



Report and Accounts For the year ended 31 December 2014

Registered Charity Number 272258 Scottish Charity Registration Number 041347

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Chairman's Report



2014 saw a significant change for the National Ankylosing Spondylitis Society. Hedley Hamilton had made it clear that after 6 years of chairing NASS it was time for him to make way for a new Chair. On June 21, I was appointed a trustee of NASS and its' Chair. On behalf of all our members I would like to thank Hedley for all his hard work in helping NASS to grow so effectively.

The team and the Trustees took it upon themselves to bring me up to speed as quickly as possible as to what NASS was up to "behind the scenes".

As a supporter of NASS I was always aware that NASS was working to raise awareness of AS but until you get under the skin of NASS it isn't always apparent the efforts that made to ensure that both diagnosed and as yet undiagnosed sufferers are being given the best support, advice and treatment available. I have to admit that most of the summer was taken with me playing catch up!

After the Trustee meeting in Bath in September, a number of trustees and I went to see the "Don't Turn Your Back On It" event in town. This event, led and funded by AbbVie, asks people to not live with long term chronic back pain and to go back and have it properly looked at by specialists. To date the number of people using the back pain checker has been remarkable and I hope that it has moved a number of those individuals who felt the need to check out their symptoms to go and talk their doctor about the pain they are experiencing.

In September I also made my first visit to a branch (in Cardiff) where I participated in my first hydrotherapy session. After the session I had a chance to talk to the members and understand what they got from their weekly physio-led sessions both physically and emotionally and I was pleased to see that the social aspect of the branch sessions was rated if not more important than, at least as important as, the physical aspect. Whilst saying this, members also reported on the importance to them of regular exercise and commented how having access to a hydrotherapy pool once a week formed part of their regime.

In September, NASS also hosted the first of its Newly Diagnosed Conferences. This event was held in Birmingham and I had the great pleasure of being able to attend it. Having been diagnosed in the pre-internet days and been sent "out into the cold" to look largely after myself, I am aware of the importance of accurate knowledge. However, anyone doing a quick check online having been newly diagnosed can be overwhelmed by the amount of information and misinformation available. It was fabulous to be able to talk about the impact that AS might have on patients not just with the patients themselves but also with family members who were also actively encouraged to attend. Having a rheumatologist, a physiotherapist and representatives from NASS present in the room meant that attendees really did have the best resources just at arms reach! Whilst I maintain my own active fundraising efforts, these are often personal challenges. At the beginning of October I was able to participate in the NASS organised "Peak Pursuit" event. Our guide for this event had, in consultation with NASS's team, perfectly planned a walking route in Peak District that would challenge but not defeat all participants. The weather helped!

Also in October I was invited to attend the Arthritis Research UK Parliamentary event. Here I witnessed first-hand the high regard with which NASS's team is held and also the reach that NASS has within not just the medical profession but also within the "corridors of power". Not long after attending this charity hosted event, I attended another Parliamentary event, this time hosted by Pfizer, focusing on the future of treatment for arthritic conditions. And this time I saw the way in which NASS was regarded by the pharmaceutical companies and was again impressed. NASS' professionalism, independence and patient led focus is key to all that we achieve is this area of its work.

Attending the National Voices Chairs' Dinner, a focussed affair with a wide range of charities represented, also was a learning experience. Understanding the challenges that are facing all charities at this time is critical to our medium to long term success and being able to discuss these challenges with the representatives from both significantly smaller and significantly larger charities was an education for all.

In November I had the honour of representing NASS at the Ankylosing Spondylitis International Federation (ASIF) conference in Sofia, Bulgaria. The local hosts put on a great event, with NASS leading a number of sessions to give other patient organisations an insight into current best practice. Whilst there is some way to go to achieve perfect practice, I am happy to say that NASS is leading the way on many fronts. Hedley and Debbie Cook, our chief executive, have had significant impact on that organisation. During that conference Debbie officially stood down from her role as an executive committee member of ASIF to focus more on matters in the UK and I succumbed to pressure to stand to fill that role. This is just one way that NASS continues to be influential on an international level with both Hedley (as Vice President) and I (as executive committee member) playing our roles with ASIF.

In November it was NASS' turn to host a parliamentary event. Despite there being a major bill going through the Commons at the same time, many MPs attended the event. Huw Irranca-Davies and NASS Member, long-time supporter and patient, Paul Curry made speeches to the guests about their road to diagnosis. This event was, as always, important on two levels: firstly to thank the numerous supporters of NASS who go out of their way to raise, not only vital funds for, but also vital awareness of NASS; and secondly to raise awareness of our *AS it is* campaign.

We are now well into 2015 and I have to say, the pace hasn't let up yet! Working with Debbie and the team at NASS HQ has been a great pleasure, meeting and talking to the wider NASS network both face to face and online has been equally brilliant. I have also got to know the Trustees and our Medical Advisory Board well over the past few months and am very impressed by the time and dedication that they give to NASS.



NASS – Highlights of 2014

- AS it is campaign
 - NICE began work on the Clinical Guidelines for spondyloarthritis
 - NASS held an event at the Welsh Sennedd with half of all Assembly Members pledging to a higher standard of care for people with AS in Wales.
- AS and You events for people diagnosed with AS in the last 18 months were launched in September.
- 4,950 helpline enquiries (up by 15% on 2013) with increased capacity to deal with work and benefits enquiries.
- 261,408 visitors to the NASS website (up by 17% on 2013).
- The NASS Patient Guidebook was reviewed and updated.
- Increase in media coverage for AS.
- £70,000 raised by our reactive fundraisers at various events around the country, including the NASS London Bridges Challenge and Peak Pursuit.
- Investing in our members by updating the NASS members' forum.
- The NASS 5-year strategy was launched.

Campaigning

AS it is & NASS in Parliament

We continued our AS *it is* campaign which started at the end of 2013 and resulted in NICE commencing work on Clinical Guidelines, with an event at the Welsh Sennedd in March 2014, hosted by Janice Gregory AM. We asked Assembly Members to sign a pledge committing to a higher standard of care for people with AS in Wales.

We were delighted that the Health Minister, Professor Mark Drakeford and Dr Zoe McLaren of Betsi Cadwaladr University Health Board spoke, along with myself, Grant Poiner, NASS Trustee and Tudur Philips, S4C TV presenter who has AS (pictured right). A short film made by Huw Irranca-Davies, MP expressing his support for NASS and the campaign and telling his own personal AS journey, was also broadcast. There was a fantastic response across social media with over 1,600 views of tweets sent from the event and lots of 'likes' and comments on the NASS Facebook page.



The response to the initial Welsh campaign was excellent - 28 Assembly Members (almost half of all AM's) attended, including 7 Government Ministers (70% of the cabinet) and 1 Deputy Minister. Following on from the event:

- The Welsh government issued a press release
- Heno (a Welsh language) television programme included interviews with Mark Drakeford, Health Minister and Tudur Phillips
- Interviews were recorded for radio
- There was a massive response on social media via Twitter and Facebook
- AS was subsequently discussed, particularly diagnosis times and access to physiotherapy, at the Welsh Assembly Health & Social Questions on 19 March.

November saw the launch of phase two of the AS *it is* campaign, calling on NHS England to recognise access to physiotherapy as a treatment for AS and to support patients with AS to be more physically active. NASS also called for more to be done by NHS England to recognise the delay in AS diagnosis and put more resources into educating healthcare professionals.

To launch this part of the campaign, we held a reception at the Houses of Parliament which also allowed us the opportunity to thank our fundraisers, volunteers and supporters. We were especially grateful to Huw Irranca-Davies MP and NASS member Paul Curry who spoke about their own experiences with delay in diagnosis and how physiotherapy had helped them. Paul also spoke about his experiences at the NASS Sunderland branch and the vital role that the branch played not just in terms of treatment but also being able to be with people who understood him and what it was like to live with AS. Raj Mahapatra, NASS Chairman, addressed the event and talked about NASS and the work we are doing.

The AS *it is* campaign continues and is supported by a number of people with AS and health professionals on social media, who are backing these calls using the hashtag #AS_lt_ls.



GP Awareness

NASS launched its GP Awareness campaign in 2012 in a bid to reduce the current 8.5 year delay in diagnosis. As part of this campaign we have been running Back Pain Seminars which are events aimed at GPs, physiotherapists, chiropractors and osteopaths who see people with back pain. The seminars inform delegates how to distinguish inflammatory back pain (like AS) from mechanical back pain. NASS continued this programme in 2014 with seminars held in London, Reading, Lincoln and Bath. 93% of attendees have said that they would change their practice as a result of attending the seminars. This is a vital part of our work which will remain a key priority for NASS should funding to run such events be available.

World AS Day

NASS gets involved in events such as World AS Day and World Arthritis Day as it gives us the opportunity to raise awareness about AS. It also gives people with AS he opportunity to start a conversation with those around them about what it's like to live with AS.

World Ankylosing Spondylitis Day was marked on Saturday 3 May. For World AS Day we asked our members and supporters: 'what pledge will you make for World AS Day?' 122 people took part and these were the results:

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

World Arthritis Day

To mark World Arthritis Day, NASS promoted and took part in Walk Your AS Off, where the aim was for teams to count their steps in a day. NASS also encouraged our supporters to take 'selfies' wearing something orange and tweet their photographs to @NASSexercise.

Walk Your AS Off

Walk Your AS Off is a campaign to raise awareness and understanding of AS. The campaign invited people to join up in teams and count their steps in the run up to World AS Day and for one day only on World Arthritis Day. Gillian Eames set up the Orange Apples team in the UK, helped by Jean Morton and Kathy Miller. It had 100 members and, along with raising the profile of AS, they raised a fantastic £678 for NASS to continue our work in supporting people with AS.



Influencing health locally

The end of 2014 saw a new and ambitious project from NASS looking to influence musculoskeletal services at a local level. The response has been fantastic so far – NASS has engaged positively with over 100 of the 212 Clinical Commissioning Groups (CCGs) in England. CCGs manage and procure local services and so it is vitally important that NASS provides the CCGs with information on what good care and treatment looks like for people with AS. This project will continue into 2015 and beyond as musculoskeletal (MSK) services are reviewed around England.

Don't Turn Your Back on It

This is a global campaign led by and financed by AbbVie which aims to raise awareness of the symptoms of inflammatory back pain. A different campaign was planned for each country and, in the UK, AbbVie decided to run local campaigns in two town centres.

The Don't Turn Your Back On It (DTYBOI) stand visited Reading in July and Bath in September. NASS staff and trustees attended both events with rheumatologists, along local physiotherapists and AbbVie staff (pictured right). A group of acrobats performed at both events to get the attention of local shoppers in the towns. Information leaflets were handed out and the health professionals were able to answer questions. Anyone who had back pain for longer than 3 months was encouraged to visit the campaign website, to complete a short symptom checker to assess if their back pain could be inflammatory. To date there have been 28,701 unique visitors to the Back Pain Checker UK website, 17,042 people filled out the symptom checker and the initiative had a total audience reach of 121,400 through online, print, radio and social media.

Three further events (funded by Abbvie) will run during 2015.



Information and Support

Helpline

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

	Helpline enquiries	4,950 helpline enquiries
2012	3,792	
2013	4,308	15% increase on 2013
2014	4,950	

Around 40% of our Helpline enquiries are via telephone calls and most of the remainder are emails. However, we have started to see a real increase in enquiries made via social media. People send private and public messages to us on our Facebook page and ask questions via Twitter. We will answer these questions through social media if possible, but where enquiries are more complex we will ask them to call or email so we can help.

Throughout 2013 and 2014 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. Sally Dickinson, our Information & Communications Manager was spending a significant proportion of her time advising people on these issues and writing formal letters of support to the Department for Work and Pensions.

We decided to employ a part-time member of staff (17.5 hours per week) to deal with queries concerning benefits and work. Amardeep Gill was already employed 17.5 hours per week as Fundraising Manager and, as he has a particular interest in this area, he took on this role. Amardeep received Helpline Training from The Helplines Partnership and training in ESA and PIP accordingly.

From November 2014, the Helpline has been staffed jointly by Sally and Amardeep, with Amardeep taking benefits and work queries and Sally taking all other queries. We can now answer queries of all kinds much more quickly and efficiently.

Website

Visitors to the NASS website have steadily increased over the past few years.

	Sessions	Users	261,408 website sessions
2012	146,720	94,534	, i
2013	223,085	148,145	17% increase on 2013
2014	261,408	176,626	

Two thirds (65%) of visitors are new and a third (35%) are return visitors. As expected, the majority of our website visitors are based in the UK, with smaller numbers being based in the USA, Australia, India and Canada.

NASS encourages traffic to the site by regularly updating pages and adding new information. In particular we work hard to keep our News page updated, often on a daily basis but always weekly. We have also added more photographs and reduced down text where possible.

Our aim in 2015 is to update the Home page, making it much clearer that NASS is a membership organisation. As we receive no Government funding we rely heavily on our membership income. We

hope this change to the website will encourage more people to become a NASS member. We also want to make the Home page more interactive, incorporating a carousel of information. Finally, we will include links to social media sites throughout so that people can easily share information.

Members' Forum

The website Members' forum has become an increasingly popular member benefit. However, when NASS moved to our new website platform in 2010, the original forum was maintained and 'bolted on' to the new website. The design of the forum looked outdated and it was not particularly user-friendly.

NASS therefore decided to fund an upgrade to this important member benefit during 2014. The move across to a new platform was made at the very end of 2014 and NASS forum members contributed hugely to the new look and feel of the Forum. We have made one of our forum users (Wonky Donkey) an administrator and he has worked hard on the forum for which we are very grateful, to ensure it meets the needs of other users in both function and look.

Social Media

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

During 2014 we continued to post daily on our Facebook page (National Ankylosing Spondylitis Society). At the end of December 2014 we had over 5,500 'Likes' on our Facebook page compared with 3,000 at the end of December 2013. This represents an 83% year on year increase. 63% of our Facebook followers are female and 37% male. In terms of age, 22% are under 34 and 36% are aged between 35 and 54.

We have two Twitter accounts; @NASSchiefexec and @NASSexercise. Followers for both these accounts rose steadily throughout the year. The @NASSchiefexec account had more than 2,200 followers at the end of December 2014 and @NASSexercise had more than 1,500.

Our followers include people with AS, rheumatologists, rheumatology organisations, charities, hospitals and CCGs to name but a few. This means we can target groups of influential people when necessary.

We set up a Pinterest page in autumn 2014. This is a very visual image-based way of communicating. It is like an online notice board with photographs and images forming links to further information. It is particularly useful in sharing fundraising ideas and stories with our followers.



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. During 2014 we distributed another 15,000 guidebooks. We decided to review and update the guidebook and in Autumn 2014 funding was obtained to allow us to replace the old exercise illustrations with full colour photographs. This will allow us to ensure the most up to date exercises are included, that the exercises are clearly depicted and will mean that the guidebook looks more up to date.

The new, more modern guidebooks are now available.

Other Guidebooks

In autumn 2013, NASS produced a 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.

This guide has proven very popular and many people have downloaded the guide from our website. It is a very good starting point for people having problems at work.

During 2014 we worked on two new guides:

- Managing your AS flares
- A guide to anti TNF therapy

These two new guides were published in March 2015.

Factsheets

The NASS factsheets covering uveitis, fatigue and driving have continued to be very popular. In early 2014 a new factsheet explaining more about the new terminology in AS was introduced called, 'Axial spondyloarthritis', it explains what axial spondyloarthritis is and how it fits together with AS.

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). 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. We additionally write supporting letters for people applying for a Blue Badge or appealing against a Blue Badge decision, for people in dispute with their employer and people struggling with immigration issues.

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 national magazine and he kindly volunteered his help and advice in improving the look and feel of AS News during 2013 and into 2014. His help proved invaluable and AS News now looks a far more vibrant publication.

We continue to produce NASS Active in the autumn, 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. The members are:

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

The MAB meets approximately 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. We would like to thank them all for the valuable contribution they make to NASS.

Members' Day

The NASS Members' Day 2014 (formerly the Patient Conference) was held on Saturday 21 June at King's College London. The event saw a change in format to previous years with a greater emphasis on fun, interactive sessions and practical ways to manage the symptoms of AS.



The day was supported by a grant from UCB Pharma Limited which enabled us to provide free entry to NASS members and one guest. There was a fantastic turnout of 150 people that included members, guests, trustees and health professionals. Guests were treated to fascinating presentations on 'AS – Facts and Management,' 'How Occupational Therapy can help you,' 'An Update on Genetic Research,' and 'Understanding AS for Friends and Family.' As well as informative talks, guests enjoyed practical sessions in Tai Chi (pictured above), Nordic Walking (pictured below) and essential daily stretches. The afternoon also gave delegates the opportunity to have one to one consultations with various health professionals and vote for the new NASS Chairman at the AGM, with Raj Mahapatra elected to succeed Hedley Hamilton.



We are very grateful to all the speakers and volunteers who helped make the day a success, including Dr Andrew Keat, Clare Clark, Professor Paul Wordsworth, Colin Beevor, Paul Curry, Dr Raj Sengupta, Claire Harris, Claire Jeffries, Tim Tang, Dr Richard Jacoby, Sue Gurden and Diana Gore.

After an innovative decision to conduct an online vote, York was chosen as the destination for the 2015 Members' Day.

AS & You

In September 2014 NASS launched a brand new initiative of regional events called AS & You. These events are specifically designed for people who have been diagnosed with AS in the last 18 months. The programme includes talks from a rheumatologist, physiotherapist and a member of the NASS team, but also offers the opportunity to ask the health professionals any questions attendees might not have had the opportunity to ask an their appointment in a more informal setting. This is also the perfect opportunity to chat to others with AS and their friends and families. The initial pilot events were held in Birmingham and London, with 100% of those who attended saying that they would

recommend AS & You to others. Events are planned for 2015 in Chester, Sunderland, Portsmouth, Cardiff, Leeds, Aberdeen and Plymouth.

Working with other organisations

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

NICE Clinical Guidelines

NASS campaigned hard in 2013 asking parliamentarians and the Secretary of State for Health to direct the National Institute for Health and Clinical Excellence (NICE) to start work on the production of Clinical Guidelines for spondyloarthritis. We were very grateful for all the letters that our supporters sent to their MPs and the Secretary of State for Health at the end of 2013/early 2014 in this regard. Our campaign was a success and NICE confirmed in 2014 that they would produce such guidelines. We believe that such guidelines will go a long way to a more consistent approach to good care for people with spondyloarthritis across England.

I was delighted to be appointed as a member of the Guideline Development Group. The process of producing such guidelines is prescribed by NICE and includes a detailed review of evidence; it's a huge amount of work but hugely rewarding, The Group meets about once a month for a period of about 18 months – 2 years and it is hoped that the final Guidelines will be available during the Summer of 2016.

NASS is a member of the Arthritis and Musculoskeletal Alliance (ARMA) and National Voices, a coalition of health and social care charities in England. NASS attended various meetings throughout the year to discuss future policy. NASS was involved in the initial stages of Wellbeing Our Way which focuses on patient engagement. We will be continuing to be involved in this project throughout 2015 and beyond.

NASS joined Pain UK towards the end of 2012. In 2014 NASS had a presence at several events for health care professionals via Pain UK, providing a selection of literature to be given out on AS.

The Prescription Charges Coalition (PCC) is a group of 30 organisations which campaigns on behalf of people with long term conditions for the review of prescription charges in England whilst also monitoring any developments in Wales, Scotland and Northern Ireland. NASS has been a member of the PCC since its formation in 2009. During 2014, the PCC did some excellent work around campaigning and media coverage including:

- May an open letter to the three main political party leaders resulting in coverage in The Express and The Independent
- June further coverage in The Times and on Sky News
- October submitted evidence to the Health Select Committee's enquiry into public expenditure on Health and Social Care.

NASS joined the Disability Benefits Consortium (DBC) in July 2014. The DBC is a national coalition of over 50 different charities and other organisations committed to working towards a fair benefits system. NASS understands that issues with benefits are very important to people with AS and are delighted to be on board. We are very much looking forward to working more closely with them on their campaigns in the future.

Working with the pharmaceutical industry

NASS receives some hands-off financial support from the pharmaceutical industry allowing us to deliver specific projects. We set our priorities in advance and are not influenced by the agenda of industry. We also work with colleagues in industry to deliver specific activities. One such example was the Don't Turn Your Back on It campaign which we supported to raise awareness of inflammatory back pain and which was funded by Abbvie.

The amount of support received from the industry in 2014 is as follows:-

- Abbvie core funding
- MSD branch development and clinical commissioning group engagement programme
- Pfizer Managing Flares factsheet and AS Guidebook
- UCB Members' Day and anti TNF factsheet.

Working with the media

During 2014, NASS and our supporters worked very hard to raise the profile of AS. 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.

8 March - Adam Rickitt: If I don't run 10 miles and do 1000 sit-ups a day I'll end up in wheelchair, Daily Mirror

8 March - Winkfield Man is pushing himself to limit Bracknell News (1)

12 March - Professor Mark Drakeford AM, Health Minister and the S4C presenter Tudur Phillips talk about AS on SC4 show Heno

27 March - Bye, bye back pain, Pick Me Up!

29 March - A WINKFIELD man who suffers from a little-known condition raised crucial awareness by holding a charity stall at a supermarket, Bracknell News (1)

31 March - Harpenden student goes from a double hip replacement to 10K run, Herts Advertiser

7 April - I woke up blind, Take a Break

15 July - When back ache means your spine`s starting to fuse together, Daily Mail

29 July - Struggling to peg out the washing? Daily Mail

29 July - NASS Northampton interviewed on BBC Radio Northampton

29 July - Bath nurse in training for a charity open water swim, The Bath Chronicle (2)

11 August - Bed-ridden Buckhurst man recovers to complete triathlon, East London and West Essex Guardian

14 August - Clare Gauntlett was diagnosed with ankylosing spondylitis weeks before her wedding, Kent Online

10 September - Daniel Harland interviewed on BBC Radio Cambridge (3)

25 September 2014 - Sebastian - a driving force for good causes, Bognor Regis Observer (4)

8 October - Trio of cyclists pedal from Cambridge to Brighton in aid of National Ankylosing Spondylitis Society, Cambridge News (3)

12 November - Helper dog brings joy and independence to disabled York man, The Yorkshire Press (5)

26 November - Gosport MP supports campaign, Portsmouth News

18 December - Getting Britain Moving: why access to physiotherapy is crucial, Huffington Post

Below is a selection of NASS supporters who have represented NASS in the media. Clockwise from top left is Gerry Dance, Poppy Hocken and family, Daniel Harland and team, Sebastian Cunningham and Mike Hardy and Chipper the dog.



In April, Jill Hamilton attended a meeting of physiotherapists with a special interest in AS, chaired by Claire Harris. She presented on the information, materials and support that NASS can provide. The meeting proved to be very encouraging with many NASS branch physiotherapists there speaking positively about our branches, exchanging ideas and also making new connections for potential new branches

NASS attended the 7th bi-annual AStretch conference held in Birmingham in November where we held a stand and gave a presentation updating physiotherapists on our recent work. The conference was very well attended and we were able to distribute a lot of information to physiotherapists as well as talk with them about setting up new branches.

Branches

There are currently 90 NASS branches and in 2014 we were pleased to have opened a new branch in Northampton. The branch is doing well after securing £2,500 worth of funding in late 2014. The branch physiotherapist, Vickie Farquhar and Jill Russell, branch chairman, also appeared on their local BBC Radio show in September to talk about AS and NASS Northampton.

Laura Richards and I attended meetings in Stanmore and Sheffield to discuss setting up new branches in 2015. Branch visits also took place in Doncaster, Preston, Cardiff, Brighton, Bognor and Worthing.

In November, NASS Portsmouth piloted a Friends and Family event, inspired by the ones held at our annual Members' Day conference. They extended their invite to carers of those with AS. Jill Hamilton and Laura Richards attended as part of an expert team alongside Claire Jeffries, Colin Beevor and other branch physiotherapists.

In late 2014, NASS conducted a survey, asking one member from each branch to answer questions about the facilities they have access to and the benefits members gain from attending a branch. Results from this study highlighted that our branches are lively and friendly environments, valued highly by those who attend them. Results from this study will be used to campaign for access to physiotherapy for people with AS and support work in developing further NASS branches.

During Self Care Week 2014, we also asked our branch members to write to us about what attending a NASS branch means to them. These stories will support future work in a similar fashion to results from the survey.

Branch fundraising

Branches were actively encouraged in 2014 to seek additional funding from various sources as and when they became available. Branches have been successful in securing funds from outlets such as Rotary Clubs, local funds, and supermarket community schemes held in stores such as The Co-Op, ASDA and Waitrose. NASS Stockport (pictured right) were successful in receiving £394 and NASS Brighton were also fortunate to receive £240, both from the Waitrose Community Matters scheme.



Many branches also hold social events to raise money; NASS Leeds raised over \pounds 600 at a race night, NASS Bognor Regis raised \pounds 300 at a 'Paella Party', NASS Portsmouth held a quiz night and raised \pounds 491 and NASS Plymouth raised \pounds 180 from their 'Christmas Treasure Hunt'.

Towards the end of 2014, NASS branches were regularly forwarded a funding newsletter from Funding Central notifying them of relevant funding and grant opportunities nationally and in their local area.

Branch communications & promotion

We kept in touch with our branches through regular monthly newsletters. Branches have been promoted in the form of mail outs, posters, flyers and have also featured on our social media accounts. AS awareness evenings and branch visits were promoted on Facebook and we continued to promote the branches on Twitter through regular tweets announcing the branches that were meeting on the day of the tweet. Tweets also directed people to the NASS Near You webpage where people would be able to find their nearest branch.

Branch development

Following the appointment of Laura Richards in September 2014 we were able to spend the latter half of 2014 planning branch development projects for 2015/16. These projects include organising Friends and Family events, alike the one held by NASS Portsmouth, across our branch network and developing regional events to bring the branches in the same geographical area together.

Furthermore, work started in 2014 towards developing a presence in Northern Ireland and we are looking towards developing our first branches there in 2015.

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 our funding, and this kind act enables NASS to make a positive impact for generations to come.

This year we were left a number of sizeable legacies, more than doubling our income. We acknowledge legacies from:

- Audrey Louise Pape
- William Dennis Jones
- Eric Arthur Way
- Daphne Margaret Newman
- Shelia Hegarty

Trusts

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

- Hamilton Wallace Trust
- John Coates Charitable Trust
- Lord Leverhulme's Charitable Trust

- Mary Homfray Charitable Trust
- Neville Milner Charitable Trust
- PF Charitable Trust
- Summers & May Charitable Settlement
- Bernadette Charitable Trust
- Charles Fairweather Charitable Trust
- Freemasons Grand Charity
- Khayami Foundation
- Orr Mackintosh Foundation
- Sylvia & Colin Shepherd Charitable Trust
- Vivienne & Sam Cohen Charitable Trust

Companies

- Healthcare at Home
- UCB Celltech
- AbbVie
- Novartis
- Merck sharp & dohme
- Lakeland
- TopCashBack
- British Gypsum
- Gillian Kenny Associates
- The Money MOTco
- Tinopolis
- Fuelcard Service
- RFIB
- Working at Height

London Bridges Challenge

The first ever NASS London Bridges Challenge was held on Sunday 18 May 2014 and was a great success, attracting over 80 people and raising £9,000.

The walk included 3.5 and 8 mile options that took in many of London's iconic landmarks, including Tower Bridge, Houses of Parliament and Tower of London.



Peak Pursuit

The second NASS fundraising event of the year was Peak Pursuit which was held on the weekend of Saturday 11 October in the beautiful setting of the Peak District.

Five intrepid fundraisers joined NASS' Amardeep Gill, Joe Murray and Chairman, Raj Mahapatra (pictured right) in the 14 mile walk along Kinder Scout - the highest mountain in the Peak District - to raise vital money and awareness of AS to mark World Arthritis Day. The event raised over £3,000 for NASS.



Reactive fundraising

2014 was a fantastic year for our NASS fundraisers. Over 100 people ran, cycled, skydived, swam, walked, laughed, drank tea, took pictures, shaved their head or grew a moustache for NASS, raising over $\pm 57,000$ in the process.

Our incredible fundraisers make a real difference to the lives of people with ankylosing spondylitis and are 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.

<u>Membership</u>

The total number of NASS members fell in 2014, from 6079 to 5430. The decrease was mainly due to an administration error with 649 memberships allowed to lapse as a result of only one renewal reminder letter being sent out. The normal process includes sending a second and third reminder as many people do not renew their membership until the second or third opportunity. The membership renewals procedure has now been reviewed and the 649 lapsed members have been contacted by email and by post to re-engage them with NASS and the work we are doing.

Plans are in place for 2015 to further enhance the benefits for NASS members, including monthly prize giveaways and more content on the members' area of the website. As already mentioned, the hugely popular NASS members' forum has already been upgraded.

As ever, NASS is extremely grateful to all our members for the fantastic support they continually show the charity. Being a member of NASS is about being a part of a community and contributing to the work that we do, working towards a better life for people with AS.

Royal National Hospital for Rheumatic Diseases, (the Min)

In 2014 I continued to represent NASS as a Governor on the Council of Governors of the Mineral Hospital in Bath. Much of 2014 was taken up discussing the 'joining' of the RNHRD with the Royal United Hospital in Bath. Initially I made my views against this merger very clear. I tried hard to represent the views of patients. As the year progressed however, it became clear that this merger was going to happen, and indeed had to happen to see a future for the Mineral Hospital. Towards the end of 2014 it was evident that the merger was supported by lead clinicians who believed that the AS service at the Min would likely be enhanced by joining the RUH. The merger has now gone though. Patients have been reassured that there will be no change to services for at least two years.

Ankylosing Spondylitis International Federation (ASIF)

I served for 3 years as an Executive member of ASIF. NASS Chairman, Raj Mahapatra is now representing NASS on the Executive, together with NASS Trustee Hedley Hamilton. In November 2014 I delivered three presentations about the work of NASS at the ASIF Congress in Bulgaria.

Research

Genetic Research

Funded by the Wellcome Trust, the genetic research programme at Oxford University aims to identify all the genes associated with AS. NASS has supported this project since it began, and in 2014 continued this support by writing to new members asking them to take part in the programme by providing a saliva sample. From the research and the support of NASS members it has been possible to identify chemicals which can bind to ERAP1 which have the capacity to reduce its function in a way that could be potentially useful as a drug treatment for AS.

The NASS Team

There were lots of changes in 2014 considering what a small team we have at NASS. We began the year with Jill Hamilton covering the role of Branch Development Officer in addition to her usual work, in the absence of Maddy Randall who was on maternity leave. NASS had also employed its first apprentice, Jessica Fogden, to oversee our administration.

In the summer, Maddy advised that she would not be returning after her maternity leave and Jess advised that she would be finishing at the end of her first year; both due to relocation. Catriona, our part-time Fundraising Manger also advised that she was moving on. I wish to thank them all for the contribution they made to NASS during their time with the Team.

Joe Murray joined the Team at the end of March to look after Membership and all our reactive fundraisers. This work had previously been undertaken by Jill who was newly promoted to the role of Development Manager.

In September we managed to successfully recruit Laura Richards, Amardeep Gill and Laura Garbari to undertake the roles of Branch Development Officer, Fundraising Manager and Helpline support and Finance and Administration manager respectively. Finally, for the first time in the year the Team was back at full capacity with an additional half a post to support the growing demand on the NASS Helpline. There are now 7 members in the NASS Team.

We have a fantastic dedicated team in place at NASS who work incredibly hard to deliver our charitable activities. Many people assume, given the activity we are able to achieve that NASS is a much larger organisation. This is credit to the team members we have in place.

I wish to thank them all most sincerely for their hard work, dedication and support. The work of NASS has increased dramatically since I joined in 2011 and they have embraced this additional workload, delivering an excellent service.



Trustees and MAB

In June 2014 at the Annual General Meeting a new Chairman, Raj Mahapatra was elected. Raj has been a pleasure to work with and has a huge amount of energy for the role. Our trustees and Medical Advisors undertake much work for NASS behind the scenes. I want to take this opportunity to thank them all for all they contribute to our organisation; their dedication is much appreciated.

Volunteers

NASS is hugely grateful for all the support we received from volunteers in a variety of ways throughout 2014. From the 60,000 hours of exercise delivered through our branches, invaluable guidance from our medical advisory board, helping out at our events or in the office – every hour of time is greatly appreciated.

The Future

2015 is set to be another busy year for NASS. We have already launched a 5-year Strategy outlining what our priorities will be; detailing initiatives aimed at tackling the delay in diagnosis, focussing on self management and patient empowerment, access to physiotherapy and raising awareness about AS generally. We hope to deliver new resources specifically aimed at those aged 16-24 years. Our AS and You events will continue to tour the UK, supporting those with a recent diagnosis. We will continue to work with NICE to help develop Clinical Guidelines for Spondyloarthritis. We will expand our range of patient information, our Back to Action App is to be updated and we will continue to educate health care professionals about AS and what's important to patients.

We have already launched a wonderful, much-needed, brand new Research Fund of £150,000, something which I know our members will welcome.

Our trustees have decided that we are to move offices and this move to Hammersmith, London is scheduled to take place mid-March.

With a new government in place the Team will work hard to influence health policy to ensure that people with AS are getting the care, support and services they need.

NASS can only continue to do the work we do for the patient and healthcare community with the support of our members. One of our biggest challenges for the years ahead will be a need to secure additional income through our membership and fundraising activities. NASS does not receive any government subsidy and so relies totally on this type of support.

And, thinking further ahead, 2016 is NASS' 40th birthday. We have much to celebrate. A year of extra-special activities is planned.

I would like to thank all our members, supporters and donors for their continued support. We've significantly increased what we do and we need the financial support to match this level of activity. Thank you to all our dedicated fundraisers and volunteers; we appreciate your support so much, we really could not do what we do without you.

I do, as ever, welcome the views of our members and supporters; NASS is your organisation and it's incredibly important to me that your charity lives up to your expectations.

I hope that you'll agree that 2014 has been a good year for NASS; and if we can secure the necessary funding, then 2015 promises to be even better.

Debbie Cook, NASS Chief Executive

May 2015

NASS Trustees' Report

The Trustees present their report and accounts for the year ended 31 December 2014, prepared in accordance with current statutory requirements and in accordance with the Charity Commission Statement of Recommended Practice.

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

a. Name, address and registration

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

b. Trustees

The Trustees who served during the year were:

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

a. Constitution

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

b. Appointment of Trustees

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

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

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

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

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

On appointment, new trustees are asked to spend a half day in the NASS central office for a briefing by the Chairman or Treasurer and to meet the Chief Executive, the staff and understand how the society works. Formal training is provided when required.

c. Management

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

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

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

3. Objectives and Activities

a. Objectives

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

The Society's mission is threefold:

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

b. Public benefit

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

The Society provides public benefit in several ways:

- by promoting research into the management and cure of ankylosing spondylitis and related conditions and their causes;
- by disseminating the results of research related to these conditions;
- by working with statutory bodies and others that provide for the treatment and welfare of people affected by these conditions;
- by educating people affected by these conditions, as well as healthcare professionals and the public, on the problems related to these conditions; and
- by putting people affected by these conditions in contact with expert advisers on all aspects of these conditions.

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

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

c. Strategies adopted

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

- (i) Research into ankylosing spondylitis and related conditions:
 - to facilitate research through a variety of means including campaigning, cooperation with academic centres and with pharmaceutical companies, and PR;
 - to encourage members of the Society to co-operate in research programmes;
 - to set up a grants scheme for research;
 - to communicate to members and the wider public the results of research using the most appropriate media, including AS news, websites and conferences.
- (ii) Campaigning on behalf of people with ankylosing spondylitis and related conditions:
 - to use a variety of means to increase awareness of these conditions among the public and within the healthcare profession, including such matters as early diagnosis and appropriate treatment;
 - to use a variety of means to improve access to the latest available treatments and care, in particular through lobbying elected representatives, healthcare professionals and statutory bodies;
 - to ensure that awareness of these conditions is raised with related charities and organisations so that concerted approaches can be made when appropriate including at international level.
- (iii) Education of the public about ankylosing spondylitis and related conditions:

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

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

a. Risk

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

- (i) Loss of funds: Funds are held with various first-tier banks on a short-term basis and as a result there is little risk of loss in the short to medium term.
- (ii) Loss of income: The Society seeks to broaden and expand its income from all sources. Nevertheless the Society is dependent upon voluntary income, both at branch level and at national level, and aims to continue to increase its membership locally and nationally.
- (iii) Loss of reputation: The Society seeks at all times to maintain its independent viewpoint. Assistance received from external bodies, such as members of the pharmaceutical industry, is strictly controlled so as to ensure that independence is not compromised.

b. Subscriptions

The Society charges subscriptions to its members at national and branch level. In addition the Society operates a local branch model for group exercise and most of the attendees are national members. At national level this income is used to fund the charitable activities of the Society and to defray the costs of running the Society. At branch level the income is used almost wholly to provide to members physiotherapy treatment over and above that available to them from the NHS. The Society has approximately 5,500 members at national level and around 800 attendees per week at branches. The Trustees actively encourage all those with AS and related conditions to join the Society.

c. Branch network

The Society has 90 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 one new branch was opened and two closed down.

d. Fundraising and Grants

The Society holds fund-raising events from time to time and also welcomes the efforts of individual members who undertake fund-raising activities on behalf of the Society. The Society also solicits grants from charitable trusts and from the pharmaceutical industry, subject to certain limits in order to protect the independence of the Society. In particular grants received from the pharmaceutical

industry are limited to 25% of income of the average charity income over 3 consecutive years and must be made available for the support of the Society's charitable activities without restriction.

During the year the Society received an unrestricted grant of $\pm 25,000$ (2013 - $\pm 25,000$) from Abbvie UK.

In addition grants totalling £39,996 (2013 - £53,050) were received for specific projects.

e. Expenditure on Research

The Society incurred total costs of £23,637 (2013 - £ 22,963) on research activities during the year which included support costs of £22,714 (2013 - £20,564). The Trustees are keen to foster continued research into AS and related conditions, and have implemented a grant based system for funding research projects.

f. Expenditure on Campaigning

The Society incurred total costs of \pounds 71,440 (2013 - \pounds 67,558) on campaigning activities during the year which included support costs of \pounds 68,144 (2013 - \pounds 61,693). This reflects the continuing emphasis placed by the Trustees on campaigning for wider recognition of the condition, speedier diagnosis and better treatment.

The Trustees expect to continue the Society's efforts to campaign on a wide range of issues on behalf of members concerning AS and related conditions, and expenditure in this area is likely to increase in the coming years.

g. Expenditure on Education and Support

The Society incurred total central costs of £158,847 (2013 - £137,101) on education and support activities during the year which included support costs of £113,574 (2013 - £102,821). Education and support remains a vital part of the Society's activities and the Trustees continue to seek to broaden the Society's work in these areas.

In addition the Society incurred branch costs of £191,496 (2013 - £185,799) in support of these activities.

h. Volunteers

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

i. Organisational relationships

The Society is a member of the following organisations:

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

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

j. The Future

The Society has exciting prospects for the future. The very significant increase in the Society's resources, resulting from four major legacies received during the year, has enabled the Trustees to plan for growth in all areas of the society's charitable activities. Principal among these is the establishment at the start of 2015 of a scheme to promote and fund research projects into many aspects of 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 $\pm 1,177,000$ (2013- $\pm 329,000$).

The surplus of £ 648,850 in this financial year, derived largely from the receipt of four major legacies, has substantially increased free reserves. The Trustees have established a five year strategic plan to address the use of these reserves and substantial expenditure is planned on all of the Society's charitable objectives over this five year period.

At present the Society does not have an endowment fund and therefore income must be raised each year from voluntary sources and total income is likely to fluctuate from year to year. The Trustees have therefore decided that Free Reserves should be maintained at least at a level sufficient to meet all anticipated outgoings of the Society for the next financial year.

b. Investments

The Society has hitherto adopted a policy of maximising liquidity and therefore funds available have been held in interest-bearing bank accounts or equivalent short-term deposits at varying rates of interest placed with first-tier banks. The Trustees announced in 2009 their intention to review this policy. However the effect of the lengthy economic recession downturn after 2008 and related impact on investment performance had delayed this review. The review has been further delayed by the significant increase in the Society's resources and will not now be undertaken until next year.

In addition in 2014 the Trustees decided to relocate the Society's headquarters nearer to central London in order to better administer the Society's affairs. This move took place in March 2015. The Trustees have obtained permitted development rights to convert the Society's former headquarters, in Richmond, into two residential apartments and, following conversion, it is the intention of the Trustees to rent out these apartments to generate income for the Society. As a result this asset will be reclassified in the Society's accounts as an investment and will be reflected in the balance sheet at market value. The post-conversion value is likely to be significantly higher than the current book value of £294,920.

c. Summary of financial performance

As a whole, the Society reported a surplus of income over expenditure of $\pounds 648,850$ (2013 - $\pounds 1,741$). A surplus of $\pounds 631,865$ (2013 - deficit of $\pounds 6,333$) arose centrally and a surplus of $\pounds 17,335$ (2013 - $\pounds 7,701$) arose at branch level.

Voluntary income remained buoyant in the year with significant receipts from four legacies totalling $\pm 677,798$. As a result of this substantial increase in resources the Trustees have adopted a five year strategic plan to apply these resources to all the Society's charitable activities.

For the second year running, central expenditure has risen because staff levels have grown in order to deal with the Society's increasing efforts in meeting its charitable objectives. Expenditure is set to continue to rise over the period of the five year strategic plan.

6. <u>Statement of Trustees' responsibilities in respect of the accounts</u>

The 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

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

Signed on behalf of the Trustees

Auditors' Report to the Trustees

We have audited the financial statements of The National Ankylosing Spondylitis Society for the year ended 31 December 2014 set out on pages [33 to 43]. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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

Respective responsibilities of Trustees and auditor

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

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

Scope of the audit of the financial statements

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

In addition, we read all the financial and non-financial information in the Trustees' report to identify material inconsistencies with the audited financial statements. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

Opinion on financial statements

In our opinion the financial statements:

• give a true and fair view of the state of the Charity's affairs as at 31 December 2014 and of its incoming resources and application of resources for the year then ended;

- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011, the Charities and Trustee Investment (Scotland) Act 2005 and Regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Matters on which we are required to report by exception

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

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

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

Date:

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

NASS: Statement of Financial Activities

For the year ended 31 December 2014

	Restricted Funds						
	Note	Unrestricted Fund	Branch Funds	Branch Developt Fund	Fergus Rogers Fund	Total Year ended 31 Dec	Total Year ended 31 Dec 2013
		£	£	£	£	2014	£
Incoming resources Incoming resources from generated funds						Ĩ	
Voluntary income	2	897,722	191,601	-	-	1,089,323	416,150
Activities for generating funds	3	96,645	18,065	-	-	114,710	103,801
Investment income	4	1,376	114	-	-	1,490	952
Incoming resources from charitable activities		-	-	-	-	-	-
Total incoming resources		995,743	209,780	-	-	1,205,523	520,903
Resources expended							
Costs of generating funds	5	100,205	1,249	-	-	101,454	96,465
Charitable activities	6	253,924	191,496	-	350	445,770	413,421
Governance costs	7	9,449	-	-	-	9,449	9,326
Other resources expended		-	-	-	-	-	-
Total resources expended		363,578	192,745	-	350	556,673	519,212
Net incoming (outgoing) resources before transfers		632,165	17,035	-	(350)	648,850	1,691
Gross transfers between Funds		(300)	300	-	-	-	-
Net incoming (outgoing) resources before other recognised gains or losses		631,865	17,335	-	(350)	648,850	1,691
Gains (losses) on revaluation of investments		-	-	-	-	-	50
Net movement in funds for the year		631,865	17,335	-	(350)	648,850	1,741
Funds brought forward		630,727	193,334	2,201	4,425	830,687	828,946
Total Funds carried forward	18	1,262,592	210,669	2,201	4,075	1,479,537	830,687

The notes on pages 33 to 43 form part of these accounts.

NASS: Balance Sheet

31 December 2014

FIXED ASSETS	Note	31 December 2014 £	31 December 2013 £
Tangible assets Investments Total Fixed Assets CURRENT ASSETS	9 10 -	302,333 60,540 362,873	303,325 60,540 363,865
Debtors and prepayments Cash at bank and in hand Total current assets CREDITORS	11 12 -	27,833 1,116,071 1,143,904	5,780 489,058 494,838
Amounts falling due within one year	13	27,240	28,016
NET CURRENT ASSETS	-	1,116,664	466,822
TOTAL NET ASSETS	=	1,479,537	830,687
CHARITABLE FUNDS			
Unrestricted funds Branch funds Branch development fund Fergus Rogers fund	14 15 16 17	1,262,592 210,669 2,201 4,075	630,727 193,334 2,201 4,425
TOTAL CHARITABLE FUNDS	- 18 -	1,479,537	830,687

The accounts set out on pages 33 to 43 were approved by the Trustees on 20 June 2015.

Raj Mahapatra Chairman S H Frost Treasurer

For the year ended 31 December 2014

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 2014	Year to 31 Dec 2013
	£	£
Unrestricted funds		
Subscriptions	68,799	73,976
Donations and grants	151,125	150,260
Legacies	677,798	12,250
Total	897,722	236,486
Branch funds		
Subscriptions	168,091	164,637
Donations	23,510	15,027
Total	191,601	179,664
Branch Development Fund		
Donations	-	-
Total	-	-
Fergus Rogers Fund		
Donations	-	-
Total	-	-
Total voluntary income	1,089,323	416,150

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 2014 £	Year to 31 Dec 2013 £
Unrestricted funds		_
Annual draw	10,301	11,285
Fund-raising events	80,634	73,034
Research participation	-	-
Other income	5,710	3,499
Total	96,645	87,818
Branch funds		
Fundraising events	12,909	12,616
Other Income	5,156	3,367
Total	18,065	15,983
Branch Development Fund		
Fundraising events	-	-
Total	-	-
Fergus Rogers Fund		
Fundraising events	_	_
Total		
Total income from activities for generating funds	114,710	103,801

4. INVESTMENT INCOME

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

	Year to 31 Dec 2014 £	Year to 31 Dec 2013 £
Unrestricted funds		
Dividends received	9	18
Interest received	1,367	814
Total	1,376	832
Branch funds		
Interest received	114	120
Total	114	120
Branch Development Fund		
Interest received	-	-
Total	-	-
Fergus Rogers Fund		
Interest received	-	-
Total		-
Total investment income	1,490	952

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 2014 £	Year to 31 Dec 2013 £
Unrestricted funds		_
Annual draw prizes and expenses	4,285	4,286
Fundraising expenses	15,198	17,153
CAF administration charges	1,220	1,157
Support costs (note 8)	79,502	71,975
Total	100,205	94,571
Branch funds		
Fundraising expenses	1,249	1,894
Total	1,249	1,894
Fergus Rogers Fund		
Fundraising expenses	-	-
Total	-	-
Total costs of generating funds	101,454	96,465

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 2014 £	Year to 31 Dec 2013 £
Unrestricted funds			
Research	[note 6(b)]	23,637	22,963
Campaigning	[note 6(c)]	71,440	67,558
Education and support	[note 6(d)]	158,847	137,101
Total	-	253,924	227,622
Branch funds	-		
Campaigning		-	-
Education and support	[note 6(e)]	191,496	185,799
Total	-	191,496	185,799
Branch development fund	-		
Grants made		-	-
Total	-	-	-
Fergus Rogers Fund	-		
Welfare – grants made		350	-
Total	-	-	
	-		
Total resources expended on charitable activities	-	445,770	413,421

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

	Year to 31 Dec 2014 £	Year to 31 Dec 2013 £
Grants for research and related costs	-	1,382
AS News	923	1,017
Support costs (note 8)	22,714	20,564
Total research expenditure	23,637	22,963

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

	Year to 31 Dec 2014 £	Year to 31 Dec 2013 £
Advertising and campaigning	479	222
AS News	2,767	3,050
Standards of care and training of GPs and HCPs	50	2,093
Other direct expenses	-	500
Support costs (note 8)	68,144	61,693
Total campaigning expenditure	71,440	67,558

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

	Year to	Year to
	31 Dec 2014	31 Dec 2013
	£	£
AS News	14,755	16,269
Guide books, DVDs and apps	9,863	4,809
Literature, brochures and information	10,351	3,277
Patient and member conferences	8,734	7,728
Branch conferences and support	1,570	2,197
Support costs (note 8)	113,574	102,821
Total education & support expenditure	158,847	137,101

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

	Year to 31 Dec 2014 £	Year to 31 Dec 2013 £
Treatment by healthcare professionals	146,930	144,359
Hire of venues and facilities	29,949	28,966
Grants payable	2,092	2,246
Support costs (note 8)	12,525	10,228
Total branch education & support expenditure	191,496	185,799

7. GOVERNANCE COSTS

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

	Year to	Year to
	31 Dec 2014	31 Dec 2013
	£	£
Expenses paid to Trustees	2,899	2,694
Trustees meetings and Annual General Meeting	1,870	1,032
Auditors' remuneration	4,680	5,600
Total governance costs	9,449	9,326

The Trustees received no remuneration during the year (2013 – nil). Eleven Trustees claimed expenses during the year.

8. SUPPORT COSTS

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

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

	Year to 31 Dec 2014 £	Year to 31 Dec 2013 £
Staff costs (note 8c)	206,907	192,705
Premises costs	25,516	15,618
Travel expenses	11,393	12,790
IT and Communications	23,012	18,729
Office costs	8,146	9,651
Insurance, legal and professional	8.960	7,560
Total support costs	283,934	257,053

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	22,714	20,564
Campaigning	68,144	61,693
Education and support	113,574	102,821
Fundraising activities	79,502	71,975
	283,934	257,053

b) Branch support costs incurred in the year amounted to £12,525 (2013 - £10,228), and are wholly attributable to education and support.

c) Staff costs incurred during the year consisted of:

Wages and salaries	180,130	172,114
Social security contributions	18,562	17,483
Pension contributions	7,257	2,786
Recruitment, training and other costs	958	322
Total staff costs	206,907	192,705

d) Information about employees:

	31 Dec 2014	31 Dec 2013
Average number of employees during the year	5	5
Number of employees for whom pension contributions have been made	5	5
Number of employees whose emoluments exceeded $\pounds 60,000$ per annum		
£70,000 to £80,000	1	1

9. TANGIBLE FIXED ASSETS

	Leasehold Buildings £	Office Equipment £	Total £
Cost at 31 December 2013	351,000	20,326	371,326
Additions in the year	-	9,596	9,596
Cost at 31 December 2014	351,000	29,922	380,922
Depreciation at 31 December 2013	49,060	18,941	68,001
Depreciation charge for the year	7,020	3,568	10,588
Depreciation at 31 December 2014	56,080	22,509	78,589
Net book value at 31 December 2013	301,940	1,385	303,325
Net book value at 31 December 2014	294,920	7,413	302,333

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

10. INVESTMENTS

	31 Dec 2014	31 Dec 2013
	£	£
Bronze statues, at valuation	60,000	60,000
Listed shares, at valuation	540	540
	60,540	60,540

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

The listed shares are carried at market value. The increase in value of nil (2013 – increase of \pm 50) during the year has been reflected in the Statement of Financial Activity.

11. DEBTORS AND PREPAYMENTS

	31 Dec 2014	31 Dec 2013
	£	£
Office lease deposit	8,100	-
Prepayments	13,257	5,089
Sundry debtors	6,476	691
	27,833	5,780

12. CASH AT BANK AND IN HAND

	31 Dec 2014	31 Dec 2013	
	£	£	
Deposit account balances held centrally	878,507	283,434	
Deposit account balances held by branches	205,312	188,762	
Current account balances	26,785	12,288	
Cash in hand	5,467	4,574	
	1,116,071	489,058	

13. CREDITORS: Amounts falling due within one year

	31 Dec 2014	31 Dec 2013 £	
	£		
Sundry creditors	1,520	11,716	
Deferred income	10,000	10,000	
Accrued expenses	15,720	6,300	
	27,240	28,016	

There are no creditors falling due after more than one year (2013 – nil).

14. UNRESTRICTED FUNDS

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

15. BRANCH FUNDS

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

During the year grants totalling \pounds 1,750 (2013 - \pounds 600) were paid to branches from Unrestricted Funds and donations totalling \pounds 1,450 (2013 - \pounds 600) 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 \pounds nil (2013 - \pounds 373) 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 $\pm 350 (2013 - \pm nil)$ was expended on welfare.

18. RECONCILIATION OF CHARITABLE FUNDS

	Unrestricted Fund £	Branch Funds £	Branch Dev Fund £	Fergus Rogers Fund £	Total Funds £
Tangible assets	302,333	-	-	-	302,333
Investments	60,540	-	-	-	60,540
Debtors and prepayments	27,833	-	-	-	27,833
Cash at bank and in hand	899,126	210,669	2,201	4,075	1,116,071
Less creditors	(27,240)	-	-	-	(27,240)
Total charitable funds	1,262,592	210,669	2,201	4,075	1,479,537