Report and Accounts
For the year ended
31 December 2013

Registered Charity Number 272258 Scottish Charity Registration Number 041347

Contents

Trustees

Medical Advisory Board

Chief Executive: Debbie Cook, MPA, ACIS

Auditors: Felton Pumphrey, 1 The Green, Richmond TW9 1PL
Bankers: Barclays Bank, Calverley Road Branch, Tunbridge Wells, TN1 2UZ
Solicitors: Russell-Cooke, 2 Putney Hill, London SW15

Chairman's Report

This is my final report as Chairman after another good year for NASS and I have to say what a pleasure it has been over 10 years as a trustee and 6 as Chairman.

Rather than focus on the past year it seems appropriate to also look at how far we have come and be proud of the outstanding charity NASS is.

Ten years ago NASS was a very different organisation, and the world seemed a simpler place. Now there is more demand on the NHS, greater competition for its resources and a resultant need to campaign for the right quality of treatment. Decisions on where NHS resources are deployed are taken at a high level, often looking years ahead, and if our case is not seen and well prepared there is a risk that AS will not get the attention and resources it needs.

I'm pleased to say that we are clearly on the map with NICE, across key parts of the NHS, with the Minister for Health, and with related charities and pressure groups. Key to this are the NASS profile and the close relations with and support from the leading AS rheumatologists and researchers in the country (many of whom are willingly co-opted onto the NASS board); and similar relations and support from MPs. My thanks to all of them for their hard work, especially to the rheumatologists and researchers who contribute so much that is above and beyond their day job.

While NASS has to be a strategic player it also delivers concrete interventions to improve the treatment and health of AS patients, including the following:

- We facilitated a working group of top consultants to create a template for good practice in NHS diagnosis and treatment of AS called Looking Ahead. This has been distributed to NICE and to rheumatologists across the country. And NASS have taken this further, encouraging good practice by creating an audit of hospitals across the country, where the hospitals compare their practices against those recommended in 'Looking Ahead'.

  NICE has now agreed to produce Clinical Guidelines itself. We are pressing for this to be delivered quickly and will add our input to maximise their quality once a draft is available.

- At the consultant level we deliver "meetings in a box" to facilitate teach-ins for those studying rheumatology or in a placement there. However, it is at the GP level that most work is needed as it is here that the main delay in recognition and referral occurs. Because of the competing pressures on GPs and their wider dispersion they are harder to reach. Here we have delivered GP Awareness programme across the county reaching hundreds of GPs among whom we have sought champions to whom we provide further packs that help them take the teaching further. The GP awareness campaign holds real challenge, but I'm pleased to say that it has gone well and that after seeing our success, larger charities are now asking how we did it.

- Physiotherapy is key to AS treatment and here physiotherapists have created an AS focused group called AStretch, which promotes best practice and delivers AS specific training courses for other physiotherapists. NASS now provides administrative support to AStretch, for example in liaising and organising courses, while many NASS branches pay part of the course fees (for course running costs) as a thank you to physiotherapists who take the weekly sessions run by each branch. So it's a virtuous circle, where our 91 NASS branches provide physiotherapy for AS patients every week, and we also provide training on AS exercise to physiotherapists in general and in particular to those running our sessions.

While we are all grateful for the physiotherapists in our branches, I have to pick out Claire Harris and Juliette O'Hea, the current and previous Chairs of AStretch, for particular praise as both have also been NASS trustees who give their time and expertise relentlessly on many projects.

- For patients the NASS website provides a first line information source helping people understand AS, the diagnosis and treatment paths and what they can do themselves. Meanwhile the telephone helpline which we started just 3 years ago has large and increasing numbers of calls and needs over half of one staff member's time to cope with demand. Here too the dedicated group of supporting rheumatologist consultants go above and beyond in providing back-up to answer medical issues raised on the helpline.

- To help people exercise correctly in groups or on their own NASS has moved with the times in format and in giving the latest physio advice; moving from exercise video, through CDs with multiple exercise options, to an App which can be downloaded to all types of phones and tablets. It's great to Chair an organisation that has become so capable that you simply hear that the App is finished, released, got top starring from the NHS, is well used and that all is well: and to contrast that with the production of the CD when I remember many long (but fun) meetings to choose the right exercise, agree the technique (not as easy as you'd think with 3 physios) and how to combine for various ability levels, then directing and even demonstrating exercises, before trying (and in my case failing) to do the voiceover. Oh how nice to just say "Thank you and well done everyone - especially to our key physio and trustee Claire Harris (again)!"

- Meanwhile NASS branches provide gym and hydro pool physiotherapy every week in 91 locations across the UK. Branches are run semi autonomously by devoted patients and physiotherapists who all deserve praise for their years of continual giving. From the centre we have tried to strengthen support for branches, helping where needed with local negotiations for use of the gym and hydro facilities, providing advice, and latterly creating a central budget for short term assistance. This has helped some branches survive, and others to become established so that the number of NASS branches is again on the rise.

We support research as much as we can but because we are small we have to be tactical and to influence more well off organisations to focus their efforts on AS. We are hugely aware of how important research is to our members and have conducted a survey to understand their priorities. Many years ago we would make one off purchase e.g. of a laptop to help researchers, but for the last years we have stepped up our direct involvement by sponsoring a full time research fellow. I hope that with more funding we can pump prime more research in the next years.

NASS is also active internationally. In the 1990s NASS was instrumental in setting up the Ankylosing Spondylitis International Federation (ASIF) and we re-engaged with it in 2008. I have been Vice President of ASIF for 5 years and Debbie Cook, NASS CEO, is now on its Council too. It facilitates sharing information and approaches with other AS patient organisations globally. With almost all countries in Europe being members it also provides a platform from which to influence at the European level.

ASIF is now moving at a faster pace, but its council members can only take it so far with their volunteer time and it really needs full time staff to be able to deliver properly. Its business plan is to fund at least one person, and in pursuit of this we have moved its bank account to the UK and will incorporate it as a charity here too. ASIF has in the past paid NASS for support activities and the intent is to extend that approach and co-locate the ASIF person in the NASS's office, allowing easy exchange and support.

So, NASS has evolved, has grown, is healthy and is delivering a huge amount with the limited resources of what is after all a small charity. But of course there is much, much more to do.

The strategy to get us here has been simple: to increase what we deliver and to raise the profile of AS and of NASS. Through these we are able to gain more influence, and raise more money.

In preparing for the new challenges we have consciously encouraged keen and able people to become Trustees and now have a full complement of AS patient Trustees and co-opt others as well. We have also tried to ensure representation from all parts of the UK, and to include as much of the UK as we can in events and support as we area after all a national charity. This has worked well for Scotland and Wales, and I only wish we could do the same in Northern Ireland.

Trustees have also been more closely involved with running NASS. Between the quarterly weekend meeting of the full council, 5 trustees and the NASS CEO meet midweek once a month as a management committee to cover operational decisions. My thanks to all the trustees for their time, and quality of input, but especially to those on the management committee and to our Treasurer, Simon Frost, who puts in a huge amount of work in and is a great source of sound advice.

We have prioritised and pushed for growth in what we deliver, often setting progressive budgets to invest in delivering more and to spend more than our projected income. However, this hasn't been done recklessly and our position is improving. At the same time we have introduced policies to limit the percentage of income coming from the pharmaceutical sector as we need to protect our position as an independent patient voice. So we still depend heavily on fundraising and legacies from, members, friend and supporters – all of whom we need to thank again and again for making it possible.

All this delivery of profile, influence, projects, and support can only be done with a strong executive team - and NASS has an absolutely superb one. Jane Skerrett, the previous Director of NASS, picked up the pieces after Fergus's sudden demise, implemented some of the core systems we still use and helped identify and encourage new trustees. Debbie Cook, our current Director/CEO, was chosen to increase the profile of NASS – and what a fabulous job she has done of that and of building the team we have now. I know our small team goes out of its way to provide help, support, and make things happen – remaining low key and friendly while delivering more impact than charities many times our size would be proud of. So, again my thanks to them all.

In 2014 we will move to a leased office in Hammersmith to provide flexibility as we grow, while strategically it will make it easier to continue to recruit the right people and will bring us closer to those we need to work with. Our current office in Richmond will become residential, increasing its value and providing a long term source of income.

Legacies are hugely important as although infrequent and unpredictable, they can provide a huge boost that can be invested to support long term benefits. NASS has been very fortunate to be named in legacies which we will probably receive in 2014 and which will allow us to plan and deliver further in the coming years.

So what can or should we be doing?

I've already mentioned the core work of raising the profile of AS, campaigning and influencing, helping and pressing the NHS in delivery, supporting patients and their families, and targeting research. These will undoubtedly continue, with more emphasis on research and direct aid to patients and branches in need.

Young people with AS have a different approach to membership and aren't so likely to join NASS branches, but they still need access to support and to exercise (with other young with AS). Similarly women may have been underdiagnosed, and may benefit from targeted groups and interventions. My working title for these groups has been YAS and WAS (Young with AS and Women with AS), but we will soon be asking our members, to suggest names that would work best for them.

Early diagnosis will remain a core focus until we have a break-through in identification but that appears to be a long way off yet. In the meantime we will have to continue with awareness raising in the public and NHS. However, one of the most far reaching changes would be a mechanism to track the frequency and accuracy/success of referrals from GPs to consultants. This would identify GPs who need help either because they aren't identifying AS patients when other GPs in their practice/group, or because they are being over-zealous. The benefits would apply beyond AS to many other conditions where early diagnosis is problematic.

So there is still much to do. I will step down as Chairman but will remain a trustee to help the handover in the next year. However I will always be a supporter of NASS, hopefully helping with the international campaign while remaining on the committee of my local NASS branch in Lewisham.

Finally I'm grateful for the experience which NASS has given me, a wee boy from Belfast, to try to influence the great wheels of the system and make them to move just a little more in the right direction.

Here's to NASS's future!

Hedley Hamilton
Chairman 13 June 2014

Chief Executive's Report on the year

NASS - Key Achievements in 2013

- Audit of UK Rheumatology Departments on the recommendations within Looking Ahead
- 1630 involved in NASS Patient Survey - helping NASS to campaign and raise awareness
- 4308 Helpline enquiries (up by 14% on 2012)
- 223,085 visitors to NASS website (148,145 unique)
- 15,000 Patient Guidebooks distributed
- Guide to Managing your AS at Work launched
- Back to Action App - over 10,000 downloads
- 89 NASS physiotherapy branches
- First ever Research Priorities for NASS produced

CAMPAIGNING

GP Awareness

2013 was another fantastic year for NASS in terms of GP education. This is such an important area of work for NASS as the delay to diagnosis is still about 8 years. As part of the GP awareness campaign, we ran four large back pain seminars in London, Cardiff, Manchester and Leicester; which reached a fantastic 545 delegates that included GPs, physiotherapists, osteopaths and chiropractors. We hope that these delegates will all have gone back to their respective practices to pass on their knowledge to the rest of their teams. The seminars were often oversubscribed due to their popularity and feedback has been excellent.

> ***"Very useful and informative. I learned new information which will be extremely useful in my practice".***

> ***"Excellent presentations, highly relevant to GPs".***

In April 2013, NASS launched the Back Pain seminar initiative as a 'Meeting in a Box' at the British Society for Rheumatology conference in Birmingham. This puts all the back pain seminar materials onto a CD Rom which can then be used by healthcare professionals to run the seminar in their local area. The aim is to encourage local education about inflammatory back pain to take place. Our 'Meeting in a Box' has had a significant reach both across the UK and indeed internationally, as seen in figure 1.

Figure 1: Meeting in a Box Distribution

NASS is hoping that soon it will be demonstrated that this work is helping to reduce the delays in diagnosis. This is a vital area of work for NASS which will continue into 2014.

Conferences attended by NASS

NASS had exhibition stands at the following conferences:

- British Society for Rheumatology – April 2013
- NB Medical London – April 2013
- Primary Care – May 2013
- Physiotherapy UK – October 2013

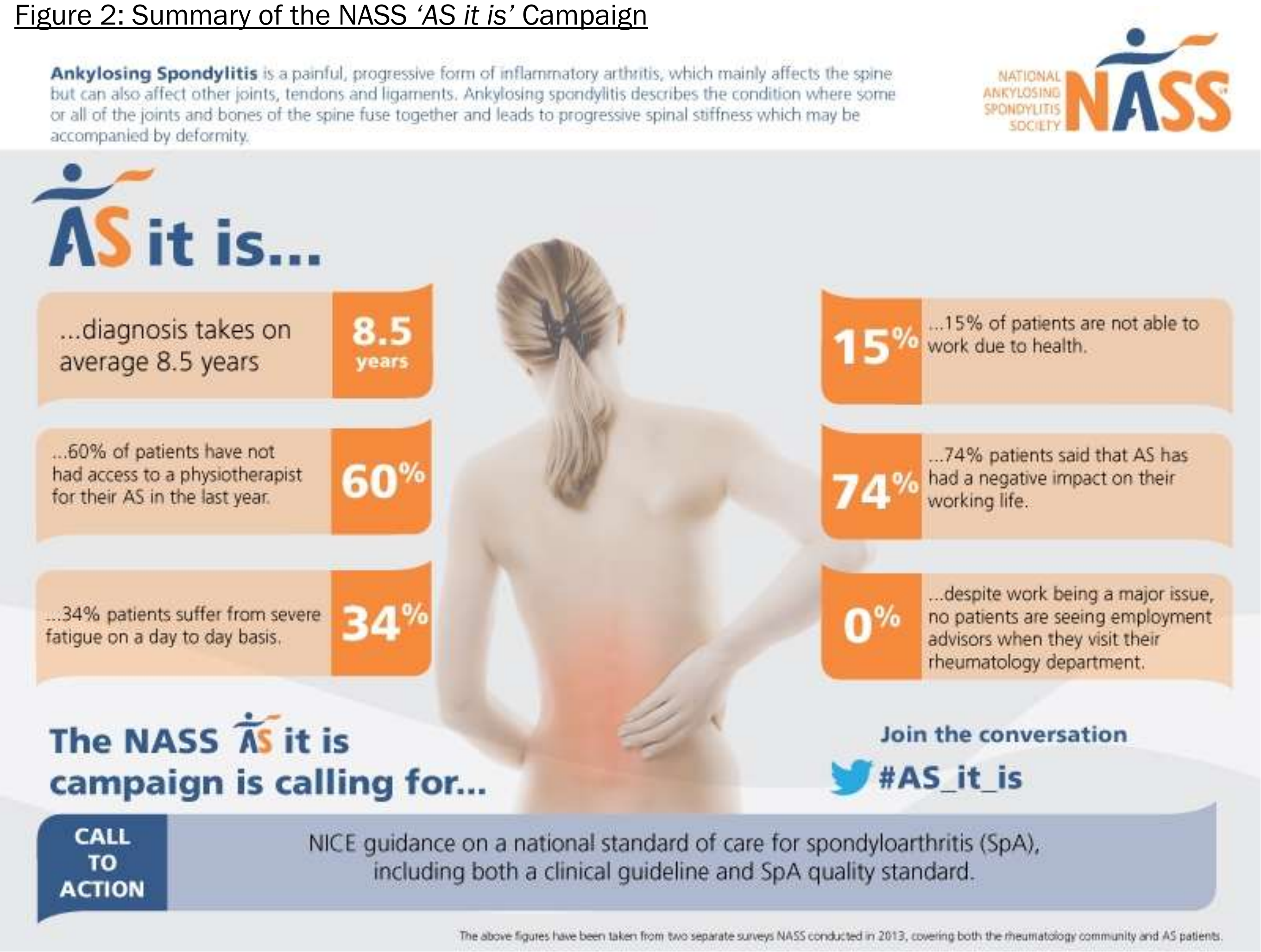
AS it is

On 7th November 2013, NASS launched its *'AS it is'* campaign in Westminster. The sponsored launch event provided a perfect opportunity to once again thank all our wonderful, loyal supporters but also to highlight the reality for people with AS today. See figure 2 for a summary of the campaign.

The launch event at the House of Commons was hosted by Huw Irranca-Davies, MP and Andrew George, MP, both of whom are wonderful supporters of NASS. The National Clinical Director for Musculoskeletal Diseases, Peter Kay also attended and spoke at the event, supporting our campaign. The *AS it is* campaign specifically called on the National Institute for Health and Care Excellence (NICE) and the Government to take swift and appropriate action to introduce a national standard of care for the treatment of spondyloarthritis.

I would like to thank all of our supporters who subsequently wrote to their MPs using our standard letter and encouraged them to write to Earl Howe regarding the issues identified in the campaign.

Figure 2: Summary of the NASS *'AS it is'* Campaign



Ankylosing Spondylitis is a painful, progressive form of inflammatory arthritis, which mainly affects the spine but can also affect other joints, tendons and ligaments. Ankylosing spondylitis describes the condition where some or all of the joints and bones of the spine fuse together and leads to progressive spinal stiffness which may be accompanied by deformity.

...diagnosis takes on average 8.5 years

...60% of patients have not had access to a physiotherapist for their AS in the last year.

...34% patients suffer from severe fatigue on a day to day basis.

...15% of patients are not able to work due to health.

...74% patients said that AS has had a negative impact on their working life.

...despite work being a major issue, no patients are seeing employment advisors when they visit their rheumatology department.

The NASS AS it is campaign is calling for...

NICE guidance on a national standard of care for spondyloarthritis (SpA), including both a clinical guideline and SpA quality standard.

The above figures have been taken from two separate surveys NASS conducted in 2013, covering both the rheumatology community and AS patients.

Parliamentary Events and activities

On 25 February 2013 an adjournment debate was introduced on AS in the House of Commons by Huw Irranca-Davies, MP (below left). His manifesto was based on the recommendations of the NASS Looking Ahead report. As a result of the debate, the Minister for Care and Support, Norman Lamb MP, agreed to meet with Huw Irranca-Davies MP, Andrew George MP, and NASS. This meeting took place in October 2013 and was also attended by Arthritis Research UK with Gillian Eames representing the patient community. The adjournment debate attracted a lot of press attention and subsequently resulted in an article in the Chartered Society of Physiotherapists' Magazine, Frontline which is distributed to 50,000 physiotherapists.

In March 2013, Norman Lamb, MP referred to the importance of early diagnosis for AS in a written answer to a question on disability and musculoskeletal conditions asked by Andrew Gwynne, MP.

During the year, I met with several MPs to discuss the importance of early diagnosis for those with AS and the need for standards of care.

On 2 October a meeting in the Scottish Parliament took place, hosted by the Cross Party Group on Musculoskeletal Conditions. Dr David Marshall and Dr Raj Sengupta, consultant rheumatologists, myself and patient Iain Macdonald (who volunteers for NASS in Scotland) spoke at the event. Patricia Ferguson MSP, attended this event and subsequently asked a number of parliamentary questions about AS.

NASS hosted a sponsored Round Table discussion in December 2013 in the Scottish Parliament attended by MSPs, members of the Scottish Government, the NHS and patients. All of this work is helping to raise AS-related issues with policy-makers and those involved in health care provision.

World AS Day and NASS en Masse

The first Saturday in May has been named as World AS Day by the Ankylosing Spondylitis International Federation (ASIF). NASS hold events every year to mark the occasion and in 2013 held 3 NASS en Masse 5 km sponsored walk events in Glasgow, Portsmouth and London during May and June. London's event in Hyde Park also saw a 10 km run.

NASS en MASSE 2013

3 Cities

300 Participants

Over £10,000 raised!

James O'Brien organised an awareness day at Rylands Farm in Dorset featuring some of the top health professionals in their respective fields. Thank you to the 300 plus people who took part, volunteered at and organised the events, raising over £10,000 for NASS and much-needed awareness of AS.

We also asked our members to use World AS Day as the perfect opportunity to spread the word about AS – giving a portfolio of facts and figures for them to pass on to their friends and family.

World Arthritis Day

World Arthritis Day takes place on 12 October every year and is recognised by the United Nations as an official 'day'. In 2013, following on from our fact sharing exercise on World AS Day, NASS asked members to come up with one sentence to describe how it feels to live with AS and share it with their friends and families to help raise awareness. The day was also marked with attendance at the Physiotherapy UK Conference on 11 and 12 October. All NASS branches were asked to contact their local newspapers to mark the occasion and were provided with a standard press release accordingly.

World Autoimmune Arthritis Day

This was marked with a 2 day online exhibition where organisations were invited to display their materials in a virtual booth. This is the first time that NASS has participated in this event.

Looking Ahead Audit

Looking Ahead was produced in 2010 and is the NASS guide to best practice for the care of people with AS.

In 2012 we decided to conduct an audit of UK rheumatology departments to assess how far the 7 Looking Ahead recommendations for best practice have been implemented. The main objective of the Looking Ahead audit was to improve standards of care in rheumatology departments across the UK. NASS would like to ‘level the playing field’, ensuring that all rheumatology departments are working at an equally high standard, avoiding inequalities of care.

Other aims included:

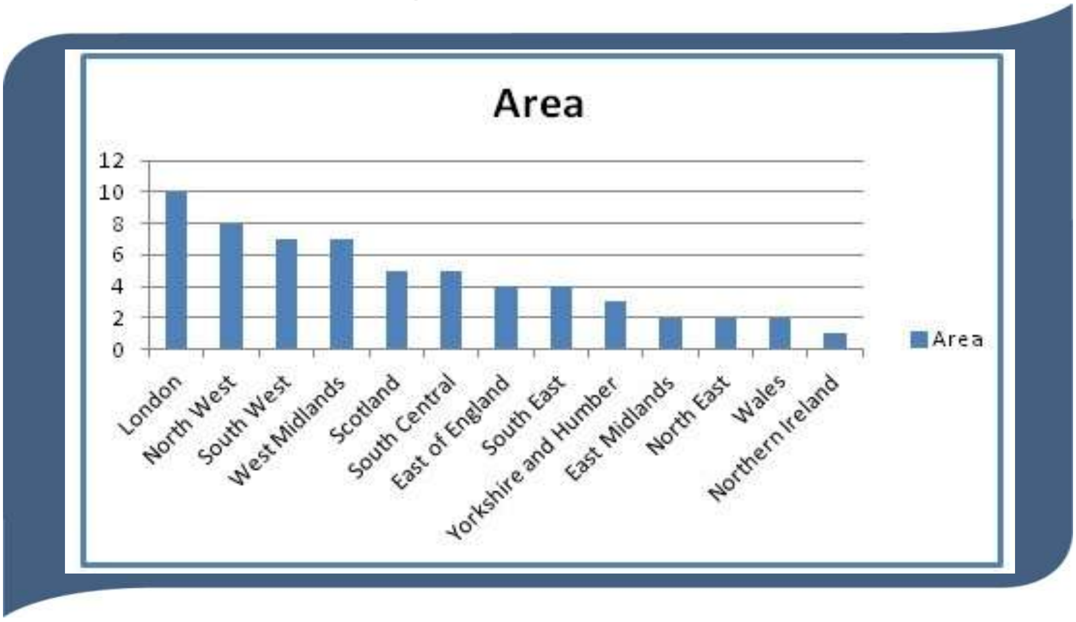
- Gaining a snapshot of current practice in rheumatology departments throughout the UK
- Understanding the strengths and weaknesses of rheumatology departments across the UK regions
- Understanding which Looking Ahead recommendations have been implemented and which have not, thus guiding NASS’s future work programme.

Colin Beevor, Senior Clinical Nurse Specialist for Rheumatology Services at Portsmouth Hospitals NHS Trust had already conducted an independent internal audit of his department’s AS services using Looking Ahead. NASS took the system he used to audit his department and grow it into a national project.

At the beginning of September 2012 NASS emailed all the rheumatology departments in the UK asking them to take part in the audit. The audit closed in January 2013. In total 60 rheumatology departments took part in the audit.

Demographics

Figure 3: Distribution of Rheumatology Departments in the UK



Rheumatology departments from across the UK responded to the research

In the vast majority of cases, at least two members of the rheumatology team filled out the audit together and commonly more were involved. A consultant rheumatologist was involved almost all (96%) of the time.

Seven in ten (71%) of audits included a rheumatology physiotherapy and six in ten (61%) included a rheumatology nurse. Occupational therapists were less likely (20%) to be included.

Although NASS did strongly recommend including a patient at some stage in the process, only 12% of departments were able to involve a patient. Judging by some of the comments from departments this was often due to logistical issues.

For the rest of the audit we asked that each individual rheumatology department assess themselves on each of the recommendations of the Looking Ahead guide using a Red, Amber, and Green rating. It was explained that:

Red means your unit does not meet this recommendation

Amber means your unit is working towards this recommendation but has not yet achieved it

Green means your unit meets this recommendation

The main research showed that the best met recommendations were:

90% - People with AS should be made aware of the availability of anti TNF therapy and offered treatment if eligible.

73% - People with AS should have access to all appropriate specialists and treatments.

72% - People with suspected AS should be referred to a rheumatologist.

71% - Diagnosis of early AS/axial SpA should be made without waiting for x-ray changes: MRI is the investigation of choice.

The worst met recommendations were:

57% - People with severe spinal deformity should have access to expert surgical assessment and treatment.

65% - People with AS should be followed up regularly and have ready access to expert reassessment.

65% - Back pain assessment pathways should include a system for the recognition of inflammatory back pain.

AS it is patient survey

To complement the Looking Ahead audit, we decided to conduct a survey of people with AS living in the UK. The main aims of this research were to:

- Raise AS awareness through the media
- Raise AS awareness within Parliament
- Provide a better understanding of how AS patients are managed in the UK
- Campaign for better services in the UK for people with AS

An online self completion questionnaire comprising a mix of 55 open and closed questions was used. The survey link was emailed to NASS members and was advertised via NASS E-News, Twitter, Facebook and the NASS website. The survey was set up to only accept one entry from an IP address. The survey was only for people living in the UK. 1630 UK AS patients completed the questionnaire between 9 August and 6 September 2013.

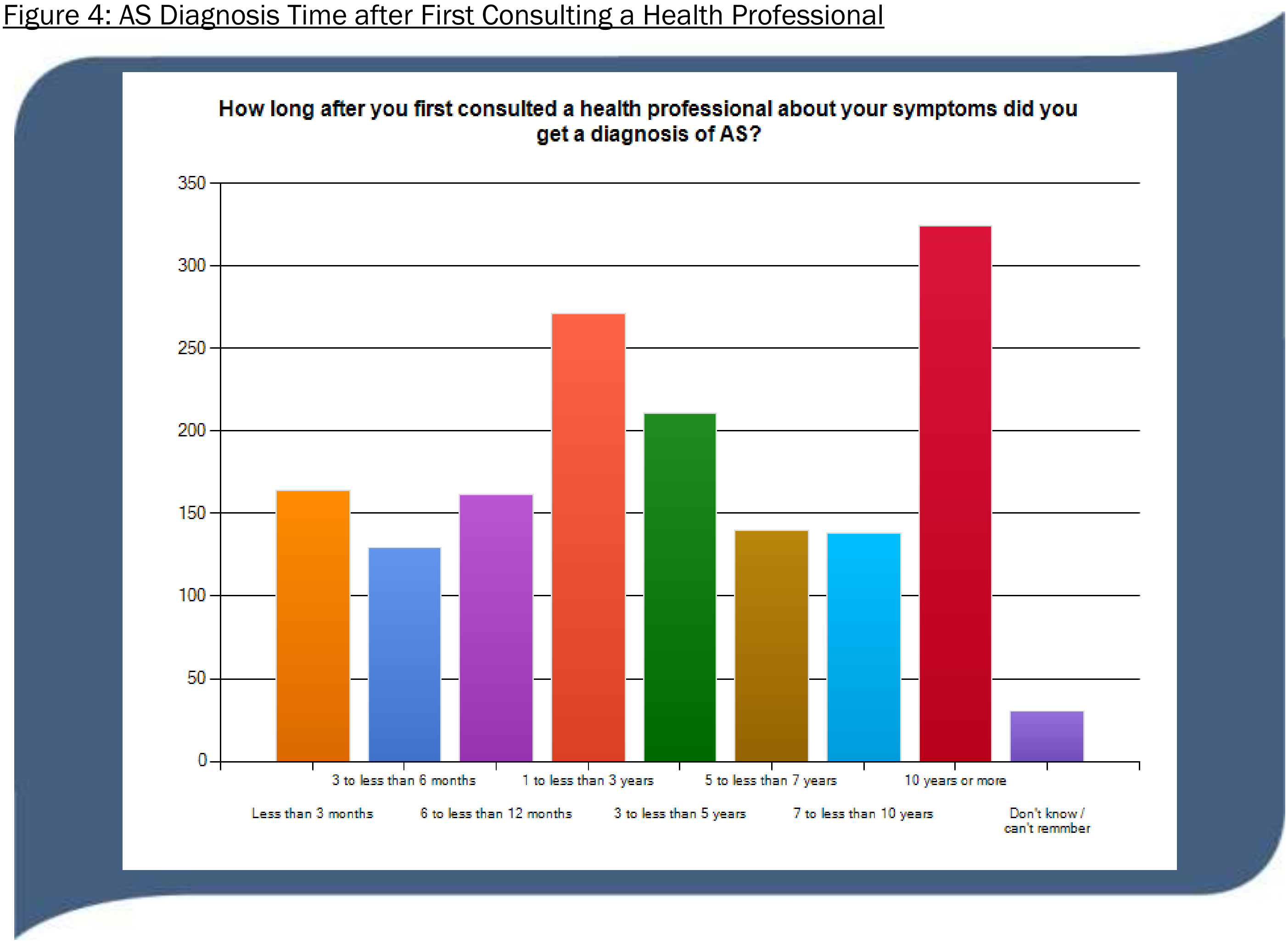
Key findings from the survey were:

- 78% are now under the care of a rheumatologist (compared to 68% in 2010)
- The average satisfaction rating with rheumatologists was 4.09 out of 5
- However, average satisfaction ratings with help and advice from departments during a flare drops to 3.63 out of 5

- 60% have not received any physiotherapy in the past 12 months
- The overall satisfaction with care received in the past 12 months is an average 3.56 out of 5
- Help with employment issues is currently missing from care in the UK

Figure 4 emphasises the importance of NASS campaigns such as the GP awareness initiative as over 300 participants of the *AS it is* survey said it took them over 10 years to get an AS diagnosis after first consulting a health professional.

Figure 4: AS Diagnosis Time after First Consulting a Health Professional



INFORMATION AND SUPPORT

Helpline

During 2013, Sally Dickinson (Information and Communication Manager) received and responded to 4,308 Helpline enquiries, compared with 3,792 in 2012. This represents a year on year rise of 14%.

4,308 helpline enquiries

14% increase on 2012

10,000 helpline cards distributed

The Helpline is advertised in all our publications and on every page of the website. Early in 2012 we produced business card sized Helpline cards which we distributed to rheumatology departments throughout the UK. Rheumatologists, rheumatology nurses and physiotherapists can hand these cards out to patients who they feel would benefit from contacting NASS. Since the start of 2012 we have distributed approximately 10,000 Helpline cards to rheumatology departments.

Throughout 2013 the number of people calling the Helpline regarding benefits issues, including Disability Living Allowance, Personal Independence Payment and Employment and Support

Allowance continued to increase. This remains largely due to the changing political landscape resulting in the potential for members to lose benefits they have been receiving for many years. Sally now spends a significant proportion of her time advising people on these issues and writing formal letters of support to the Department for Work and Pensions.

Website

During 2013 NASS had 223,085 visitors to the website (www.nass.co.uk), of which 148,145 were unique visitors. This compares with 146,720 visitors to the website in 2012, of which 94,534 were unique visitors. This represents a year on year rise in visitors of 57%.

Welcome to NASS - working for people affected by ankylosing spondylitis

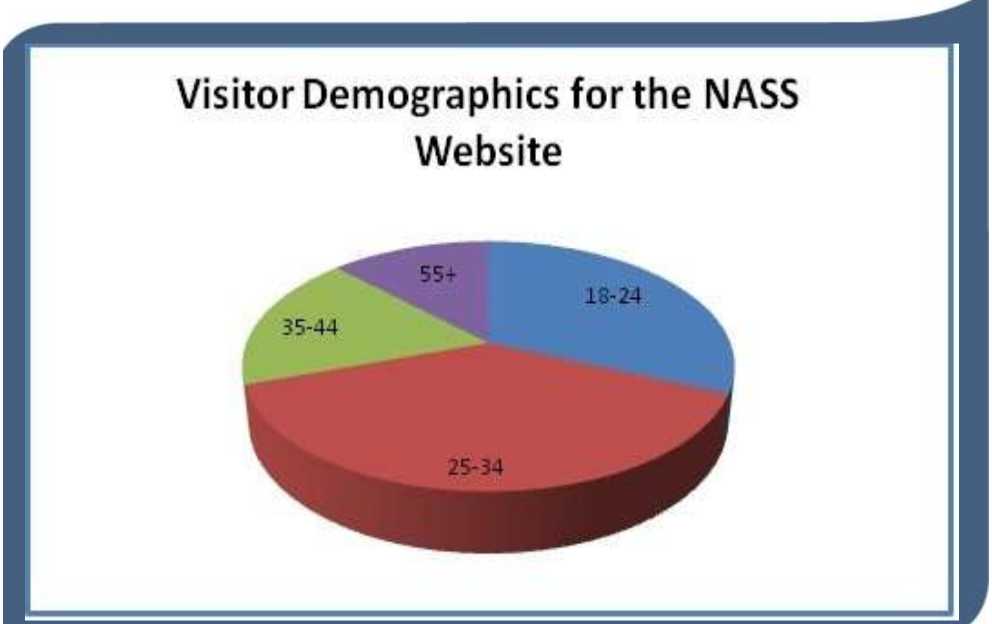
Join NASS and make your voice heard

Resources for health professionals

	2012	2013
Website Visitors	146,720	235,085
Unique Visitors	94,534	148,145

57% increase in visitors to our website from 2012

Figure 5: Age Distribution of NASS Website Visitors in 2013



65% of visitors to the NASS website were new visitors. In terms of demographics, 46% are female and 54% male. Our visitors tend to be younger. 28% fall into the 18-24 age category, 34% 25-34 and 16% are 35-44. Just 11% are 55+ (see figure 5). An Age UK report 'Later life in the UK' published in February 2014, shows that 64% of those aged 65+ have internet access at home, but only 5% of people visiting the NASS website are 65+. We perhaps need to do more to encourage 'silver surfers' to the NASS website.

As expected, the majority of our website visitors are based in the UK, with smaller numbers being based in the USA, Australia, India, Canada and Ireland.

On a typical visit, people will look at an average 3.5 different web pages. After the home page the most popular pages are:

- About AS (pictured right)
- Inflammatory back pain
- Exercise
- NASS Near You
- News
- Forum
- The AS Pathway
- Getting my diagnosis

NASS encourages traffic to the site by regularly updating pages and adding new information. In particular we work hard to keep our news pages updated, often on a daily basis but always weekly. We have also added more photographs and reduced down text where possible. Our aim in 2014 is to add more videos, both of clinicians talking about AS and people with AS discussing their personal experiences.

Members' Forum

The website forum became increasingly popular throughout 2013. The number of members joining the forum and the number of posts on the forum have increased significantly and the forum is now perceived as a worthwhile member benefit. By the end of 2013, more than 1,000 people were members of the forum and there were daily postings.

However, when NASS moved to our new website platform, the original forum was maintained and 'bolted on' to the new website. The design of the forum now looks outdated and it is not particularly user-friendly. NASS will be looking to upgrade the forum in 2014 accordingly.

A particular problem with the forum is that once NASS members have gone through the login process, they cannot leave it open and stay logged in. In response to requests from forum members, NASS experimented with having open access to the forum for 1 month (mid-November to mid-December). For the first week the experiment worked well, new members joined and existing members were far more easily able to access the forum. By week two we started to have problems with spam postings and by week three we needed to spend an hour each day clearing spam postings. Part way through week four, the task of managing the spam become overwhelming and we were forced to cut short the experiment and close the forum again. A newly designed forum with better security to avoid spam could alleviate these problems.

Social Media

In order to optimise our target audience NASS has engaged 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 that we are is communicated to others, both in a timely manner and through various channels.

During 2013 we continued to post on our Facebook page (National Ankylosing Spondylitis Society). We try to post at least once a day, Monday to Friday. By the end of December 2013 we had over 3,000 'Likes' on our Facebook page.

We have two Twitter accounts; @NASSdirector (now changed to @NASSchiefexec) and @NASSexercise. Followers for both these accounts rose steadily throughout the year. Twitter continues to be a great way of interacting with our supporters.

Over 1,000 Followers on Twitter

Over 3,000 Likes on Facebook

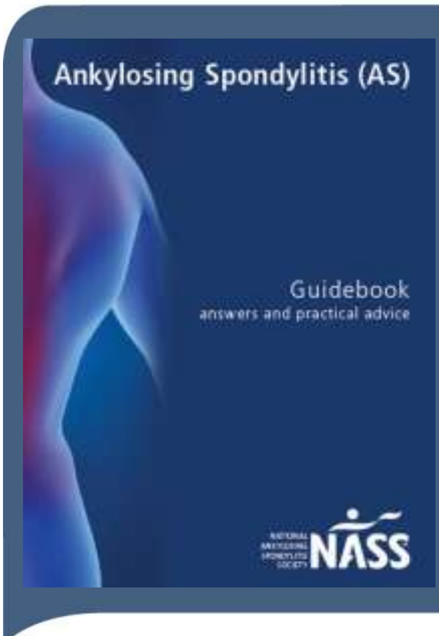
I believe that our social media work is an extremely valuable part of our work in terms of communicating and interacting with patients, supporters, clinicians, policy-makers, and researchers. NASS will look to develop further social media channels throughout 2014.

Printed materials

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.

During 2011 NASS distributed 5,000 guidebooks. 10,000 guidebooks were distributed during 2012 and 15,000 guidebooks were distributed during 2013.



Ankylosing Spondylitis (AS)

Guidebook
answers and practical advice

NASS

15,000 Patient Guidebooks distributed in 2013

Factsheets

We aim to build a portfolio of factsheets on issues which members tell us are important. During 2012 three new factsheets covering uveitis, fatigue and driving were introduced. These proved very popular. Fatigue has been our most popular with around 5,000 copies being distributed in 2013. Approximately 4,000 copies of the uveitis leaflet have been distributed, along with 2,000 copies of the driving leaflet.

In autumn 2013, NASS produced a new guide to 'Managing your AS at Work.' This 16 page guide is 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.

As with our guidebooks and leaflets, this new guide is distributed free of charge to rheumatology departments and is posted out to anyone who requests a copy.

Benefits & Work guides

State benefits remain a major issue for many with AS. NASS has a professional subscription to the Benefits and Work website which allows us access to a whole range of practical guides to claiming or appealing benefits. These include guides to claiming and appealing Employment and Support Allowance (ESA), Disability Living Allowance (DLA) and Personal Independence Payment (PIP). This website offers the advantage of ensuring all these documents are regularly updated.

Due to copyright restrictions we cannot put these reports onto the website but we do email them or print and mail copies to any NASS member who contacts us. NASS also regularly writes supporting letters to the Department for Work and Pensions for individuals with AS. In 2013 we wrote 91 supporting letters.

AS News

AS News, our members' magazine is produced twice a year in the spring and autumn. NASS trustee Ben Hoare, works as an editor for a magazine and he kindly volunteered his help and advice in improving the look and feel of AS News during 2013. His help proved invaluable and AS News now looks a far more vibrant publication, as can be seen in the examples below.

We continue to produce NASS Active in the autumn, the magazine celebrating all the wonderful supporters raising money for NASS. We advise all supporters that they will be featured in NASS active and encourage them to send in photographs of their event. This supplement celebrates our fundraisers and aims to show how grateful we are to them for their continued efforts. It also helps show what can be achieved, aiming to inspire future fundraisers for NASS.

Medical Advisory Board (MAB)

The MAB is integral to all the information produced by NASS. It comprises:

- 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 3 times a year and additionally individual members write articles for AS News, provide guidance for the website, help with the information for guidebooks, factsheets and leaflets and assist with more complex Helpline queries.

Patient Conference

The NASS Patient Conference and AGM was held on 29 June 2013 at Birmingham City Football Club. The conference was supported by a grant from UCB Pharma Limited allowing NASS members plus one guest to attend free of charge. The conference was attended by 150 members, guests, trustees and health professionals. Guests were treated to a series of presentations and interactive workshops in the areas of 'AS: all the facts', 'Fatigue: management and measurement', 'Coping with a flare' and a 'Research in AS' update. The afternoon session saw a choice of round table discussions as well as a 'friends and family' session which ran at the same time as the AGM.

We are very grateful to all the speakers for giving their time including Dr Raj Sengupta, Ingrid Hill, Brisa France, Dr Jane Martindale, Professor Dennis McGonagle and John Boyle.

NASS plans to hold conferences in Wales, Scotland and Northern Ireland should the funding become available.

Due to feedback received largely through the NASS Members' Forum, the Patient Conference has now been renamed the NASS Members' Day to give it a less formal, friendlier feel, particularly to encourage new members to come along.

Back to Action

Following the successful launch of the Back to Action App on the iPhone OS and android platform, the App has now been downloaded over 10,000 times with users giving it a 5* rating. Back to Action is now also featured in the NHS Health App Library and the European Directory for Health Apps. 2014 is likely to see further development of the App with a prospective upgrade in 2015.

WORKING WITH OTHER ORGANISATIONS

ARMA

NASS is a member of the Arthritis and Muscloskeletal Alliance (ARMA). We are working with ARMA to pursue these goals:

- Musculoskeletal (MSK) disorders to be recognised as a health priority
- Care that meets the needs of people with MSKs
- Access to the right care, in the right place, at the right time
- People with MSKs to be able to live a healthy, independent and fulfilling life

NASS attends various ARMA meetings for discussions on policy. I also attend the Chief Executives' meetings to share best practice and look for opportunities to work together with other organisations. In October, I was also elected to serve as an ARMA trustee for a second year.

Scottish Medicines Consortium (SMC)

The Scottish Medicines Consortium (SMC) is responsible for providing advice to the NHS in Scotland about the use of new medicines, including the value of each new medicine and the patients for whom these would be of most benefit.

In doing so, it undertakes an assessment of clinical and economic information provided by the pharmaceutical company introducing the medicine. It takes account of the assessments undertaken by its own pharmacists and health economists, contacts clinical experts for their views and receives submissions from groups which represent the views of patients, their carers and families.

In January 2013 the SMC approached NASS to make a Patient Interest Group Submission (PIG) for the new indication of adults with severe axial spondyloarthritis for adalimumab (Humira). This basically meant that adalimumab could be prescribed to people with AS who did not have changes on x-ray.

NASS emailed all our Scottish members to ask for their views and used the responses to formulate a detailed submission to the SMC. We took a positive view, strongly supporting the submission and were delighted when the SMC found in favour of this new indication for Scotland.

All Wales Therapeutics and Toxicology Centre (AWTTC)

The Welsh Government has a fast track appraisal system for new medicines for use within NHS Wales, which can result in their use and funding ahead of guidance from the National Institute for Health and Clinical Excellence (NICE). The All Wales Therapeutics and Toxicology Centre (AWTTC) provide administrative and professional support to the All Wales Medicines Strategy Group (AWMSG) which gives advice to the Minister for Health and Social Services.

The AWTTC also contacted NASS in early 2013 regarding the new indication for adalimumab and asked us to make a PIG. Again we emailed all NASS members in Wales to ask for their views and again we took a positive view, strongly supporting the submission. The AWTTC found in favour of this new indication for Wales.

National Voices

NASS is a member of National Voices, a coalition of health and social care charities in England. NASS attended various meetings throughout the year to discuss future policy and help establish the House of Care which has since been adopted by NHS England.

Prescription Charges Coalition

The Prescription Charges Coalition brings together 29 organisations calling 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.

NASS, as part of the Prescription Charges Coalition continued to campaign for free prescriptions for people with long term conditions. The Paying the Price report was launched on 11 March 2013. It highlighted the significant, detrimental impact that prescription charges are having on people with long-term conditions. Following on from the launch of this report, a campaign saw almost 3,000 people write to their MP on this issue.

Pain UK

NASS joined Pain UK towards the end of 2012. In 2013 NASS had a presence at several events for health care professionals via Pain UK, providing a selection of literature to be distributed about AS.

British Society for Rheumatology (BSR)

NASS continues to work with the BSR on a number of rheumatic conditions-related activities. In October 2013 NASS was awarded as ‘Highly Commended’ in the BSR Best Practice initiative which identified and rewarded organisations in rheumatology and musculoskeletal services, quality and efficiency outcomes whilst maintaining the highest levels of patient care. This was a huge accolade for a small organisation such as NASS.

I am now a member of the BSR AS Biologics Register Committee and I continue to work on the Anti TNF guidelines group. I would like to thank Robin Brittain who also attends meetings of this group to represent the patient community.

2020 Health

During the year NASS and other stakeholders worked with 2020 Health on a report seeking to raise the profile of ankylosing spondylitis and how it should be managed with policy-makers. This report is expected to be launched in 2014.

Arthritis Research UK (ARUK)

I continue to represent NASS on the ARUK Clinical Studies Group for Spondyloarthritis which makes recommendations to ARUK on research proposals. NASS continues to work with ARUK on a number of initiatives and policy-related activities.

WORKING WITH THE MEDIA

During 2013 NASS and our supporters worked very hard to raise the profile of AS. We had a particularly successful year. We were very successful in achieving media coverage for the NASS 'AS it is' campaign. Following on from this the new anti TNF therapy, certolizumab (Cimzia) was launched in December 2013. I attended a media advisory board and there was a great deal of subsequent media coverage.

NASS would not be so successful in achieving media coverage without the generosity of members in giving their time to talk with journalists about their personal experiences of living with the condition.

- Learning to live with chronic pain, The Irish Times, 16 January
- Hydrotherapy pool closures leave NHS patients high and dry, The Guardian, 22 January
- Singing and music kept me going, Portsmouth News, January
- Huw Irranca Davies MP puts AS in the news, BBC News Wales, February
- Huw Irranca-Davies talks about his AS, South Wales Echo, 26 February
- Greg gets ready for marathon challenge, Newmarket Journal, March
- A lifetime prescription of exercise, Frontline, Chartered Society of Physiotherapy, 6 March
- MPs hear call for better treatment for AS, Frontline, Chartered Society of Physiotherapy, 6 March
- Back pain advice on offer as hospital roadshow visits Ilford, Redbridge Guardian, 13 March
- 34,500 GPs hear about our recommendations for the care of AS, GP magazine, 15 March
- Simone aims to be a star in 13-mile `Moon Walk`, The Derby Telegraph, 2 May
- Kelyvn Morris talks AS, BBC Radio Wales, August
- I was often in unbearable pain. This drug is amazing, it has changed my life, Western Mail, 12 August
- Adrian O`Hanlon talks AS, Newry radio Q100.5, September
- National standard could improve AS care, Primary Care Today, 21 October
- BBC Radio 5 Live, 17 November
- MP supports calls for chronic arthritis care, Burton Mail, 28 November
- Yes, the NHS can improve the patient experience for people with AS. Primary Care Today, Winter issue
- MP adds support to back sufferers' charity, Belper News, 3 December
- Lancing man's painful condition was undiagnosed for seven years, Sussex Argus, 2 December
- Plagued by backache doctors can`t explain? The Daily Mail, 3 December
- MPs support AS patients bid for better care, Primary Care Today, 5 December
- NHS to offer spinal arthritis drug Evening Standard, Belfast Telegraph, Herts & Essex Observer, The Times Series, Yahoo! And MSN, 12 December
- New jab to alleviate the misery of back pain, Daily Express, 12 December

PHYSIOTHERAPY

NASS was delighted to promote another 2 training courses for physiotherapists which were held by AStretch, a group of physiotherapists that steer the management and improve the understanding of AS. Claire Jeffries and Karen Irons, both members of AStretch led the courses in Portsmouth in July, and London in October.

BRANCHES

We were delighted that a further 2 branches became active in 2013 in Preston and Leeds. This took the total number of branches at the end of 2013 to 89. Maddy Randall and Jill Hamilton attended AS Awareness Evenings with a view to setting up branches at Guy's & St Thomas' (London), Ilford, Salford, Greenock, Luton and Wrexham.

Branch fundraising, communications & promotion

Branches were actively encouraged in 2013 to seek additional funding from various sources as and when they became available. Many branches took the opportunity to apply for a small grant with the Galaxy Hot Chocolate Fund and were awarded grants of £300. Many branch members also go to extreme lengths to raise money, like NASS Camden's Phil McMullan (above right) who did a sponsored skydive.

Towards the end of 2013, every e-news featured a 'branch of the month' and daily tweets were sent out via the @NASSexercise account on Twitter advertising branches meeting that day.

Branch development

The final stages of the 3-year branch development plan were put into action as 3 further branch development conferences were held in Bristol, Portsmouth and London, attended by 31 branches in total. The feedback from these conferences has been excellent, with many branches changing their practices for the better.

I was also able and delighted to visit the Brighton, Leicester, Oxford and Rotherham branches in 2013.

89 active NASS branches

3 branch development conferences

31 branches attended

FUNDRAISING

Legacies

We are incredibly grateful to all those who have chosen to leave a gift to NASS in their will. Legacies are a vital source of core funding, and this kind act enables NASS to make a positive impact for generations to come.

This year we acknowledge legacies from:

- Marion Alice Zanella
- Douglas Adams
- Percy Brian Moseley
- Dawn Houlden

Trusts

We express huge thanks to the charitable trusts and grant making organisations that provided much appreciated support throughout the year:

- Reuben Brothers Foundation
- Alys & Graham Ferguson Trust
- G C Gibson Charitable Settlement
- C M Keyser Charity Trust
- The Vivienne and Sam Cohen Charitable Trust
- PF Charitable Trust
- The Simon Gibson Charitable Trust
- Grantham Lions Club
- Longview Trust
- The Bernadette Charitable Trust
- C M Keyser Charity Trust
- G C Gibson Charitable Trust
- John Coates Charitable Trust
- The Charles Fairweather Charitable Trust
- The Michael and Anna Wix Charitable trust

Companies

We have been delighted to receive support during 2013 from the following companies:

- Healthcare at Home
- UCB Celltech
- RHWL Architects
- AbbVie Ltd
- Pearson Assessment
- Medicys

- FirstEnergy Capital LLP
- BRPI
- Nicky Spode Medical Market Research
- Working at Height
- Merck, Sharp and Dohme

Reactive fundraising

In 2013 over 70 fundraisers took part in, or organised, events around the country ranging from a coffee morning to walking 100 km, raising over £55,000 in the process. Our fundraisers are amazing and an inspiration to us all. I would like to thank them once again for all the effort they put in for the charity; we simply could not function without them and we love having the pleasure of working with such amazing fundraisers and supporters.

Our fantastic fundraisers raised over £55,000 in 2013!

THANK YOU!

WORKING WITH THE PHARMACEUTICAL INDUSTRY

NASS continues to be transparent about the work we do that is supported by the pharmaceutical industry. Each year we set our priorities in advance. NASS has been able to achieve enormous growth in terms of the work we have delivered for patients and in terms of education; much of this could not have been achieved without 'hands-off' support from industry. All of our projects specifically state clearly if they have been supported by industry. NASS also works in partnership with industry colleagues by sharing our experiences of the patients' needs in order that industry can thus improve their approach; ensuring that the patient benefits from this partnership working.

MEMBERSHIP

Subscription rates remained the same in 2013. At the end of 2013, NASS had 6079 members. Following on from the production of our membership strategy approved at the end of 2012, a number of practices were introduced, including a follow up with new members to offer any additional help they may need, mailing those who contacted the Helpline asking them to become members and one month's free access to the members' only forum on the website. Plans are in place for 2014 – 2015 to further implement plans such as conferences for newly diagnosed patients.

By the end of 2013, NASS had 6079 members

NASS is very grateful to all our members for the fantastic support that they show the charity. Without our members we could not claim to be the voice of people with AS – we believe in strength in numbers. 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. I remain passionate about listening to our members and we continue to implement practical ideas at their request where possible. Retaining and recruiting members is as important as ever, so thank you for all your support.

> **“Being a member of NASS is about being a part of a community”**

Royal National Hospital for Rheumatic Diseases (RNHRD), Bath

I continue to serve as a governor on the Council of Governors at the RNHRD. I have endeavoured throughout the year to represent the patients’ view about AS services in particular and to express opinion about the proposed ‘acquisition’ of the RNHRD by the Royal United Hospital in Bath. I have also endeavoured to keep our supporters fully up-to-date with information about the RNHRD through the NASS website and on my blog pages.

Ankylosing Spondylitis International Federation (ASIF)

I continue to serve on the ASIF Executive and participate in monthly conference calls and worldwide email exchange in order to co-ordinate the good AS-related work which is taking place across the ASIF organisations. Our Chairman, Hedley Hamilton also continues to serve as ASIF Vice-President.

RESEARCH

Research Strategy

Early in 2013 NASS commenced work to develop our research strategy, working in partnership with the Faculty of Health and Medicine at Lancaster University. While NASS does not have a huge research budget, we are still able to influence the research agenda. We wanted to ensure that our research priorities took into account the views of our members, the AS community and health care professionals.

NASS members were asked to send in their research priorities. More than 150 people sent emails containing detailed suggestions. Thank you to everyone who took the time to contribute. Your suggestions were invaluable.

The team at Lancaster University brought all these suggestions together and fed them into a one day workshop which was held on 2 February 2013 at the university and attended by 25 people, including NASS members, rheumatologists and physiotherapists. During the first part of the day research priorities were identified and then the group discussed how they would prioritise the areas of research they had identified.

We then shared the research suggestions from that day and gave you the chance to assess the suggestions and prioritise them in terms of how important they are to you. There was also the opportunity to tell us your research suggestion if you felt it hadn't been covered in the current suggestions. 716 NASS members took part in the research.

These are your top 11 research priorities. You might also like to download and read the full report which is on the research section of the NASS website.

1. Develop a greater understanding of AS triggers that lead to flares
2. Evaluate different ways of improving GP and health care practitioner understanding of AS
3. Develop better understanding of the impact of fatigue on people with AS
4. Provide better understanding of the type of exercise needed depending on age/severity
5. Develop a self-management programme to help people manage their AS effectively
6. Review anti-TNF to help people make more informed decisions
7. Review efficacy and side effects of medications to help people make more informed decisions
8. Develop a greater understanding of the impact of dealing with other conditions associated with AS
9. Evaluate different strategies to manage pain
10. Improve information flow between primary and secondary care
11. Develop and evaluate different approaches to exercise

Genetic Research

The support for the genetic research being undertaken at Oxford University by Professor Paul Wordsworth and his team continues. A further 229 members were mailed in March 2013 asking them to take part in the research by providing a saliva sample. Several research papers were also published in 2013 as a result of the funding from NASS for a research assistant between 2010 and 2012.

THE NASS TEAM

There were a number of changes in the NASS Team during 2013. In March, Catriona Finlayson joined us as a part-time Fundraising Manager. In September Jessica Fogden joined us as our very first Apprentice and at the same time Maddy Randall commenced her maternity leave. At the end of the year we said goodbye to Sophie Matthew as her temporary contract came to an end. (Sophie continues to support NASS and join us at events when she can and so it didn't really feel like a proper goodbye). At the end of the year the organisation was running with half a post less than when I joined in 2011 but as this report and our statistics demonstrates, NASS has tripled its output during that time. I wish to formally thank all of the Team for their hard work and dedication. They all continue to show extraordinary commitment in their roles at NASS and to the AS community.

The NASS team in 2013 were from left to right, Camila Garces-Bovett, Debbie Cook, Jessica Fogden, Jill Hamilton, Catriona Finlayson, Sally Dickinson and Sophie Matthew.

At our Annual General Meeting in June, Roger Stevens (the Chairman of NASS Portsmouth) joined the Council of Management as a co-opted trustee. Hedley Hamilton advised members at that meeting of his intention to stand down as Chairman in 2014. I wish to thank all of our trustees and Medical Advisory Board for all of their hard work and dedication throughout the year – attending meetings at weekends, participating in evening and early morning conference calls, most of which goes unseen by our supporters generally. I would also like to thank Hedley Hamilton for his work as Chairman of NASS during the last 6 years.

NASS is also grateful for the support received from volunteers throughout 2013. Volunteers support our work in many ways. From the 60,000 hours of exercise delivered through branches each year, invaluable guidance from the medical advisory board, to the weekends given up to cheer on fundraisers, help out at events or in the office – every hour of time given is greatly appreciated.

THE FUTURE

With an organisation like NASS, how can we fail to be excited about the future? We've lobbied hard for Clinical Guidelines and have been advised that NICE will commence a process in 2014 to produce such guidelines which will hopefully see an improvement and indeed consistent quality of care for AS patients. The NICE Clinical Guideline process usually takes about 2 years from start to finish.

Our GP awareness project continues to be a priority area of work for NASS. Further Back Pain seminars are scheduled to take place in Reading, Lincoln and Bath for certain in 2014 with others likely to be arranged.

Our patient information library continues to grow. As well as publishing the much-requested Guide to AS at Work at the end of 2013, two new factsheets on Flares and Anti TNF are planned for 2014.

You can see how our website hits continue to rise. It is fantastic to see how NASS is seen as a credible source of AS information and we know that clinicians are increasingly referring their patients to us, which is great. In 2014 NASS will be investing in improving our online forum for our members. We know that this is an excellent way of gaining peer-to-peer support and want to see it improved.

2014 will also see the introduction of a new initiative from NASS; our 'AS and you' events for newly diagnosed patients will be piloted across the UK, aiming to bring together young people with a recent AS diagnosis in an informal, relaxed setting, to help out with understanding and managing their condition. I am really excited about this initiative which is likely to be further developed to form a young persons' specific organisation within NASS.

NASS will continue to work hard to raise awareness about AS in the media and through our campaign work. We are planning to be involved in an industry supported initiative called 'Don't Turn Your Back On It' in 2014. We will also be further developing our *AS it is* campaign to highlight that patients need better access to physiotherapy in particular.

In 2013 we really struggled to get our planned work in Northern Ireland off the ground but we will continue to work hard to see NASS activity there in 2014. A Welsh Senedd event took place in March 2014, as is further work in the Scottish Parliament. Indeed, if we can secure funding we'd also like to do more specific work in Scotland and Wales with the AS patient community.

Thank you to everyone who has once again made 2013 a successful year for NASS and who continue to support us going forward. It is a pleasure to work for this fabulous organisation. We have another busy year ahead; there still continues to be much to do to see ankylosing spondylitis get the recognition and attention it deserves within our healthcare systems.

Debbie

Debbie Cook

Chief Executive 13 June 2014

NASS Trustees' Report

The Trustees present their report and accounts for the year ended 31 December 2013, prepared in accordance with current statutory requirements and in accordance with the Charity Commission Statement of Recommended Practice.

1. REFERENCE AND ADMINISTRATIVE DETAILS

a. Name, address and registration

The name of the charity is the National Ankylosing Spondylitis Society and its address is Unit 0.2, One Victoria Villas, Richmond, Surrey TW9 2GW. 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	
Hedley S Hamilton	(Chairman)
Simon H Frost	(Treasurer)

Ordinary Members
John Boyle
Stephen Dean
Eric N C Eustance FCMA MCT
Dr Karl Gaffney
Claire Harris
Ben Hoare
Dr Richard Jacoby MD FRCP
Dr Andrew Keat
Ruth Miller
Grant Poiner
Peter Wheatley-Price
Professor Paul Wordsworth

Co-opted Members
Dr Raj Sengupta
James O'Leary
Roger Stevens

No Trustees resigned in the year and no new Trustees were appointed, other than as shown above.

2. STRUCTURE, GOVERNANCE AND MANAGEMENT

a. Constitution

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

b. Appointment of Trustees

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

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

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

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

In advance of each AGM members of the Society are widely encouraged to nominate a fellow member as Trustee.

On appointment, new trustees are asked to spend a half day in the NASS central office for a briefing by the Chairman or Treasurer and to meet the director, 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 Director 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 6,000 members at national level and around 1,000 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 89 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 two new branches were opened and none closed down.

d. Fundraising and Grants

The Society holds fund-raising events from time to time and also welcomes the efforts of individual members who undertake fund-raising activities on behalf of the Society. The Society also solicits grants from charitable trusts and from the pharmaceutical industry, subject to certain limits in order to protect the independence of the Society. In particular grants received from the pharmaceutical industry are limited to 25% of income of the average charity income over 3 consecutive years and must be made available for the support of the Society's charitable activities without restriction.

During the year the Society received an unrestricted grant of £25,000 (2012 - £25,000) from Abbvie UK. In addition grants totalling £53,050 (2012 - £53,269) were received for specific projects.

e. Expenditure on Research

The Society incurred total costs of £22,963 (2012 - £ 54,122) on research activities during the year which included support costs of £20,564 (2012 - £22,969). The reduction reflects the ending in 2013 of two year grant to a PhD student undertaking genetic research. The Trustees are keen to foster continued research into AS and related conditions, and are actively seeking further projects in this area.

f. Expenditure on Campaigning

The Society incurred total costs of £67,558 (2012 - £48,095) on campaigning activities during the year which included support costs of £61,693 (2012 - £20,098). This reflects the 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 £137,101 (2012 - £210,347) on education and support activities during the year which included support costs of £102,821 (2012 - £155,042). Education and support remains a vital part of the Society's activities and, despite the reduction in spending in the year, the Trustees continue to seek to broaden the Society's work in these areas.

In addition the Society incurred branch costs of £185,799 (2012 - £186,355) 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.

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 plans for the future. They include further development of the information resources for patients and their families; the launch of additional online guidance on exercise for people who are just diagnosed; the dissemination of best practice guidelines; increasing the awareness of the condition amongst GPs and HCPs generally; and further work in the devolved regions and at the Westminster Parliament. Developments in AS are taking place at a great pace both in the treatment and understanding of the condition: NASS must strive to respond and direct these, wherever appropriate, so that the Society provides an effective voice for members and everyone in the UK with AS.

5. FINANCIAL REVIEW

a. Reserves

In 2005 the Society invested part of its reserves in acquiring a long term leasehold (999 years) office building in order to facilitate the activities of the Society. Free Reserves, defined as the balance of unrestricted funds less the amount invested in the office building, currently amount to circa £329,000 (2012- £324,000).

In recent years the Society has expanded its charitable activities with expenditure growing from £280,000 in 2008 to £499,000 in 2013. In addition in recent years the Trustees have set budgets for the Society which reflect expenditure in excess of income of significant amounts and expect to continue to do so for some time to come.

At present the Society does not have an endowment fund and therefore all 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 a level sufficient to meet all anticipated outgoings of the Society for the next 9 to 12 months. Currently Free Reserves are equivalent to 10 months expenditure.

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 since 2008 and related impact on investment performance has delayed this review which will now take place in 2014.

In the meantime the Society has been able to avoid any significant losses on investments which situation has widely affected the charity sector in the UK. Nevertheless the Trustees are conscious that, at current interest rates, income from the Society's funds is much reduced and this situation is therefore under frequent review.

c. Summary of financial performance

As a whole, the Society reported a surplus of income over expenditure of £1,741 (2012 - deficit of £91,181). A deficit of £6,333 (2012 – deficit of £83,089) arose centrally and a surplus of £7,701 (2012 - deficit of £8,135) arose at branch level.

Voluntary income remained buoyant in the year with significant receipts of grants and legacies. However the Trustees are aware that the current economic recession may well reduce the level of income in this area and are seeking to ensure that subscription income is maximised for future years.

In 2012 central expenditure rose considerably because staff levels had been increased to deal with the Society's increasing efforts in meeting its charitable objectives. Although some savings have been achieved in 2013, expenditure is set to continue to rise and the Trustees are examining opportunities to increase income where necessary to meet these costs.

6. STATEMENT OF TRUSTEES' RESPONSIBILITIES IN RESPECT OF THE ACCOUNTS

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.

7. AUDITORS

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

Signed on behalf of the Trustees

H S HAMILTON
Chairman

Richmond
13 June 2014

Auditors' Report to the Trustees

We have audited the financial statements of The National Ankylosing Spondylitis Society for the year ended 31 December 2013 set out on pages 40 to 49. 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 2013 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.

Felton Pumphrey

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

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

Statement of Financial Activities

For the year ended 31 December 2013

			Restricted Funds				
	Note	Unrestricted Fund	Branch Funds	Branch Development Fund	Fergus Rogers Fund	Total Year to 31 Dec 2013	Total Year to 31 Dec 2012
		£	£	£	£	£	£
Incoming resources							
Incoming resources from generated funds							
Voluntary income	2	236,486	179,664	-	-	416,150	427,754
Activities for generating funds	3	87,818	15,983	-	-	103,801	107,519
Investment income	4	832	120	-	-	952	1,007
Incoming resources from charitable activities		-	-	-	-	-	-
Total incoming resources		325,136	195,767	-	-	520,903	536,280
Resources expended							
Costs of generating funds	5	94,571	1,894	-	-	96,465	117,493
Charitable activities	6	227,622	185,799	-	-	413,421	499,269
Governance costs	7	9,326	-	-	-	9,326	10,705
Other resources expended		-	-	-	-	-	-
Total resources expended		331,519	187,693	-	-	519,212	627,467
Net incoming (outgoing) resources before transfers		(6,383)	8,074		-	1,691	(91,187)
Gross transfers between Funds		-	(373)	373	-	-	-
Net incoming (outgoing) resources before other recognised gains or losses		(6,383)	7,701	373	-	1,691	(91,187)
Gains (losses) on revaluation of investments		50	-	-	-	50	6
Net movement in funds for the year		(6,333)	7,701	373	-	1,741	(91,181)
Funds brought forward		637,060	185,633	1,828	4,425	828,946	920,127
Total Funds carried forward	18	630,727	193,334	2,201	4,425	830,687	828,946

The notes on pages 41 to 47 form part of these accounts.

Balance Sheet

31 December 2013

	Note	31 December 2013	31 December 2012
		£	£
FIXED ASSETS			
Tangible assets	9	303,325	313,279
Investments	10	60,540	60,490
Total Fixed Assets		363,865	373,769
CURRENT ASSETS			
Debtors and prepayments	11	5,780	5,092
Cash at bank and in hand	12	489,058	478,786
Total current assets		494,838	483,878
CREDITORS			
Amounts falling due within one year	13	28,016	28,701
NET CURRENT ASSETS		466,822	455,177
TOTAL NET ASSETS		830,687	828,946
CHARITABLE FUNDS			
Unrestricted funds	14	630,727	637,060
Branch funds	15	193,334	185,633
Branch development fund	16	2,201	1,828
Fergus Rogers fund	17	4,425	4,425
TOTAL CHARITABLE FUNDS	18	830,687	828,946

The accounts set out on pages 40 to 47 were approved by the Trustees on 13 June 2014.

H S Hamilton
Chairman

S H Frost
Treasurer

Notes to the Accounts

For the year ended 31 December 2013

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. Gains or losses arising during the period are included in the Statement of Financial Activities accounts when realised.

(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***: Depreciation is charged on the leasehold property over its expected useful life of 50 years from its acquisition in 2007. Other 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 2013	Year to 31 Dec 2012
	£	£
Unrestricted funds		
Subscriptions	73,976	78,020
Donations and grants	150,260	128,222
Legacies	12,250	56,750
Total	236,486	262,992
Branch funds		
Subscriptions	164,637	154,557
Donations	15,027	10,215
Total	179,664	164,762
Total voluntary income	416,150	427,754

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.

	Year to 31 Dec 2013	Year to 31 Dec 2012
	£	£
Unrestricted funds		
Annual draw	11,285	11,772
Fund-raising events	73,034	70,993
Research participation	-	-
Other income	3,499	5,151
Total	87,818	87,916
Branch funds		
Fundraising events	12,616	13,790
Other Income	3,367	5,420
Total	15,983	19,210
Branch Development Fund		
Fundraising events	-	393
Total	-	393
Total income from activities for generating funds	103,801	107,519

4. INVESTMENT INCOME

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

	Year to 31 Dec 2013	Year to 31 Dec 2012
	£	£
Unrestricted funds		
Dividends received	18	40
Interest received	814	819
Total	832	859
Branch funds		
Interest received	120	148
Total	120	148
Total investment income	952	1,007

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 2013	Year to 31 Dec 2012
	£	£
Unrestricted funds		
Annual draw prizes and expenses	4,286	2,770
Fundraising expenses	17,153	20,044
CAF administration charges	1,157	1,190
Support costs (note 8)	71,975	89,005
Total	94,571	113,009
Branch funds		
Fundraising expenses	1,894	4,484
Total	1,894	4,484
Total costs of generating funds	96,465	117,493

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 2013	Year to 31 Dec 2012
		£	£
Unrestricted funds			
Research	[note 6(b)]	**22,963**	54,122
Campaigning	[note 6(c)]	**67,558**	48,095
Education and support	[note 6(d)]	**137,101**	210,347
Total		**227,622**	312,564
Branch funds			
Campaigning		**-**	-
Education and support	[note 6(e)]	**185,799**	186,355
Total		**185,799**	165,862
Branch development fund			
Grants made		**-**	-
Total		**-**	-
Fergus Rogers Fund			
Welfare – grants made		**-**	350
Total		**-**	350
Total resources expended on charitable activities		**413,421**	499,269

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

	Year to 31 Dec 2013	Year to 31 Dec 2012
	£	£
Grants for research and related costs	**1,382**	30,000
AS News	**1,017**	1,153
Support costs (note 8)	**20,564**	22,969
Total research expenditure	**22,963**	54,122

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

	Year to 31 Dec 2013	Year to 31 Dec 2012
	£	£
Advertising and campaigning	**222**	17,516
AS News	**3,050**	3,459
Standards of care and training of GPs and HCPs	**2,093**	6,959
Other direct expenses	**500**	63
Support costs (note 8)	**61,693**	20,098
Total campaigning expenditure	**67,558**	48,095

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

	Year to 31 Dec 2013	Year to 31 Dec 2012
	£	£
AS News	**16,269**	18,446
Guide books, DVDs and apps	**4,809**	10,000
Literature, brochures and information	**3,277**	8,609
Patient and member conferences	**7,728**	12,691
Branch conferences and support	**2,197**	5,559
Support costs (note 8)	**102,821**	155,042
Total education & support expenditure	**137,101**	210,347

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

	Year to 31 Dec 2013	Year to 31 Dec 2012
	£	£
Treatment by healthcare professionals	**144,359**	138,675
Hire of NHS facilities	**28,966**	27,087
Grants payable	**2,246**	8,010
Support costs (note 8)	**10,228**	12,583
Total branch education & support expenditure	**185,799**	186,355

7. GOVERNANCE COSTS

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

	Year to 31 Dec 2013	Year to 31 Dec 2012
	£	£
Expenses paid to Trustees	**2,694**	3,885
Trustees meetings and Annual General Meeting	**1,032**	1,920
Auditors' remuneration	**5,600**	4,900
Total governance costs	**9,326**	10,705

The Trustees received no remuneration during the year (2012 – nil). 11 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 2013	Year to 31 Dec 2012
	£	£
Staff costs (note 8c)	**192,705**	217,329
Premises costs	**15,618**	13,107
Travel expenses	**12,790**	15,035
IT and Communications	**18,729**	19,653
Office costs	**9,651**	14,718
Insurance, legal and professional	**7,560**	7,272
Total support costs	**257,053**	287,114

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

Charitable activities		
Research	**20,564**	22,969
Campaigning	**61,693**	20,098
Education and support	**102,821**	155,042
Fundraising activities	**71,975**	89,005
	257,053	287,114

c) Branch support costs incurred in the year amounted to £10,228 (2012 - £12,583), and are wholly attributable to education and support.

d) Staff costs incurred during the year consisted of:

Wages and salaries	**172,114**	192,272
Social security contributions	**17,483**	19,952
Pension contributions	**2,786**	4,200
Recruitment, training and other costs	**322**	905
Total staff costs	**192,705**	217,329

e) Information about employees:

	31 Dec 2013	31 Dec 2012
Average number of employees during the year	**6**	6
Number of employees for whom pension contributions have been made	**5**	1
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 2012	351,000	20,326	371,326
Additions in the year	-	-	-
Cost at 31 December 2013	**351,000**	**20,326**	**371,326**
Depreciation at 31 December 2012	42,040	16,007	58,047
Depreciation charge for the year	7,020	2,934	9,984
Depreciation at 31 December 2013	**49,060**	**18,941**	**68,001**
Net book value at 31 December 2012	308,960	4,319	313,279
Net book value at 31 December 2013	**301,940**	**1,385**	**303,325**

The leasehold building is held on a 999 year lease with 990 years remaining.

10. INVESTMENTS

	31 Dec 2013	31 Dec 2012
	£	£
Bronze statues, at valuation	**60,000**	60,000
Listed shares, at valuation	**540**	490
	60,540	60,490

The bronze statues, by Elizabeth Frink, were acquired at a cost of £2,156 in 2009. These were revalued in September 2010 and the revaluation surplus of £59,844 was reflected in the Statement of Financial Activity for that period.

The listed shares are carried at market value. The increase in value of £50 (2012 – increase of £6) during the year has been reflected in the Statement of Financial Activity.

11. DEBTORS AND PREPAYMENTS

	31 Dec 2013	31 Dec 2012
	£	£
Prepayments	**5,089**	4,701
Sundry debtors	**691**	391
	5,780	5,092

12. CASH AT BANK AND IN HAND

	31 Dec 2013	31 Dec 2012
	£	£
Deposit account balances held centrally	**283,434**	282,570
Deposit account balances held by branches	**188,762**	181,278
Current account balances	**12,288**	10,583
Cash in hand	**4,574**	4,355

	489,058	478,786

13. CREDITORS: Amounts falling due within one year

	31 Dec 2013	31 Dec 2012
	£	£
Sundry creditors	11,716	10,001
Deferred income	10,000	8,700
Accrued expenses	6,300	10,000
	28,016	28,701

There are no creditors falling due after more than one year (2012 – nil).

14. UNRESTRICTED FUNDS

Unrestricted Funds represent the accumulated surplus income of the Society and from 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 £600 (2012 - £600) were paid to branches from Unrestricted Funds and donations totalling £600 (2012 - £2,016) 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 a further £373 (2012 - £393) 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 £nil (2012 – £350) was expended on welfare.

18. RECONCILIATION OF CHARITABLE FUNDS

	Unrestricted Fund	Branch Funds	Branch Development Fund	Fergus Rogers Fund	Total Funds
	£	£	£	£	£
Tangible assets	303,325	-	-	-	303,325
Investments	60,540	-	-	-	60,540
Debtors and prepayments	5,780	-	-	-	5,780
Cash at bank and in hand	289,098	193,334	2,201	4,425	489,058
Less creditors	(28,016)	-	-	-	(28,016)
Total charitable funds	630,727	193,334	2,201	4,425	830,687