NICE did not recommend trying another anti TNF. Now your rheumatologist can think about trying you on another anti TNF if your first anti TNF didn't work or if the effect has worn off over time.

NICE approached NASS after the MTA meetings to praise us for the evidence we had submitted and the approach we had taken into gathering such evidence. NICE want to use the work that NASS did in gathering, compiling and presenting the evidence as an example of good practice. I wish to thank NASS Team member Sally Dickinson for all the hard work and effort she put into our NICE submission.

You may recall that NASS also campaigned actively in Parliament 2012 and 2013 for Clinical Guidelines for AS. Our campaign was successful and the Secretary of State for Health asked NICE to produce such guidelines. I have been a member of the Spondyloarthritis Guideline Development Group at NICE since it was started in the latter part of 2014. In 2015 I attended 7 full days of meetings of the Group and this work will continue until November 2016.

Sally and I attended the NICE Secukinumab Single Technology Appraisal Scoping meeting in March 2015 and at the time of writing this report we have just conducted a further member survey and submitted our evidence to the NICE appraisal process. The appraisal committee is scheduled for May 2016.

Work Foundation

NASS continues to have a working relationship with the Work Foundation. I am a member of the Fit for Work UK Coalition. In October Jill and I attended the Fit for Work Coalition's Parliamentary event to discuss the issue of work and musculoskeletal health. I spoke at the event to also launch the 'My Care Plan for Life' resource.

British Society for Rheumatology

I continue to sit on the BSR's AS Registers Committee and also the Anti-TNF Guidelines Committee.

European League Against Rheumatism (EULAR)

NASS continues to work with EULAR. In February 2015 I attended a 2-day event of CEOs from across Europe to share ideas and best practice.

Arthritis and Musculoskeletal Alliance (ARMA)

In 2015 I remained a trustee of ARMA and Jill continued to attend its policy group meetings. Jill also worked on designing and producing a survey on disability benefits and analysing the results on behalf of ARMA.

National Voices

NASS is a member of National Voices and continues to support and comment on National Voices' work around the NHS and healthcare for people with long term conditions, as well as being members of special interest groups. Members of the NASS team were also lucky enough to benefit from several 'POW WOW' sessions, workshops from their 'Wellbeing Our Way' programme to help with day to day work and projects.

Prescription Charge Coalition

NASS is a member of the Core Group of the coalition. The Coalition called on the Government to extend exemption from prescription charges to all those with long-term conditions in England. In recent years, there has been a broad political consensus that the current system is unfair as some long-term conditions qualify people for free prescriptions whilst others don't. This sense of unfairness has been exacerbated since the introduction of free prescriptions for people living in Wales, Scotland and Northern Ireland. In 2015 the Northern Ireland Assembly announced that it was considering re-introducing prescription charges. However after persistent pressure from the Coalition this idea was abandoned, signalling a triumph.

Arthritis Research UK (ARUK)

I continue to be a member and attend meetings of the ARUK Spondyloarthritis Clinical Studies Group which predominantly considers research proposals and makes recommendations to the grants structure at ARUK.

Jill took part in a symposium on 'work' in June organised by RUK, presenting findings on the subject from patient organisations to key members of NHS England, Public Health England and the Department of Work and Pensions. Findings from this symposium are now set to be delivered as a policy document and Jill is part of the resulting working group.

Arthritis Action

This charity re-launched in July 2015 and contacted NASS to see how we could work together, resulting in Martin Lau, dietician for Arthritis Action, helping to re-draft our website pages on diet. Martin has also agreed to speak at Members' Day 2016.

Jill and I also attend various other policy meetings to represent the views and needs of people with AS.

Disability Benefits Consortium (DBC)

The DBC is a national coalition of over 40 different charities and other organisations committed to working towards a fairer benefits system. Benefits are a hugely important issue to many people with AS, especially in the current political climate, and we have been delighted to support the DBC's work. We have been involved in a range of activity with the DBC in 2015:

- Lobbying for benefit assessments to better understand the impact of progressive conditions such as AS
- Protesting at the Houses of Parliament against the proposed £30 a week cut in Employment and Support Allowance, which would affect many of our members

We look forward to working closely with the DBC again in 2016.

NASS BRANCHES

NASS currently has 91 branches and in 2015 we were delighted to open a new branch in Lancaster. In October, NASS embarked on a project we had been hoping to fulfil for a while; to have NASS branches in Northern Ireland. Laura Richards, our former Branch Development Officer, facilitated a meet and greet event in Belfast with the help of the Team. Patients and physiotherapists from Northern Ireland came together to discuss setting up branches. The event was successful and there was a great deal of interest. Work has already begun on developing branches in Derry and Belfast. We also hope to launch a branch in Newry. Other work we undertook in Northern Ireland is covered elsewhere in the report.

Laura Richards attended AS Awareness evenings throughout the year with a view to establishing branches in Barnstaple and Llandudno.

NASS Portsmouth and NASS Orpington held fantastic anniversary celebrations in 2015. NASS Orpington celebrated 25 years with a 'Puddings Evening' at Ightham Mote in Kent which was attended by NASS Chairman, Raj Mahapatra. In September, NASS Portsmouth celebrated their 25th anniversary with a wonderful event at the Mary Rose Museum. Myself, Sally, Amardeep and Laura all attended a packed out, fabulous evening. Both events encapsulated what is great about our branch network; a real, supportive community.

Branch Fundraising

We encourage and support all our branches to seek and apply for additional, usually local funds when they become available. During the year, NASS Glasgow (Gartnavel) received a donation from the Scottish Academy of Thai Marital Arts and Culture. NASS Portsmouth was successful in receiving £500 from the Hampshire and Isle of Wight Community Fund and £200 from Scottish and Southern Electric. This year branches held successful social events to raise money; NASS York raised £1300 from their York Walls fundraising walk. NASS Bognor Regis raised £284.50 at their annual 'Cream Tea by the Sea', £94 of which came from a raffle they held. NASS Portsmouth held a quiz night and raised £819 - the highest amount the branch has ever raised from a single event in the 25 years that it has been in existence. NASS Birmingham also raised £200 from a sponsored swim undertaken by the son of one of its members, Kellie Wacogne.

Branch communications and promotion

Monthly newsletters helped us keep in touch with our branches throughout the year. Branches have been promoted in the form of mail outs, posters, press releases and flyers as well as featured on our social media accounts. We have continued to promote AS awareness evenings and branches through Facebook and Twitter.

Laura Richards was able to visit Basingstoke, Burton-on-Trent, Cannock Chase, Jersey, London (Harrow), Milton Keynes, Perth, Redhill, Salisbury, Winchester and Yeovil during the year. I visited our Blackpool branch in September.

Some of our branches continue to experience ongoing issues. It is a concern that it often seems that cutting hydrotherapy appears an easy option when hospitals look to reduce costs; this is a very short-term view in my opinion. We continue to work with various branches to negotiate with hospital managers, to improve relationships with rheumatology and thus increase branch member numbers and indeed to campaign for access to hydrotherapy. We worked very hard during the latter part of the year to campaign to protect hydrotherapy pools in West Lothian. This campaign took us to the Scottish Parliament where we lobbied MSPs on the importance of hydrotherapy. Margaret McCulloch MSP sponsored the event and pledged her support for the campaign. Maureen Watt, Minister for Wellbeing attended and has since corresponded with NASS about the issue.

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; in 2014, a number of sizeable legacies more than doubled our income, making a huge difference to our work. We would like to acknowledge legacies in 2015 from:

- Gordon Bicket
- Joan Wilton
- Dr Allan S Dixon
- Denis Thompson

A memorial service for one of NASS' founder members Dr Allan Dixon was held in Bath in June. I was sadly unable to attend but NASS Team members Sally and Jill attended to mark our sincere thanks for the wonderful support that Dr Dixon gave to NASS.

<u>Trusts</u>

We would like to express our gratitude to the wide variety of trusts and grant-making organisations that provide vital support for our work each year:

- 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

- Sunflower Accounts
- Working at Height
- BritainThinks
- Google
- Northern Trust
- UCB Celltech
- AbbVie
- Novartis
- Merck Sharp & Dohme
- Pfizer
- Call Connection Ltd



NASS Capital Challenge

The first NASS Capital Challenge took place on Sunday 17 May 2015. We were delighted to have over 50 people take part, and we raised a total of almost \pm 4,000.

The walk included 3 and 6 mile options that incorporated many of London's landmarks, and began at an events room donated free of charge by the Doggett's Coat & Badge pub.

Jurassic Trek

Following the success of Peak Pursuit in 2014, our Jurassic Trek took place during the weekend of 4th 6th September. A fantastic team of 10, including NASS Trustees Grant Poiner, Ben Hoare and Raj Mahapatra, and NASS Team members Amardeep and Joe, trekked 16 miles along the beautiful Dorset coastline. A brilliant total of £2,231 was raised for NASS.

Reactive fundraising

Our fundraisers had a fantastic 2015, 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 £67,035 (including Gift Aid).

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.I undertook my own fundraising adventure for NASS in November, running my first ever 10k to raise money for NASS. I will be taking on a bigger challenge in 2016.

Bucket collections

In February and May 2015, NASS held our first bucket collections at train stations across the country, raising awareness of AS and funds for NASS. The collections took place at the London stations of Cannon Street, Waterloo, London Bridge, Charing Cross, Euston, Paddington and Victoria, as well as at Edinburgh Waverley and Leeds.

We want to thank each of our volunteers who braved the cold to help raise £1,200, including a



donation of £300 from London & Capital, a wealth management company.

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 and the charity is not influenced by the agenda of industry in any way. We also work with colleagues in industry to deliver specific initiatives funded by them.

In October I had the opportunity to address the UK staff at Novartis to talk about the work of NASS and what is important to people with AS. I believe that these opportunities are incredibly important as it ensures that our industry colleagues have further knowledge thus helping them to improve services to patients.

The amount of support received from the industry in 2015 was as follows:-

- £ 11,000 Abbvie Scottish Parliament
- £ 12,000 Pfizer AS&You
- £ 25,000 Abbvie Core funding
- £ 25,000 Novartis Back to Action
- £ 10,000 MSD MD/Wellbeing
- £ 10,000 MSD Northern Ireland

Membership

The total number of NASS members rose from 5430 to 5886 as of August 2015. Joe Murray who looked after our members in his role left in September 2015 and was replaced by Matthew Briggs who took over the newly created Membership and Information Officer role. Matthew is looking to evolve the membership process and is also looking into developing the membership renewals procedure giving it more of a personal touch.

Plans are in place to further enhance membership numbers in 2016 with a campaign planned in the Spring to attract more members. There are also plans in place to upgrade and simplify how prospective new members can join NASS, with an updated, fully mobile optimised website for users.

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.

Office Move

In 2014, NASS was advised that planning permission had been sought to convert the office we owned into flats along with the rest of the building. (You can apply for planning permission on a building even if you do not own it). Our trustees explored many options over the next few months. After much deliberation and negotiation the Council of Management decided to transfer the NASS team into rented accommodation at Hammersmith and to convert the NASS office into two self-contained flats, thus increasing their value. The Team, acted on the instructions of the Council of Management and moved to new rented offices in Hammersmith in March 2015 and by the end of 2015 the two new flats were ready to be rented out, as agreed by the charity's trustees.

Research

Research Fund

Back in 2013 we held an event at Lancaster University and then asked our supporters to tell us what they saw as being the main areas they would like to see covered in research into ankylosing spondylitis (axial spondyloarthritis) (AS). From this work, our Research Priorities document 2013 - 2018 was produced. In 2015 we launched the first ever NASS Research Fund and were delighted to award 4 grants totalling £75,000 to:

Dr Tatiana Macfarlane, University of Aberdeen For her project into 'Role of diet in the aetiology of ankylosing spondylitis'

Ms Emma Sargeant, University of Wales Hospital, Cardiff For her project 'A service evaluation of the one week and two-week Ankylosing Spondylitis Intensive Rehabilitation Programme'

Dr Helen Davies of Swansea University For the project 'Mindfulness intervention in ankylosing spondylitis'

Dr Kirstie Haywood of Warwick Medical School For the project 'Fatigue and Ankylosing Spondylitis (AS): improving patient outcomes'.

Education Bursaries

Alongside the Research Fund, we also launched our Educational Bursaries Fund of up to £1,000. In our inaugural year we awarded 3 of these bursaries to Jacqueline Mullan (University of the West of England), Marie Therese McDonald (NHS Greater Glasgow & Clyde) and Nathan Pearson (University of Warwick).

Oxford University Genetic Research

For the fourth consecutive year, we gave the opportunity to our new members – over 350 people - to take part in the Oxford University research programme aimed at identifying genetic factors contributing to the development of Ankylosing Spondylitis. The team at Oxford University led by Professor Paul Wordsworth and Matthew Brown have been exploring why AS only affects some individuals and why some are more severely affected than others. It now appears that many genes (not only HLA-B27) are involved in AS. A better understanding of them should help diagnosis and treatment of the condition more effectively.

The NASS Team

There are 7 members of the NASS team but because the profile of the charity has been raised significantly over recent years, people often assume there are more of us and that we are a much larger charity. When I am out and about representing NASS, many healthcare professionals will often say to me that they can't believe how much NASS does as an organisation given its limited resources. I believe that we only achieve this amount of work and impact because of the quality and dedication of our team and I am very grateful to all members of the team who work so hard to make NASS the organisation that it is. I wish to say an extra-special thank you to the team this year; I needed 3 months off work following my neck surgery in March and the Team 'stepped-up' in my absence, ensuring the good work of the charity continued and I was incredibly grateful for that. They also managed an office move in my absence, ensuring that it happened as smoothly as possible; again something which I was incredibly grateful for.

In September Joe Murray moved on to pastures new and Matthew Briggs joined us in October as Membership and Information Officer. Laura Richards left the position of Branch Development Officer in November. My thanks to both Joe and Laura for the work they did during their time at NASS. Laura's departure presented a challenge as the Branch Development Officer role has traditionally been a difficult post to recruit to as it requires a huge mix of skills. I must express my thanks to Jill who has stepped up many times to work with our branches in the absence of a Branch Development Officer.

I continue to be hugely proud of the NASS team for the dedication and support they give to our wonderful charity. I continue to be hugely grateful to the team for all the support they give to me both professionally and personally.

Volunteers

NASS is hugely grateful for the fantastic support we received from volunteers across much of our work in 2015. From the 60,000 hours of exercise delivered through our national network of branches, the invaluable guidance from our Medical Advisory Board, braving the cold at bucket collections, cheering runners at events, and helping in the office, every hour given is enormously appreciated. Thank you to all our volunteers.

The Future

2016 looks to be an amazing year for NASS and I feel proud and privileged to be a part of it. We are 40 years old! We have many celebratory events planned, including our 'Fab at 40' fortnight and a party in October in London. Our Members' Day will return to where we were founded and the event in Bath will be bigger and better than ever before.

NASS continues to work on the priorities contained within our 5-year strategic plan; tackling the delay to diagnosis, focussing on self management and patient empowerment and access to physiotherapy and raising awareness about AS.

The early part of 2016 looks to be incredibly busy as we will also be launching our 3-yearly patient survey. The results of this survey will help us build our Parliamentary campaign messages for this year and next, meaning that we are able to ask for what is most important to people with AS. The results of this survey also help us to advise the rheumatology community on the issues most important to patients. We will also work with the British Society for Spondyloarthrtis on a Unit Survey of all rheumatology departments in the country. The results of this survey will strengthen our campaign messages even further. NASS will take our campaign to parliament in November 2016.

Last year our supporters voted on a name for our new 16-25 year old initiative and accordingly our exciting ASOne initiative will be launched in 2016. NASS is also working towards the delivery of two online learning modules with the Royal College of GPS. NASS will fund this initiative which has the potential to reach 50,000 GPs and many other healthcare professionals. Our AS and You events for people newly diagnosed will also continue to tour the UK.

In February 2016 we will launch a new project 'Back Pain Plus' aimed at raising awareness of skin, eye and bowel disease associated with axial spondyloarthritis with gastroenterologists, dermatologists and ophthalmologists. We will continue to work with NICE and all of our other partners to deliver improved services for people with AS.

NASS can only continue to do the work we do with the support of our members. Our biggest challenge comes from the need to secure more members and additional income through fundraising activities. NASS does not receive any government subsidy and so relies on this type of support. I would like to thank most sincerely, all our members, supporters and donors for their continued support. Thank you to all our dedicated fundraisers and volunteers; we appreciate your support very much and we really could

not do what we do without you. Huge thanks also to the NASS Medical Advisory Board and the NASS Trustees who give up so much of their time for NASS.

Our 2016 survey will give our supporters further opportunity to let us know what you think of NASS but I hope you all know by now that NASS welcomes your views always any time to inform our work. NASS is your organisation and it's very important to me that your charity lives up to your expectations and delivers what we can within our given resources.

I hope you'll agree that 2015 has been a good year for NASS. The highlight for me has to be the results of the NICE Multiple Technology Appraisal and what this will mean for people with AS. 2016 looks to be a fabulous year, with us set to deliver more than ever.

The ote.

Debbie Cook, NASS Chief Executive 2015

NASS Trustees' Report

The Trustees present their report and accounts for the year ended 31 December 2015, prepared in accordance with current statutory requirements, in accordance with the Charity Commission Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Entities published on 16/07/14, the Financial Reporting Standard for Smaller Entities (FRSSE) and the Charities Act 2011 and applicable regulations.

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

1. <u>Reference and administrative details</u>

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 OQT. 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 Simon H Frost	(Chairman) (Treasurer)
<i>Vice Presidents</i> Dr Andrei Calin Hedley Hamilton Dr Richard Jacoby MD FRCP	(appointed 20 June 2015) (appointed 20 June 2015)
Ordinary Members John Boyle Stephen Dean Eric N C Eustance FCMA MCT Dr Karl Gaffney Claire Harris Ben Hoare Dr Andrew Keat Ruth Miller Grant Poiner Dr Raj Sengupta Roger Stevens Peter Wheatley-Price Professor Paul Wordsworth	(resigned 20 June 2015) (appointed 20 June 2015)
Co-opted Members Gillian Eames Jean Morton Pete Townsend Tim Warburton	(appointed 20 June 2015) (appointed 20 June 2015) (appointed 20 June 2015) (appointed 20 June 2015)

2. <u>Structure, Governance and Management</u>

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.

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. Achievements and Performance

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 to them from the NHS. The Society has approximately 5,500 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 91 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 three new branches were opened and two 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 $\pm 25,000$ (2014 - $\pm 25,000$) from Abbvie UK. In addition grants totalling $\pm 68,000$ (2014 - $\pm 39,996$) were received for specific projects.

e. Expenditure on Research

The Society incurred total costs of £109,860 (2014 - £ 23,637) on research activities during the year which included support costs of £31,083 (2014 - £22,714). The Trustees are keen to foster continued research into AS and related conditions, and have implemented a grant based system for funding research projects.

f. Expenditure on Campaigning

The Society incurred total costs of £100,664 (2014 - £71,440) on campaigning activities during the year which included support costs of £93,249 (2014 - £68,144). 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, and expenditure in this area is likely to increase in the coming years.

g. Expenditure on Education and Support

The Society incurred total central costs of £204,157 (2014 - £158,847) on education and support activities during the year which included support costs of £155,415 (2014 - £113,574). 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 $\pounds 208,546$ (2014 - $\pounds 191,496$) 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

The Society has also worked closely with the National Rheumatoid Arthritis Society (NRAS) and highly values the constructive co-operation between the two organisations.

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 (described further below), has enabled the Trustees to plan for growth in all areas of the society's charitable activities. Principal among these is the establishment at the start of 2015 of a continuing scheme to promote and fund research projects into many aspects of AS.

5. Financial Review

a. Reserves

The conversion of the Society's former office into residential flats (described further below) has given rise to a substantial increase in the Society's reserves. Free reserves, defined as the balance of unrestricted funds less tangible fixed assets, currently amount to \pm 1,244,000 (2014 - \pm 1,177,000).

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 and will not now be undertaken until next year.

As reported last year the Trustees decided to convert the Society's former headquarters, in Richmond, into two residential apartments and, following conversion, rent out these apartments to generate income for the Society. Conversion was completed in December 2015 and both flats are now let out on shorthold assured tenancies. As a result this asset has been reclassified in the Society's accounts as an investment and is reflected in the balance sheet at market value of $\pounds 675,000$, giving rise to an unrealised gain of $\pounds 179,000$. In addition the Society's investment in four Elisabeth Frink statues has been revalued giving rise to a further gain of $\pounds 12,000$.

c. Summary of financial performance

As a whole, the Society reported a surplus of income over expenditure of £2,863 (2014 - £648,850). A deficit of £1,570 (2014 - surplus £631,865) arose centrally and a surplus of £5,457 (2014 - \pounds 17,335) 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. <u>Statement of Trustees' responsibilities in respect of the accounts</u>

The charity 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 Charity 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 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 charity's transactions and disclose with reasonable accuracy at any time the financial position of the Charity and to enable them to ensure that the accounts comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008, the Charities Accounts (Scotland) Regulations 2006 and the provisions of the Trust deed. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are responsible for the maintenance and integrity of the charity and financial information included on the charity'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 4 June 2016

Auditors' Report to the Trustees

We have audited the financial statements of The National Ankylosing Spondylitis Society for the year ended 31 December 2015 set out on pages [33 to 43]. 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).

This report is made solely to the Charity's trustees, as a body, in accordance with section 144 of the Charities Act 2011 and regulations made under section 154 of that Act, section 44 (1c) of the Charities and Investment (Scotland) Act 2005 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the Charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity and its members, as a body, for our audit work, for this report, or for the opinion we have formed.

Respective responsibilities of Trustees and auditor

As explained more fully in the Statement of Trustees' responsibilities, 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 auditors 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 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. 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 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
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

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

Date:

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 2015

	Restricted Funds						
	Note	Unrestricted Fund	Branch Funds	Branch Developt Fund	Fergus Rogers Fund	Total Year ended 31 Dec	Total Year ended 31 Dec 2014
		£	£	£	£	2015	£
Incoming resources Incoming resources from generated funds							
Voluntary income	2	266,081	199,005	-	-	465,086	1,089,323
Activities for generating funds	3	93,048	16,249	-	-	109,297	114,710
Investment income	4	2,277	145	-	-	2,422	1,490
Incoming resources from charitable activities		-	-	-	-	-	-
Total incoming resources		361,406	215,399	-	-	576,805	1,205,523
Resources expended							
Costs of generating funds	5	129,508	978	-	-	130,486	101,454
Charitable activities	6	414,681	208,546	-	1,024	624,251	445,770
Governance costs	7	10,453	-	-	-	10,453	9,449
Other resources expended		-	-	-	-	-	-
Total resources expended		554,642	209,524	-	1,024	765,190	556,673
Net incoming (outgoing) resources before transfers		(193,236)	5,875	-	(1,024)	(188,385)	648,850
Gross transfers between Funds		418	(418)	-	-	-	-
Net incoming (outgoing) resources before other recognised gains or losses		(192,818)	5,457	-	(1,024)	(188,385)	648,850
Gains (losses) on revaluation of investments	10	191,248	-	-	-	191,248	-
Net movement in funds for the year		(1,570)	5,457	-	(1,024)	2,863	648,850
Funds brought forward		1,262,592	210,669	2,201	4,075	1,479,537	830,687
Total Funds carried forward	18	1,261,022	216,126	2,201	3,051	1,482,400	1,479,537

The notes on pages 38 to 45 form part of these accounts.

NASS: Balance Sheet

31 December 2015

FIXED ASSETS	Note	31 December 2015 £	31 December 2014 £
Tangible assets Investments Total Fixed Assets	9 10	16,907 747,540 764,447	302,333 60,540 362,873
CURRENT ASSETS Debtors and prepayments Cash at bank and in hand Total current assets CREDITORS	11 12	16,816 759,033 775,849	27,833 1,116,071 1,143,904
Amounts falling due within one year	13	57,896	27,240
NET CURRENT ASSETS	<u>-</u>	717,953	1,116,664
TOTAL NET ASSETS	-	1,482,400	1,479,537
CHARITABLE FUNDS			
Unrestricted funds Branch funds Branch development fund Fergus Rogers fund	14 15 16 17	1,261,022 216,126 2,201 3,051	1,262,592 210,669 2,201 4,075
TOTAL CHARITABLE FUNDS	18	1,482,400	1,479,537

The accounts set out on pages 34 to 45 were approved by the Trustees on 04 June 2016.

Raj Mahapatra Chairman S H Frost Treasurer

For the year ended 31 December 2015

1. ACCOUNTING POLICIES

- (a) Accounting convention: The accounts are prepared under the historical cost convention, modified to include the revaluation of investments, in accordance with the Charities Act 1993, with the Charity Commission Statement of Recommended Practice and with applicable accounting standards.
- (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.
- (c) *Investments*: Investments are included in the accounts at market 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: 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) 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.
- (g) Fixed assets: Fixed assets are depreciated at 25% per annum on a straight line basis.
- (h) Expenditure: 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 charity and include the audit fees and fess linked to the strategic management of the charity. Support costs are allocated to charitable activities in proportion to the estimated time expended by the Society's staff on these activities.
- *(i)* **Pension contributions:** The charity operates a defined contribution pension scheme and the pension charge represents the amounts payable to the fund in respect of the year.

2. VOLUNTARY INCOME

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

	Year to 31 Dec 2015 £	Year to 31 Dec 2014 £
Unrestricted funds		
Subscriptions	69,419	68,799
Donations and grants	127,372	151,125
Legacies	69,290	677,798
Total	266,081	897,722
Branch funds		
Subscriptions	179,538	168,091
Donations	19,467	23,510
Total	199,005	191,601
Branch Development Fund		
Donations	-	-
Total	-	-
Fergus Rogers Fund		
Donations	-	-
Total		
Total voluntary income	465,086	1,089,323

3. INCOME FROM ACTIVITIES FOR GENERATING FUNDS

Income in this category is primarily associated with activities undertaken to raise funds to support the Society's charitable activities. It includes income from fund-raising events and from lotteries.

Unrestricted funds	Year to 31 Dec 2015 £	Year to 31 Dec 2014 £
Annual draw	9,719	10,301
Fund-raising events	74,521	80.634
Other income	8,808	5,710
Total	93,048	96,645
Branch funds		
Fundraising events	14,248	12,909
Other Income	2,001	5,156
Total	16,249	18,065
Total income from activities for generating funds	109,297	114,710

4. INVESTMENT INCOME

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

	Year to 31 Dec 2015 £	Year to 31 Dec 2014 £
Unrestricted funds		
Dividends received	19	9
Interest received	2,258	1,367
Total	2,277	1,376
Branch funds		
Interest received	145	114
Total	145	114
Total investment income	2,422	1,490

5. COSTS OF GENERATING 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 2015 £	Year to 31 Dec 2014 £
Unrestricted funds		
Annual draw prizes and expenses	4,266	4,285
Fundraising expenses	16,452	16,418
Support costs (note 8)	108,790	79,502
Total	129,508	100,205
Branch funds		
Fundraising expenses	978	1,249
Total	978	1,249
Total costs of generating funds	130,486	101,454

6. RESOURCES EXPENDED 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 2015 £	Year to 31 Dec 2014 £
Unrestricted funds			
Research	[note 6(b)]	109,860	23,637
Campaigning	[note 6(c)]	100,664	71,440
Education and support	[note 6(d)]	204,157	158,847
Total	-	414,681	253,924
Branch funds	-		
Campaigning		-	-
Education and support	[note 6(e)]	208,546	191,496
Total	-	208,546	191,496
Branch development fund	-		
Grants made		-	-
Total	-	-	-
Fergus Rogers Fund	-		
Welfare – grants made		1,024	350
Total	-	-	-
	-		
Total resources expended on charitable activities	-	624,251	445,770

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

	Year to 31 Dec 2015 £	Year to 31 Dec 2014 £
Grants for research and related costs	77,844	-
AS News	933	923
Support costs (note 8)	31,083	22,714
Total research expenditure	109,860	23,637

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

	Year to 31 Dec 2015 £	Year to 31 Dec 2014 £
Advertising and campaigning	4,616	529
AS News	2,799	2,767
Support costs (note 8)	93,249	68,144
Total campaigning expenditure	100,664	71,440

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

	Year to 31 Dec 2015 £	Year to 31 Dec 2014 £
AS News	14,927	14,755
Guide books, DVDs and apps	6,184	9,863
Literature, brochures and information	3,539	10,351
Patient and member conferences	21,579	8,734
Branch conferences and support	2,513	1,570
Support costs (note 8)	155,415	113,574
Total education & support expenditure	204,157	158,847

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

	Year to	Year to
	31 Dec 2015	31 Dec 2014
	£	£
Treatment by healthcare professionals	155,470	146,930
Hire of venues and facilities	36,279	29,949
Grants payable	2,687	2,092
Support costs (note 8)	14,110	12,525
Total branch education & support expenditure	208,546	191,496

7. GOVERNANCE COSTS

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

	Year to 31 Dec 2015 £	Year to 31 Dec 2014 £
Expenses paid to Trustees	3,389	2,899
Trustees meetings and Annual General Meeting	1,064	1,870
Auditors' remuneration	6,000	4,680
Total governance costs	10,453	9,449

The Trustees received no remuneration during the year (2014 – 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 2015 £	Year to 31 Dec 2014 £
Staff costs (note 8c)	256,923	206,907
Premises costs	67,043	25,516
Travel expenses	12,599	11,393
IT and Communications	26,344	23,012
Office costs	12,525	8,146
Insurance, legal and professional	13,103	8,960
Total support costs	388,537	283,934

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		
Research	31,083	22,714
Campaigning	93,249	68,144
Education and support	155,415	113,574
Fundraising activities	108,790	79,502
	388,537	283,934

- b) Branch support costs incurred in the year amounted to £14,110 (2014 £12,525), and are wholly attributable to education and support.
- c) Staff costs incurred during the year consisted of:

227,665	180,130
21,726	18,562
5,713	7,257
1,819	958
256,923	206,907
	21,726 5,713 1,819

d) Information about employees:

	31 Dec 2015	31 Dec 2014
Average number of employees during the year	6	5
Number of employees for whom pension contributions have been made	4	5
Number of employees whose emoluments exceeded £60,000 per annum		
£70,000 to £80,000	1	1

9. TANGIBLE FIXED ASSETS

	Leasehold Buildings £	Office Equipment £	Total £
Cost at 31 December 2014	351,000	29,922	380,922
Additions in the year	-	14,270	14,270
Disposal in the year		(21,543)	(21,543)
Transfer to Investments (note 10)	(351,000)	-	(351,000)
Cost at 31 December 2015	-	22,649	22,649
Depreciation at 31 December 2014	56,080	22,509	78,589
Depreciation charge for the year	1,755	4,776	6,531
Disposal in the year	-	(21,543)	(21,543)
Transfer to Investments	(57,835)	-	(57,835)
Depreciation at 31 December 2015		5,742	5,742
Net book value at 31 December 2014	294,920	7,413	302,333
Net book value at 31 December 2015		16,907	16,907

10. INVESTMENTS AND INVESTMENT GAINS

Investments	31 Dec 2015 £	31 Dec 2014 £
Transfer from Tangible Fixed Assets	351,000	-
Additions in the year (conversion costs)	202,587	-
Revaluation Surplus	121,413	-
Leasehold property at valuation (total at 31.12.15)	675,000	-
Bronze statues, at valuation	72,000	60,000
Listed shares, at valuation	540	540
	747,540	60,540
Investment gains	31 Dec 2015	31 Dec 2014
	£	£
Leasehold property at valuation	179,248	-
Bronze statues, at valuation	12,000	-
Listed shares, at valuation	-	-
	191,248	-

During the year the Society completed the conversion of its former office in Richmond in to two residential flats and these have been 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 £40,000 is due in relation to the conversion work and therefore the value reflected in these accounts is £675,000. This valuation gives rise to an unrealized gain of £179,248 which has been included in this year's Statement of Financial Activities.

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 is reflected in this year's Statement of Financial Activities.

The listed shares are carried at market value. These shares were sold in February 2016 and a small loss was incurred.

11. DEBTORS AND PREPAYMENTS

	31 Dec 2015	31 Dec 2014
	£	£
Office lease deposit	8,100	8,100
Prepayments	8,100	13,257
Sundry debtors	616	6,476
	16,816	27,833

12. CASH AT BANK AND IN HAND

	31 Dec 2015	31 Dec 2014	
	£	£	
Deposit account balances held centrally	449,651	878,507	
Deposit account balances held by branches	215,661	205,312	
Current account balances	87,755	26,785	
Cash in hand	5,966	5,467	
	759,033	1,116,071	

13. CREDITORS: Amounts falling due within one year

	31 Dec 2015	31 Dec 2014	
	£	£	
Sundry creditors	8,543	1,520	
Deferred income	37,000	10,000	
Accrued expenses	12,353	15,720	
	57,896	27,240	

There are no creditors falling due after more than one year (2014 - 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 ± 550 (2014 - $\pm 1,750$) were paid to branches from Unrestricted Funds and donations totalling ± 968 (2014 - $\pm 1,450$) 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 (2014 - £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 \pounds 1,024 (2014 – \pounds 350) was expended on welfare.

18. RECONCILIATION OF CHARITABLE FUNDS

	Unrestricted Fund £	Branch Funds £	Branch Dev Fund £	Fergus Rogers Fund £	Total Funds £
Tangible assets	16,907	-	-	-	16,907
Investments	747,540	-	-	-	747,540
Debtors and prepayments	16,816	-	-	-	16,816
Cash at bank and in hand	532,201	221,580	2,201	3,051	759,033
Less creditors	(52,442)	(5,454)	-	-	(57,896)
Total charitable funds	1,261,022	216,126	2,201	3,051	1,482,400