NATIONAL ANKYLOSING SPONDYLITIS SOCIETY NASS UK

Report and Accounts for the year ended 31 December 2012

Registered Charity Number in England and Wales 272258 Registered as a charity in Scotland 041347

Contents

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Chairman's Report

2012 has been another very successful year for NASS. Our aim in the last few years has been to raise both what we do and NASS's profile, so that we better support patients and their families directly and also have greater influence to achieve medium and long term objectives with external bodies like the NHS and NICE.

In terms of delivering support to patients and families we are reaching and helping more people; compared to last year we have distributed twice as many guidebooks, had twice as many calls to the helpline, and seen twice the use of the website. Meanwhile we are providing support in new ways (telephone helpline began last year, new apps this year).

We are pleased to see more consultation with NASS from key bodies, and to see the NHS publishing specific, positive responses NASS. Looking Ahead (a best practice guide for hospitals and consultants) has been followed up by our 1st audit of best practice in hospitals – raising awareness and hopefully standards too. Not resting there, Looking Ahead is already being enhanced with the intention of having it further endorsed and embedded in the NHS with the aim of again increasing the quality of care for those with AS. At this point I must give great thanks to the superb advisory board of consultants for the huge amount of work which they have put into defining best practice and creating this document as well as guiding the NASS board and supporting the helpdesk. Their names are given on page 10 of this report. (If you meet them - please say thank you). There are more plans for raising awareness and standards in hospitals which we are delivering in 2013, but more about that in next year's report.

Our Director, Debbie Cook, and her team remain outrageously busy, with Debbie being told "NASS is everywhere" by people from much larger organisations impressed with how much we achieve. Debbie is also being invited to join standing committees/boards in some of the organisations we work with – a testament to how both NASS and Debbie are regarded.

The Richmond office remains the hub for core staff and volunteers though as our interactions with other bodies grow we are sometimes just that little too far out for easy working and meetings.

Branches have figured highly in the recent years as we try to improve cohesion and support. For many patients their NASS branch is their main contact with and one of the most important aspects of NASS. Great thanks are due to the branch organisers without whom branches simply wouldn't be able to operate. We have had to ensure that exercise is led by suitably qualified people which raised some issues but we are pleased to see that after some years of decline the number of branches is growing, with a total of 87 across the UK (though sadly none in Northern Ireland).

However, all these great things come at a cost and NASS needs more income to be able to maintain the current level of activity.

For some years we have set a strategy to increase NASS's presence and the support it delivers. Initially when we set an investing budget (intending to spend more than we raised), income quickly increased as a result and we actually made a slight surplus. We have continued to invest but in 2012 made a larger loss than intended as some income sources tightened in the recession. We have resources and can continue to invest, but at the same time we need to raise more income to balance our budget in the long term.

Membership is slowly increasing and more people are doing their bit to raise money, so thank you to all our members and fundraisers. Let's keep NASS in mind and keep working together.

Hedley Hamilton
Chairman
8th June 2013

Director's Report on the year

Having joined NASS in June 2011, it still felt like fairly early days when we looked to establish priorities for 2012; growing and supporting our branch network, educating GPs to recognise the signs of inflammatory back pain and to understand the principles contained in *Looking Ahead*, together with engaging young people through social media. When you read through this report, I hope you'll agree that we managed to do all those things and much, much more.

CAMPAIGNING

In January 2012 NASS welcomed Sophie Matthew to the new post of Campaigns Officer with a one year contract.

The GP Awareness Campaign

The team has worked hard to raise awareness of AS, the unacceptably long average delay in diagnosis, and to promote awareness of NASS's publication 'Looking Ahead: Best practice for the care of people with ankylosing spondylitis (AS).'

NB Medical

NASS has worked with a well-respected medical education company, NB Medical, who provide regular and well attended update courses for qualified GPs. With input from Sophie and Dr Karl Gaffney, NB Medical produced and published a 'Hot Topic' on AS, based on Looking Ahead. This was delivered as part of their conference programme at their update courses for GPs in the spring and autumn of 2012, reaching over **10,000 GPs** all around the UK. The Hot Topic on AS has also been distributed, as part of their materials, to many other GPs.

NASS also had exhibition stands at 15 of these GP conferences run by NB Medical, giving direct access to **5,000** GPs.

NB Medical used this Hot Topic to produce a module for Pulse Learning which includes the 'diagnosis and management of AS'. These modules can be completed by GPs as part of their accredited continuing professional development (CPD).

Over 16,000 GPs reached in 2012

Conferences attended by NASS

NASS has had exhibition stands at the following conferences:-

- British Society for Rheumatology Conference in May 2012
- Primary Care Conference in Birmingham attended by 6,000 primary healthcare professionals in May 2012.
- Arena Rheumatology Nurse event in May 2012.
- Royal College of GPs conference in Glasgow attended by 1,600 GPs in October 2012.

- Primary Care Rheumatology Society conference in York in November 2012.
- NASS provided an information poster on ‘AS and uveitis’ to the annual conference of the Royal College of Ophthalmologists in April 2012.
- Dr Antoni Chan spoke on AS and NASS had an exhibition stand at the Annual Conference of the British Chiropractic Association in Warwickshire in September 2012.
- Dr Andrew Keat spoke on AS and NASS had an exhibition stand at the Annual Conference of the British Osteopathic Association in York in November 2012.

In September 2012, NASS was part of the IMID (Immune Mediated Inflammatory Diseases) London conference Steering Committee. The IMID event ‘A Bigger Voice for a Better Future’ was funded by Abbott Laboratories and brought together patient organisations from all over the world. As well as being involved in the organisation of this 2-day event, NASS was able to showcase its work on an exhibition stand.

Ophthalmologists, chiropractors, nurses and primary care workers targeted for awareness

I was privileged to attend the Spondyloarthritis (SpA) convention in Gent, Belgium in October 2012. My attendance was funded by Pfizer Ltd. This was an excellent opportunity to learn about the latest research in AS /Axial SpA and to represent NASS at various meetings scheduled during the event.

The Primary Care Back Pain Initiative

The NASS Medical Advisory Board (MAB) was convened in March 2012 to help further shape the NASS GP Awareness Project. Several further meetings have taken place in 2012 from which the Back Pain Seminar initiative has evolved. The Seminar was developed as a learning programme for primary healthcare professionals (specifically GPs, physiotherapists, osteopaths and chiropractors) in order to optimise the diagnosis and management of patients with inflammatory back pain/AS. It uses both plenary sessions and interactive videos and workshops and was jointly developed with and sponsored by Abbott Laboratories.

The Primary Care Back Pain Initiative aims to improve the understanding and recognition of inflammatory vs. mechanical back pain in primary care, provide an overview of the evaluation, investigation and management of patients with back pain and support appropriate referral of patients from primary care to specialists.

93% of GPs to change practice after attending Back Pain Seminars

During November 2012 this Back Pain Seminar was delivered in Birmingham and Norwich and plans have been made to deliver more during 2013. In Birmingham the seminar was oversubscribed and ran to a full house of 100 delegates. NASS Trustees and Medical Advisory Board members, Dr Karl Gaffney, Dr Raj Sengupta, Claire Harris and I gave presentations. In Norwich Dr Karl Gaffney delivered the seminar to more than 50 GP trainees in the Norwich Deanery. I gave a presentation on the work of NASS.

NASS received excellent feedback from both these seminars and:

- 100% of respondents said that their overall impression of the meeting was ‘excellent’, ‘very good’ or ‘good’;

- More than 95% of respondents said that the meeting content was ‘very relevant’ or ‘relevant’ to their work;
- 100 % of respondents said that it was ‘extremely useful’, ‘very useful’ or ‘useful’;

and significantly

- 93% of GPs said that they would completely or considerably change their practice as a result of attending the seminar.

> I think it is essential that GPs and physios involved in ICATs triaging services attend this course in order to recognise SpA

> Excellent presentations, highly relevant to GPs

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

Parliamentary Awareness

NASS continued to make contact in various ways with ministers, MPs and officials in the Department of Health (DoH) to raise issues relating to the treatment and care for those with AS.

NASS corresponded with the Secretary of State for Health, initially Andrew Lansley MP and subsequently Jeremy Hunt MP. We also corresponded with the Minister for Care and Support, Norman Lamb MP, and the Chief Medical Officer, Dame Sally Davies, and many other MPs. NASS has an excellent relationship with both Andrew George, MP and Huw Irranca-Davies, MP, both of whom have AS. I wish to thank them both, in particular, for their support for NASS. In June 2012 NASS prepared a briefing for Andrew George, MP on ‘Ankylosing Spondylitis, a forgotten condition’ and we also supplied suggested parliamentary questions on AS. I took part in a round table event hosted by Andrew George, MP in June 2012 which helped shape a ‘Forgotten Conditions’ lobbying report. Work to further develop some of the recommendations within this report is planned for 2013.

Flying the Flag for NASS

On 5 November 2012 NASS held a reception in the House of Commons to thank our supporters and fundraisers. This reception was kindly hosted for us by Andrew George, MP. We asked all those attending to invite their MP and took the opportunity to raise awareness about AS with MPs both on the day and after the event.

The reception was attended by 150 friends and supporters of NASS. Seventeen MPs attended the event, with a further 12 MPs making contact with us thereafter. This was a fabulous event and a particular highlight of the year for me. It provided a chance not only to meet so many of our loyal supporters but also to raise the profile of AS in Parliament.

NASS issued a call to action asking MPs, our supporters and members to write to the Secretary of State for Health regarding the delay in diagnosis for people with AS. As a result of this successful exercise the DoH subsequently acknowledged our campaign for better services for people with AS and the need for early diagnosis on their website. NASS also received letters from both the Secretary of State for Health, and the Minister of State for Care and Support, stating that the DoH is committed to improving health outcomes for people with AS; a step in the right direction.

NASS launched a new logo at Flying the Flag for NASS after consulting on a positive brand image at the 2012 AGM.

The Scottish Parliament

NASS attends meetings of the Cross Party Group on Arthritis and Musculoskeletal Conditions which meets regularly in the Scottish Parliament in Edinburgh. In 2012 we arranged for a meeting specifically on AS to take place and this is scheduled for October 2013. NASS is very grateful to our volunteers in Scotland who also attend these meetings to represent NASS.

World AS Day/ NASS en Masse

NASS en Masse – 7 events, 600 participants, £15,000 raised

The first Saturday in May has been designated World AS Day by the Ankylosing Spondylitis International Federation (ASIF). In 2012 a new approach was taken towards the annual NASS en Masse event holding 7 events across the UK in the form of five 5k sponsored walks and two family fun days. The sponsored walks were held at Portsmouth, Richmond Park, Pollok Park in Glasgow, Rosliston Forestry Centre in Derbyshire and Bute Park in Cardiff. John Boyle organised a family fun day at Trafford MV Rugby Club and James O’Brien a family day at Rylands Farm, Yeovil. We are incredibly grateful to the 600 people who took part in these events and raised approximately £15,000 for NASS.

INFORMATION AND SUPPORT

NASS Helpline

While our information officer, Sally Dickinson, was available to take patient enquiries throughout 2011, our official Helpline was launched in September 2011 to make it clear that this service was available to all.

During 2012 Sally received and responded to 3,792 Helpline enquiries.

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. During 2012 more than 5,000 Helpline cards were distributed on request to rheumatology departments.

3,972 helpline enquiries
5,000 helpline cards distributed

We have set Helpline hours between 0900 and 1200. This is working very well, with the majority of people making contact during those hours. This system aims to free up some of the afternoon for Sally to work on other information resources including the website and AS News. Diagnosis and the management of AS, including medication and exercise are key reasons for contacting the Helpline. Currently anti TNF therapy is perhaps the most common concern.

Throughout 2012 the numbers of people calling the Helpline regarding benefits issues, including Disability Living Allowance and Employment and Support Allowance increased significantly. This was largely due to the changing political landscape resulting in the potential for members to lose benefits they had 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.

NASS Website

The AS information pathway is a guide to what information is available and might be useful for you at every key stage of your journey.

All the information you need to help you towards a diagnosis of your back pain.

The facts you will want to know when you first get your diagnosis.

Use this section to help manage your AS most effectively throughout your life.

Practical advice on living with your AS

Exercise is vital in managing your AS and we have lots of ways to help

Read about how others deal with their AS

The NASS website is one of the main ways people now access information about NASS and AS. During 2012 NASS had 146,720 visitors to the website, of which 94,534 were unique visitors. 63% of visitors to the site were new visitors. The majority of site visitors were from the UK (75%), with other visitors coming from the USA (9%), India (3%), Australia (2%) and Canada (1%). NASS encourages traffic to the site by regularly updating and adding new information. In particular we work hard to keep our news pages updated, often on a daily basis but always weekly. The website forum became increasingly popular throughout 2012. 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.

Social Media

NASS has fun engaging with the AS community through social media. I was keen for NASS to embrace social media as part of our everyday business. Social media platforms have enabled NASS to reach a wider, younger audience and ensure that the active, vibrant organisation that we are is communicated in a timely manner and through various channels. It has been very rewarding to see the AS community actively engage with NASS through social media and I am convinced that we have made contact with and been able to provide support to a section of the community that we might have missed previously.

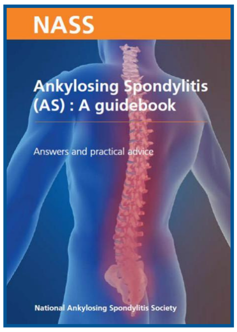
NASS has had a Facebook page since 2010. During 2012 Jill Hamilton has ensured that she posts on the Facebook page on a daily basis, highlighting news about NASS, AS and NASS members that users might find interesting. Her hard work has seen the number of 'Likes' increase significantly over the year. In December 2012 the page had received almost 2,000 'Likes'.

Maddy Randall (@NASSexercise) and I (@NASSdirector) have each had Twitter accounts since autumn 2011. During 2012 we have tried to post on at least a daily basis. Maddy Randall has concentrated on exercise-based information whilst I post on all aspects of NASS, AS and news that followers would find of interest. By December 2012 @NASSdirector was on course to receive 1,000 followers.

Anyone accessing the NASS website can sign up on the Home page to receive the NASS monthly E-News. E-News was started in February 2011 and by December 2012 we had more than 3,500 signed up to receive it. E-News highlights the news on AS and NASS from the previous month, including any new web pages. The combination of Facebook, Twitter and E-News has certainly contributed to the increased traffic to the NASS website as well as raising the profile of AS and NASS.

94,534 unique visitors to the website
2,000 Facebook 'likes'
1,000 Twitter followers
3,500 subscribers to E-news

Printed Materials

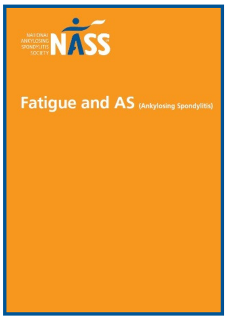


NASS Patient Guidebook

The guidebook for patients is 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. During 2011 NASS distributed 5,000 guidebooks. 10,000 guidebooks were distributed during 2012.

10,000 guidebooks distributed
DOUBLED from 2011
3,000 factsheets distributed

Factsheets



NASS believed it was important to have additional factsheets on offer within rheumatology departments for patients to be able to pick up during a visit. We aim to build a portfolio of factsheets on issues which members tell us are important. Research among members and rheumatology departments indicated that uveitis, fatigue and driving would be valued factsheet topics. These three new factsheets were produced early in 2012 and immediately proved very popular. During 2012 around 3,000 copies of each of the factsheets were distributed.

Benefits and Work guides

State benefits are a major issue for many people with AS who contact NASS on this issue. NASS has tried to help people by taking out a professional subscription to the Benefits and Work website which has allowed us to download a whole range of practical guides to claiming or appealing such benefits. Due to copyright restrictions we cannot put these reports onto the website but we can email them or print and mail copies to anyone who contacts us. NASS also regularly writes supporting letters to the Department for Work and Pensions for individuals with AS.

AS News

NASS continues to produce AS News, our members' magazine, twice a year (spring and autumn). In spring 2012 NASS introduced 'You Said, NASS listened' into AS News. The NASS team prides itself on how much we listen to our members and will continue to use this strap-line to show what actions we take specifically in response to member requests/feedback.

We also produced NASS Active in autumn, the magazine celebrating all the wonderful supporters raising money for NASS. Jill advises all supporters that they will be featured in NASS active and encourages them to send in photographs of their event. This is a wonderful, vibrant publication that 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

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

- Colin Beevor, Senior Clinical Nurse Specialist for Rheumatology Services
- Dr Andrei Calin, Rheumatologist
- Dr Karl Gaffney, Consultant Rheumatologist
- Claire Harris, Senior Physiotherapist
- Dr Andrew Keat, 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 and help Sally answer more complex individual patient queries. In 2012 Dr Sengupta and Dr Gaffney made a substantial additional contribution to the Back Pain seminar work, helping film the videos and devise the education programme.

Looking Ahead audit

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

Nationwide survey of rheumatology departments conducted

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 wanted to take 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. NASS will report on the results in 2013 and these findings will help shape the work of NASS over the next 2-3 years.

NASS Patient Conference

The NASS Patient Conference & AGM was held on 23 June 2012 at Weetwood Hall in Leeds. The conference was supported by an educational grant from UCB Pharma Limited allowing NASS members plus one guest to attend for free. The conference was attended by 150 members, guests, trustees and health professionals who were treated to a series of presentations by leading health professionals in the areas of research, the psychological impact of AS, and osteoporosis. In addition NASS provided a choice of round table sessions on a variety of topics. We are extremely grateful to all the speakers for giving their time including Dr Chris Deighton, Professor Dennis McGonagle, Diane Aronson and Dr Ashok Bhalla. A special thank you to Dr Helena Marzo Ortega and Leeds NHS Teaching Trust for their help with organising the conference. The feedback from the conference was excellent. Ideally NASS would like to be able to hold such a conference every year separately in England, Scotland, Wales and Northern Ireland but so far lack of sufficient finance has prevented us achieving this aim.

Back To Action

Following the successful launch of the Back to Action App on the Apple platform and requests from members, an android version of the App was launched to coincide with World AS Day on 5 May 2012. By the end of 2012 Back to Action had been downloaded over 6,000 times. Sales of the hard copy Back to Action book continued steadily with 150 copies sold in 2012.

Over 6,000 downloads of Back to Action App

Supporting people with AS - case studies

We pride ourselves at NASS on the various ways we provide support to the whole AS community; not just people with AS, but their families and friends as well. The following case studies provide the stories of just a few people we've been able to assist in 2012.

Funding for two NASS members to access regular physiotherapy sessions

In autumn 2011 Gareth, a NASS supporter offered to pay for a year of private physiotherapy sessions for a NASS member who was unable to access physiotherapy either through a NASS group or the NHS. This offer was advertised in the autumn 2011 AS News and applications were invited. Ultimately Gareth chose to fund physiotherapy for two NASS members starting from April 2012.

Kelly was 27 years old and had been diagnosed with AS for 2 years. She experienced profound benefits from her weekly one to one physiotherapy sessions. She noted that it made a tremendous difference to her mobility and was instrumental in controlling the level of pain and stiffness she experienced on a daily basis.

Adrian from Northern Ireland was diagnosed with AS in 2005. Married with two children aged 11 and 8 Adrian worked as a chef by profession. Before starting the physiotherapy sessions, the physical and mental demands of his work as a chef and the challenges of raising two young children, along with the constant pain and restricted mobility of AS made his life a real struggle. He had a constant need for medication to reduce the pain. His morale was low and he was left with little energy, when it came to interacting with his family after work.

Adrian reported impressive benefits from the regular physiotherapy sessions. He now has a reduced need for pain control, benefits from increased mobility and feels much more relaxed. His morale is higher and he has more energy for engaging with his family. Adrian is now working hard to improve access to physiotherapy sessions for others with AS in Northern Ireland and aims to raise awareness of AS in Northern Ireland by telling his story to the press.

Whole body cryotherapy

Using ice packs to reduce inflammation or swelling, is one of the oldest therapeutic treatments available to physiotherapists and is an internationally accepted way to accelerate recovery from injury. Whole body cryotherapy originated in Japan in 1978, but was pioneered in Germany, in the 1980s, by Professor Reinhard Fricke as a way to relieve chronic pain and arthritis. Whole body cryotherapy is a now a widely accepted medical treatment in both Germany and Poland where it is also used in the field of professional sports and athletics. During whole body cryotherapy treatment the patient enters a special cryotherapy pod in their bathing suit, with socks, gloves, mouth and ear protection, and the pod is cooled to a temperature of -80°C for three minutes. Whilst in the pod, the patient's average skin temperature never drops lower than 5°C. The core body temperature remains unchanged.

BMI, The Garden Hospital in Hendon, London has a cryotherapy pod and offered three NASS members six free cryotherapy pod sessions each. This offer was advertised in the spring 2012 edition of AS News.

Each of the volunteers had a short (4 to 5 minute) session in the cryotherapy pod, followed by a warm up session on an exercise bike and then a 30 minute Pilate's session. The volunteers had 6 sessions each. Their experiences were reported on in the autumn 2012 edition of AS News.

WORKING WITH OTHER ORGANISATIONS

National Institute for Health and Clinical Excellence (NICE)

In 2008 NASS worked with NICE on the multiple technology appraisal for the new anti TNF drugs (TA143) which gave access to adalimumab (Humira) and etanercept (Enbrel). NASS worked with NICE again in 2011 when another anti TNF, golimumab (Simponi), was approved for AS.

In November 2012 NICE agreed that, an update of TA143 should take place in the context of a multiple technology appraisal to include:

- a broadening of the indication to include axial spondyloarthritis without radiographic evidence of AS
- all TNF-inhibitors that are licensed for the relevant indications or that will be licensed within the timeline of the appraisal.

This expanded remit would encompass an update of TA233 'Golimumab for the treatment of ankylosing spondylitis' which is currently due to be considered for review in August 2014.

In order to be completely confident that this was appropriate, NICE asked NASS, along with other consultees, to inform them of any evidence which would suggest that an earlier review would be beneficial. NASS responded to NICE highlighting 3 issues which we believe should be considered when reviewing TA143:

- The definition of ankylosing spondylitis (AS) and introduction of the term axial spondyloarthritis (SpA)
- The use of anti TNF therapy in axial SpA
- Switching to a second anti TNF after failure of the first agent due to either side effects or efficacy.

The definition of AS and introduction of the term axial spondyloarthritis (SpA)

Within current NICE guidance, AS is defined only using the modified New York Criteria. This criteria requires x-ray (radiographic) evidence of bilateral sacroiliitis. However, diagnosis has moved on over the past few years and people can now be diagnosed using MRI scanning and imaging of the spine (non-radiographic axial SpA - early AS).

Thus AS, as defined by the modified New York criteria, no longer describes the wider spectrum of disease which has been revealed by MRI scanning and by imaging the whole spine. It will be important for NICE guidance to take account of these changes.

NASS is aware from our conversations with AS patients, that people with non radiographic AS often suffer with the same symptoms as people with radiographic AS and these symptoms have the same impact on daily living with all the worries for the future that go with that.

The use of anti TNF therapy in axial SpA

In August 2012 The European Medicines Agency (EMA) approved adalimumab (Humira) for the treatment of adults with severe axial spondyloarthritis (axSpA) who have no X-ray evidence of structural damage but have objective signs of inflammation by elevated c-reactive protein (CRP) and/or MRI and who have had an inadequate response to, or are intolerant to non-steroidal anti-inflammatory drugs (NSAIDs).

Humira was previously only indicated for the treatment of adults with severe active AS who have had an inadequate response to conventional therapy. This means there previously had to be changes on x-ray for rheumatologists to be able to prescribe this anti TNF.

It's important to bear in mind that, although this means that Humira now has a license to be used in this way, in the UK rheumatologists follow NICE guidance for the prescribing of anti TNF therapy and NICE guidance has not yet changed.

Switching to a second anti TNF after failure of the first agent due to either side effects or efficacy

Under current NICE guidance AS patients can only try one anti TNF. If this does not prove effective, or if the efficacy decreases over time, there is nothing in NICE guidance to allow for a change in therapy, despite the increasing weight of evidence that moving to a second or even a third anti TNF can prove beneficial. If anti TNF therapy fails then patients have effectively reached the end of the line as far as treatment goes.

This puts an enormous pressure on patients to ‘pick the right anti TNF therapy' when they discuss which of the three therapies they would like to try with their nurse. We know that, unless there is a particular clinical reason for patients to have one particular anti TNF therapy they will be offered a choice. Patients can get very stressed and upset when making this choice as they are made aware they don't have the option to change to another anti TNF if this proves to be the wrong choice for them. They currently call the NASS Helpline and join the debate on the forum in an attempt to try and make the right choice.

When anti TNF therapy is first discussed, patients do hear stories of the possible ‘life-changing' results of such therapies. However, we know that, although around 7 in 10 patients get benefits from anti TNF therapy, 3 in 10 do not find them efficacious. These patients experience a great deal of disappointment and upset when their anti TNF therapy fails, especially if they cannot be offered a second anti TNF. They can be told by their rheumatology department that there is nothing more that can be done for them and are left struggling on NSAIDs and opioids. These are often relatively young people. They may have young families and be working. Anti TNF failure and the inability to try another effective therapy can destroy their lives and lead to psychological problems.

Another issue for patients is where the efficacy of anti TNF therapy slowly wears off over time, leaving patients struggling. Currently these patients are unable to try a switch to a different anti TNF to see if this improves efficacy.

NASS awaits news from NICE on the guidelines review.

NASS has also asked NICE to draw up clinical guidelines for AS. Clinical guidelines are recommendations on the appropriate treatment and care of people with specific diseases and conditions within the NHS in England and Wales. Clinical guidelines are based on the best available evidence. We are also seeking Quality Standards for the care of those with Spondyloarthritis.

ARMA

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

- Musculoskeletal (MSKs) 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 attended various ARMA meetings throughout the course of 2012. Towards the end of the year I was approached by the Chairman of ARMA and asked if I would become an ARMA Trustee. I was delighted to accept the position.

National Voices

NASS is a member of National Voices, a national coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them.

Prescription Charges Coalition

NASS continues to be a member of the Prescription Charges Coalition. During 2012 the coalition felt that, in the current economic and political situation it was unlikely to achieve its stated aim of obtaining free prescriptions in England for people living with a long term condition. Instead the coalition concentrated on working together with the Department of Health to ensure the prescription prepayment certificate was better advertised and that the price was frozen.

Work Foundation

NASS made links with the Work Foundation in 2012 and helped contribute to some of their research through our membership. We look forward to continuing to working together.

Working with the media

AS featured in 14 local and national publications

The 2012 on-line membership survey showed that NASS members want to see AS covered more in the media. I am particularly keen to raise the profile of AS amongst the general public as I have stated previously. NASS cannot take the credit for all the media AS coverage but we contributed and engineered media activity on many occasions. During 2012, AS was covered in:

- Lee Hurst: Why I`m standing up to my arthritis, Daily Express
- Ankylosing Spondylitis - it`s a medical mouthful..... Leicester Mercury
- What are sacroiliac joints? Daily Mirror
- Parking abuses slammed, Badenoch and Strathspey Herald
- Partnership raising the profile of little-known illness, Burton Mail
- Chronic illness doesn`t care if it`s your birthday or you`re getting married, Mail on Sunday You magazine
- AS Support Group Launched, Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trus
- Getting Australian residency isn`t easy - especially if you`re not in tip-top health, Daily Telegraph
- Cinderella disease can be so hard to diagnose, Eastern Daily News
- Patients with back pain face postcode lottery, Evening Standard

- I spent our wedding day wracked by pain, Daily Express
- Pain in the bum! Real People
- Patients and staff stride out to raise cash and awareness, Leicester Mercury,
- Charity calls for long-term physiotherapy to help patients manage AS, Frontline

Physiotherapy

In 2012 NASS was delighted to promote another 2 successful AS specialist training courses for physiotherapists, in Nottingham in June and in London in October, carried out by two members of AStretch, Karen Irons and Claire Jeffries. The courses were both well attended. NASS funded the attendance of a number of physiotherapists working with NASS branches.

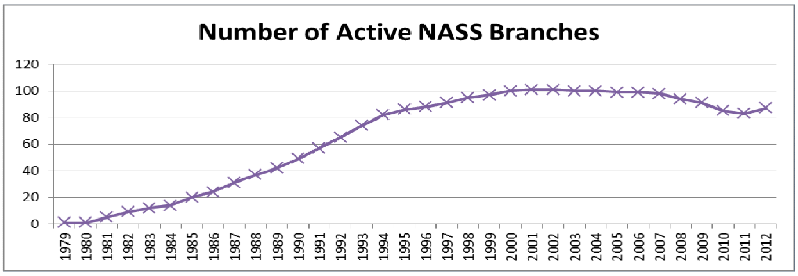
NASS was invited to participate in the 6th AStretch conference in November held in Birmingham. The conference, titled 'Physiotherapy Hot Topics in Ankylosing Spondylitis' was attended by 58 Allied Health Professionals and I welcomed the opportunity to talk about the work of NASS.

AStretch is a group of physiotherapists that steer the management and improve the understanding of AS.

Branches

An additional 5 branches became active across the UK during 2012, making a total of 87 active branches. We are delighted to welcome some brand new branches to the network and to welcome back some old friends:

- NASS Shropshire & Welsh Marches – February
- NASS Mansfield – March
- NASS Exeter – August
- NASS Dudley – September
- NASS Stockport – December



Branch Fundraising

Stretch for NASS events were held before, on and after World Arthritis Day in October in Abergavenny, Bangor, Bedford, Birmingham, Bognor Regis, Burton-on-Trent, Leicester, Newport, Portsmouth, Southampton, Worthing and Woking & Weybridge. The Big Bath Stretch took place at the Royal National Hospital for Rheumatic Diseases in Bath involving members from our Bath, Bristol, Taunton, Swindon and Yeovil branches as well as a number of other patients, supporters and healthcare professionals. Sophie and I represented NASS.

Branch Development

It has been a busy year for branch development which started off with a redesign of the branch area on the NASS website where communication and fundraising guides were published as a part of the 3-year branch development plan. Special branch development conferences were arranged for 2012 and 2013 and were advertised in the spring edition of AS News and in the quarterly branch updates sent out by email.

The conference aims were to provide support and guidance to branches on membership, safety and public awareness of AS and covered the issues and challenges that branch members have told us about over the last couple of years. Each conference provided an opportunity to share good practice and ideas.

> It was a great team building experience and we felt it brought us closer to other groups and made us feel part of something bigger and stronger. The personal connection was just what was needed.

Two successful branch development conferences were held in Edinburgh and Birmingham, together attended by 22 branches, many of whom NASS had only been in contact with sporadically for some years. We hope that this will mean improved communication links in the future. We had some fantastic feedback from the members who came along.

24 branches visited

NASS has plans for a further 3 conferences in 2013 in Bristol, Portsmouth and London.

As well as our contact with branches during the branch conferences Maddy Randall and I were also able to make individual visits to the following 24 branches in 2012:

NASS London (Tooting)	NASS London (Enfield)	NASS Glasgow
NASS Reading	NASS Norwich	NASS Dingwall
NASS Burton-upon-Trent	NASS Plymouth	NASS Chester
NASS Birmingham	NASS Stevenage	NASS Grimsby
NASS Southampton	NASS Wexham Park	NASS Chester
NASS York	NASS Croydon	NASS Aberdeen
NASS London (Ealing)	NASS London (Lewisham)	NASS Bath
NASS Tyne & Wear	NASS Bristol	NASS West Lothian

Trustee induction

In February and March, two brand new formal 3-hour induction sessions were held for NASS Trustees. Trustees were invited to the NASS office and were given presentations by the staff on *Trustee Responsibilities & NASS Priorities* (Debbie Cook) *Information Services* (Sally Dickinson), *Campaigning* (Sophie Matthew), *Branches* (Maddy Randall), *Membership* (Jill Hamilton) and *Communications & Fundraising* (Ingrid van der Weide). The aim of these sessions was to allow the Council of Management to gain an updated understanding of the day to day running of the office and the challenges faced by staff. I am grateful to the trustees who gave up their valuable time to attend.

INCOME

Fundraising

75 fundraisers raised £48,000 – we couldn't function without them

In 2012 75 fundraisers took part in, or organised, events ranging from marathons to coffee mornings and raised between them approximately £48,000. NASS was also offered the opportunity to allow some fundraisers to appear at the Olympic Stadium in London to thank them for their fundraising efforts as part of The Gold Challenge. All of our fundraisers are inspirational. NASS could not function without their support and dedication. I want to take this opportunity to thank them all again.

Legacies

We are incredibly grateful to all those who have left a gift in their will to NASS. Legacies are a vital source of core funding for the charity allowing us to continue with our activities, in particular providing information and support.

This year we acknowledge legacies from:

Kathleen Arthur
Edna Alice Champkins
Caroline M Crook
Muriel Flora Glen

Trusts & Companies

Our sincere thanks to the charitable trusts and grant making organisations for supporting our work throughout the year:

G C Gibson Charitable Settlement
Hamilton Wallace Trust
John Coates Charitable Trust
Longview Trust
Neville Milner Charitable Trust
Reuben Brothers Foundation
Roger Vere Foundation
Stella Symons Charitable Trust
Summers & May Charitable Settlement
The Albert Hunt Trust
The Bernadette Charitable Trust
The Coutts and Co. Charitable Trust
The George John and Sheilah Livanos Charitable Trust
The Khayami Foundation
The Kirby Laing Foundation
The Mary Homfray Charitable Trust
The Michael and Anna Wix Charitable Trust
The Sovereign Health Care Charitable Trust
The Sylvia and Colin Shepherd Charitable Trust
The Vivienne and Sam Cohen Charitable Trust
Thurlow Park Lodge

We are also hugely grateful to the following companies for nominating NASS to receive donations:

Biosector 2
Insight Research Group
PIP Health
Watkins Ryder
Working at Height Ltd

Working with the Pharmaceutical Industry

NASS agreed its Ethical Statement and Code of Conduct policy in September 2011 and a copy can be found on our website. NASS has always been, and will continue to be transparent about the support it receives from the pharmaceutical industry. NASS is clear about its priorities from year to year. NASS has good working relationships with Abbott Laboratories (part of the business is now called Abbvie), MSD, Pfizer Ltd and UCB Ltd. With their support NASS can achieve so much more for the AS community throughout the UK.

Membership

Subscription rates for the first half of 2012 remained unchanged at £6 concession, £20 standard, £25 overseas, £250 life. At the AGM on 29 June, two new subscription rates were approved: £18 standard membership by direct debit and £10 for under-25s. At the end of 2012 NASS had 5,964 members.

In April 2012 an online survey was published to ask for opinions on the NASS membership package. 556 (equalling about 10% of the total membership) responses were received providing an insight into the membership package specifically and how NASS members would like NASS to develop our activities. The two main outcomes of this were the decision to create a formal research strategy at the end of 2012 (subsequently moved to early 2013) and to hold a focus group on engaging with young people in September 2012.

As a result of the survey data and focus group results, a Membership Strategy was produced by Jill Hamilton and approved by the trustees at the end of 2012. The main aims of the strategy were to increase recruitment, improve retention rates and look at ways to engage with young people. This work is on-going and is to be implemented in the next two years.

NASS relies on and is hugely grateful to our loyal supporters. We aim to provide value for money to our membership in the support we offer. Many members advise us that they continue with their membership purely to support the charity and are less interested in what we provide in return. Many members rely heavily on the services we provide. I am passionate about continuing to listen to what our members would like to see. Clearly, we cannot always deliver all of their expectations but we work hard to do so when we can and when finances allow. In tough economic times it is ever more vital that we are listening to our members and targeting our resources appropriately. I understand that the trend globally has seen such organisations suffer a significant reduction in their membership. It is vitally important that NASS continues at current membership levels, and indeed seeks to increase its membership.

> **In tough economic times it is ever more vital that we are listening to our members and targeting our resources appropriately**

Royal National Hospital for Rheumatic Diseases (RNHRD), Bath

Royal National Hospital NHS
for Rheumatic Diseases
NHS Foundation Trust

I was appointed to the RNHRD Council of Governors at the latter end of 2011 to represent NASS as a patient governor.The RNHRD is joining with the Royal United Hospital (RUH), also in Bath. The two hospitals aim to achieve this once the RUH has achieved Foundation Trust status. This decision has been made by the Board at the RNHRD due to the RNHRD's worsening financial position.

The RNHRD provides an excellent AS course. It is highly valued by many AS patients, some have described the course as 'life-changing'. I am honored to be part of this wonderful hospital, working with a dedicated council of governors, but I have found my Governor role at the RNHRD particularly challenging. I feel like I have little influence over the Board's decisions. At the same time, I am hugely aware of how our members feel about the AS course there. I have expressed concern about the joining and have been advised by the Chief Executive that there are no plans to stop the AS course and no current plans to close the building or the facilities. The RNHRD expects the AS service to continue once the RNHRD joins with the RUH.

I appreciate the strength of feeling and the attachment patients feel for the AS course and give an assurance that I am working hard to represent patients' views. Whenever I am at Bath I always try to 'pop-in' and see patients on the AS course. I've found this one of the many highlights of my role; I really enjoy meeting patients in this way, talking to them about their journey and how NASS can also support them.

Ankylosing Spondylitis International Federation (ASIF)

In November 2011 I was elected to the Executive of the ASIF. The NASS Chairman, Hedley Hamilton is also Vice-President. I continue to participate in monthly Executive meetings and also to work on the ASIF ASleep initiative.

RESEARCH

NASS Research Strategy

At the end of 2012 NASS embarked on a study to produce a formal research strategy for the organisation. A World Style Café event was organised for November, in partnership with the University of Lancaster. This event had to be rescheduled to early 2013. This is an exciting piece of work for NASS and 2013 looks set to see a full detailed consultation with our membership on research in order for a strategy to be produced to better inform the AS research agenda.

Arthritis Research UK

I am a member of the Arthritis Research UK Clinical Studies Group on Spondyloarthropathies (CSG on SpA). The aims of the group are to produce an effective strategy for clinical studies in the future; to give people with the conditions being considered the opportunity to comment on research proposals and to suggest where research would be of particular interest and concern to patients.

The work on a NASS research strategy will enable NASS to better represent the AS community at meetings of the CSG and aim to influence the research agenda based on our members' views and experiences.

Genetic Research Programme, Oxford

£30,000 grant given to support genetic research

NASS has been supporting the genetic research at the Botnar Research Centre, Nuffield Orthopaedic Centre, Oxford for many years. In 2012 a grant for £30,000 was awarded to the centre to fund a research assistant to help continue this important research. NASS has also continued to support the research by asking members to provide genetic samples. In 2012, 317 new members were mailed asking them to provide a saliva sample. Recruitment is on-going through the NASS website and, when requested, with new NASS members.

THE NASS TEAM

Staff

In addition to my role as Director, NASS has the following team members; Ingrid van der Weide (Assistant Director), Maddy Randall (Branch Development Officer), Sally Dickinson (Information Officer), Jill Hamilton (Membership and Fundraising Assistant) and Sophie Matthew (Campaigns Officer) (temporary part-time post). We've seen the business of NASS increase substantially in 2012 and thus the team's workloads have increased consequently. I am very fortunate to have such a hard-working, dedicated team supporting me and I would like to thank them all for their hard work and support in 2012.

Sophie joined NASS in January 2012 on a temporary contract which was subsequently extended for a further year into 2013. Ingrid moved on, to new horizons in November 2012 and I wish her all the very best. Thanks also to Steph de Salvo Hall, our book-keeper, who comes into the office once a month to keep our accounts up-to-date.

Once again, I am able to say that I am hugely proud of what the team has achieved during 2012. Many people see the work that NASS is doing and assume that we are a much larger team. Clearly together we achieve much greater than the sum of our parts!

Trustees and the Medical Advisory Board

I would like to thank all of the NASS Trustees who make up our Council of Management for their hard work, supporting NASS in various ways throughout 2012. Thanks to the Executive who take on an additional commitment of monthly meetings.

I would like to thank the Medical Advisory Board for their hard work and support during 2012 and in particular Dr Karl Gaffney, Dr Raj Sengupta and Claire Harris for all their efforts and time put in to our GP awareness project and Back Pain Seminars.

NASS also receives the support of numerous other healthcare professionals; rheumatologists and physiotherapists in particular who are committed to going that extra mile to support our work. There are too many to mention but I hope they all know how much everyone at NASS appreciates their support and dedication – thank you.

The AS Community

With every week that passes, I meet more and more members of the extended 'NASS family' and the AS community, be it people with AS or their families and friends. This is a very special part of my role. I continue to meet the most wonderful, inspirational individuals. Thank you to you all for your continued support and for making my role such a rewarding, privileged one.

This report has aimed to give a snap-shot of the major projects and work of NASS during the year. We continue to do much more behind the scenes and work on many other areas, too many to mention.

The Future

In 2013 NASS will continue with our GP awareness campaign. It is essential that we work hard to reduce unacceptable delays in diagnosis. We will also campaign for Quality Standards and Clinical Guidelines for Spondyloarthritis.

The outcomes of the Looking Ahead audit will be reported in 2013 and the results will help shape the work of NASS in a much more strategic way for the forthcoming 2 -3 years.

Our Research Strategy will be put out to consultation with our full membership in 2013 and the final strategy document produced, showing categorically what the AS patient community want to see prioritised in terms of AS research. We will subsequently better understand what is important to AS patients and seek to ensure an enhanced level of priority is given to such areas. We hope to further enhance this work with a patient survey.

We are keen to develop our branch network further and would like to develop branches in Northern Ireland in particular. Our branch network is a huge asset to the AS community and we want to see it developed further.

You said . . .
***NASS** listened*

You said NASS needs to do more to raise awareness of AS...

NASS listened and has appointed a Campaigns Officer

A Work Guide will be produced in 2013 and our factsheet series further developed.

I hope it goes without saying that most importantly we will continue to listen to our members and seek to deliver on what's important to them. 'You said, NASS listened' will continue.

2013 is shaping it to be another bumper, exciting, busy year for NASS. There is still so much to do for the AS community. I assure you of my personal commitment in this role and my continued dedication to raising the profile of AS.

Debbie

Debbie Cook
Director

30 May 2013

Trustee's Report

The Trustees present their report and accounts for the year ended 31 December 2012, prepared in accordance with current statutory requirements and in accordance with the Charity Commission Statement of Recommended Practice.

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

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

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. Thirteen trustees received expenses, mainly relating to travel.

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.

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

The Trustees are keen to expand the branch network. During the year three new branches were opened, two re-opened and four 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.

The following unrestricted grants were received from the pharmaceutical industry:

Abbott UK	£25,000 (2011 - £25,000)

During the year the Society received an unrestricted grant of £25,000 (2011 - £25,000) from Abbott Laboratories UK.

In addition grants totalling £53,269 (2011 - £34,000) were received for specific projects, of which £4,700 has been deferred as it relates to 2013.

e. Expenditure on Research

The Society incurred total costs of £54,122 (2011 - £ 51,343) on research activities during the year which included support costs of £22,969 (2011 - £20,267).

The Trustees are keen to foster continued research into AS and related conditions, and expenditure in this area is likely to increase in the coming years.

f. Expenditure on Campaigning

The Society incurred total costs of £48,095 (2011 - £25,076) on campaigning activities during the year which included support costs of £20,098 (2011 - £17,733).

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 £210,347 (2011 - £189,064) on education and support activities during the period which included support costs of £155,042 (2011 - £136,800).

In addition the Society incurred branch costs of £186,355 (2011 - £165,862) in support of these activities.

The Trustees continue to seek to broaden the Society's work in these areas and this will increase the level of expenditure in this area in the coming years.

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 values the constructive co-operation between the two organisations highly.

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.

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 £324,000 (2011- £398,000).

In recent years the Society has expanded its charitable activities with expenditure growing from £280,000 in 2008 to £499,000 in 2012. 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. Annual expenditure in 2013 is expected to exceed income by a modest margin and the Society's Free Reserves will consequently be reduced.

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 to12 months. Currently Free Reserves are equivalent to 9 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 2013 or at such time as economic stability returns.

In the meantime the Society has been able to avoid any significant losses on investments a situation which 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 deficit of income over expenditure of £91,181 (2011 - deficit of £23,271). A deficit of £83,089 (2011 – deficit of £33,649) arose centrally and a deficit of £8,135 (2011 - surplus of £9,867) was incurred at branch level.

Voluntary income was particularly 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.

Central expenditure has risen considerably in the year because staff levels have been increased to deal with the Society's increasing efforts in meeting its charitable objectives. Expenditure is set to continue to rise and the Trustees are examining opportunities to increase income to meet these costs.

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.

AUDITORS

Felton Pumphrey, Chartered Accountants have expressed their willingness to continue in that capacity.

Signed on behalf of the Trustees

H S HAMILTON
Chairman

Richmond
30 May 2013

Auditor's Report to the Trustees

We have audited the financial statements of The National Ankylosing Spondylitis Society for the year ended 31 December 2012 set out on pages 33 to 42. 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 2012 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.

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

Date:
19/06/2013

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 2012

			Restricted Funds				
	Note	Unrestricted Fund £	Branch Funds £	Branch Developt Fund £	Fergus Rogers Fund £	Total Year ended 31 Dec 2012 £	Total Year ended 31 Dec 2011 £
Incoming resources							
Incoming resources from generated funds							
Voluntary income	2	262,992	164,762	-	-	427,754	403,049
Activities for generating funds	3	87,916	19,210	393	-	107,519	110,571
Investment income	4	859	148	-	-	1,007	1,220
Incoming resources from charitable activities		-	-	-	-	-	-
Total incoming resources		351,767	184,120	393	-	536,280	514,840
Resources expended							
Costs of generating funds	5	113,009	4,484	-	-	117,493	95,739
Charitable activities	6	312,564	186,355	-	350	499,269	432,269
Governance costs	7	10,705	-	-	-	10,705	9,904
Other resources expended		-	-	-	-	-	-
Total resources expended		436,278	190,839	-	350	627,467	537,912
Net incoming (outgoing) resources before transfers		(84,511)	(6,719)	393	(350)	(91,187)	(23,072)
Gross transfers between Funds		1,416	(1,416)	-	-	-	-
Net incoming (outgoing) resources before other recognised gains or losses		(83,095)	(8,135)	393	(350)	(91,187)	(23,072)
Gains (losses) on revaluation of investments		6	-	-	-	6	(199)
Net movement in funds for the year		(83,089)	(8,135)	393	(350)	(91,181)	**(23,271)**
Funds brought forward		720,149	193,768	1,435	4,775	920,127	943,398
Total Funds carried forward	18	637,060	185,633	1,828	4,425	828,946	920,127

The notes on pages 35 to 42 form part of these accounts.

Balance Sheet

31 December 2012

	Note	31 December 2012 £	31 December 2011 £
FIXED ASSETS			
Tangible assets	9	**313,279**	322,373
Investments	10	**60,490**	60,484
Total Fixed Assets		**373,769**	382,857
CURRENT ASSETS			
Debtors and prepayments	11	**5,092**	8,694
Cash at bank and in hand	12	**478,786**	560,198
Total current assets		**483,878**	568,892
CREDITORS			
Amounts falling due within one year	13	**28,701**	31,622
NET CURRENT ASSETS		**455,177**	537,270
TOTAL NET ASSETS		**828,946**	920,127
CHARITABLE FUNDS			
Unrestricted funds	14	**637,060**	720,149
Branch funds	15	**185,633**	193,768
Branch development fund	16	**1,828**	1,435
Fergus Rogers fund	17	**4,425**	4,775
TOTAL CHARITABLE FUNDS	18	**828,946**	920,127

The accounts set out on pages 33 to 42 were approved by the Trustees on 24 May 2013.

H S Hamilton
Chairman

S H Frost
Treasurer

Notes to the Accountants

For the year ended 31 December 2012

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 2012 £	Year to 31 Dec 2011 £
Unrestricted funds		
Subscriptions	**78,020**	79,617
Donations and grants	**128,222**	132,382
Legacies	**56,750**	24,360
Total	**262,992**	236,359
Branch funds		
Subscriptions	**154,557**	146,176
Donations	**10,205**	20,514
Total	**164,762**	166,690
Branch Development Fund		
Donations	**-**	-
Total	**-**	-
Fergus Rogers Fund		
Donations	**-**	-
Total	**-**	-
Total voluntary income	**427,754**	403,049

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 2012 £	Year to 31 Dec 2011 £
Unrestricted funds		
Annual draw	**11,772**	9,961
Fund-raising events	**70,993**	71,764
Research participation	**-**	4,053
Other income	**5,151**	7,131
Total	**87,916**	92,909
Branch funds		
Fundraising events	**13,790**	9,344
Other Income	**5,420**	6,883
Total	**19,210**	16,227
Branch Development Fund		
Fundraising events	**393**	1,435
Total	**393**	1,435
Fergus Rogers Fund		
Fundraising events	**-**	-
Total	-	-
Total income from activities for generating funds	**107,519**	110,571

4. INVESTMENT INCOME

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

	Year to 31 Dec 2012 £	Year to 31 Dec 2011 £
Unrestricted funds		
Dividends received	**40**	43
Interest received	**819**	1,046
Total	**859**	1,089
Branch funds		
Interest received	**148**	131
Total	**148**	131
Branch Development Fund		
Interest received	-	-
Total	-	-
Fergus Rogers Fund		
Interest received	-	-
Total	-	-
Total investment income	**1,007**	1,220

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 2012 £	Year to 31 Dec 2011 £
Unrestricted funds		
Annual draw prizes and expenses	**2,770**	2,200
Fundraising expenses	**20,044**	10,498
CAF administration charges	**1,190**	2,806
Support costs (note 8)	**89,005**	78,533
Total	**113,009**	94,037
Branch funds		
Fundraising expenses	**4,484**	1,702
Total	**4,484**	1,702
Fergus Rogers Fund		
Fundraising expenses	**-**	-
Total	-	-
Total costs of generating funds	**117,493**	95,739

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 2012 £	Year to 31 Dec 2011 £
Unrestricted funds			
Research	[note 6(b)]	**54,122**	51,343
Campaigning	[note 6(c)]	**48,095**	25,076
Education and support	[note 6(d)]	**210,347**	189,064
Total		**312,564**	265,483
Branch funds			
Research		**-**	-
Campaigning		**-**	-
Education and support	[note 6(e)]	**186,355**	165,862
Total		**186,355**	165,862
Branch development fund			
Grants Made		**-**	-
Total		**-**	-
Fergus Rogers Fund			
Welfare – grants made		**350**	894
Total		**350**	894
Total resources expended on charitable activities		**499,269**	432,239

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

	Year to 31 Dec 2012 £	Year to 31 Dec 2011 £
Grants for research	**30,000**	30,000
AS News	**1,153**	880
Website and database development	**-**	196
Support costs (note 8)	**22,969**	20,267
Total research expenditure	**54,122**	51,343

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

	Year to 31 Dec 2012 £	Year to 31 Dec 2011 £
Advertising and campaigning	**17,516**	1,746
AS News	**3,459**	2,639
Standards of care and training of GPs and HCPs	**6,959**	1,192
Other direct expenses	**63**	1,766
Support costs (note 8)	**20,098**	17,733
Total campaigning expenditure	**48,095**	25,076

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

	Year to 31 Dec 2012 £	Year to 31 Dec 2011 £
AS News	**18,446**	14,076
Guide books, DVDs and apps	**10,000**	31,041
Literature, brochures and information	**8,609**	3,170
Patient and member conferences	**12,691**	828
Branch conferences and support	**5,559**	-
Website and database development	**-**	3,149
Support costs (note 8)	**155,042**	136,800
Total education & support expenditure	**210,347**	189,064

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

	Year to 31 Dec 2012 £	Year to 31 Dec 2011 £
Treatment by healthcare professionals	**138,675**	131,355
Hire of NHS facilities	**27,087**	22,026
Grants payable	**8,010**	1,235
Support costs (note 8)	**12,583**	11,246
Total branch education & support expenditure	**186,355**	165,862

7. GOVERNANCE COSTS

Governance costs relate to the general running of the Society as a legal entity and are not connected with generating income or with charitable expenditure.

	Year to 31 Dec 2012 £	Year to 31 Dec 2011 £
Expenses paid to Trustees	**3,885**	2,537
Trustees meetings and Annual General Meeting	**1,920**	2,667
Independent examiner fees	**-**	-
Auditors' remuneration	**4,900**	4,700
Total governance costs	**10,705**	9,904

The Trustees received no remuneration during the year (2011 – nil). Thirteen 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 2012 £	Year to 31 Dec 2011 £
Staff costs (note 8c)	**217,329**	194,029
Premises costs	**13,107**	14,403
Travel expenses	**15,035**	9,291
IT and Communications	**19,653**	15,476
Office costs	**14,718**	13,458
Insurance, legal and professional	**7,272**	6,676
Total support costs	**287,114**	253,333

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 period is set out below:

Charitable activities		
Research	**22,969**	20,267
Campaigning	**20,098**	17,733
Education and support	**155,042**	136,800
Fundraising activities	**89,005**	78,533
	287,114	253,333

b) Branch support costs incurred in the year amounted to £12,583 (2011 - £11,246), and are wholly attributable to education and support.

c) Staff costs incurred during the year consisted of:

Wages and salaries	**192,272**	168,174
Social security contributions	**19,952**	18,041
Pension contributions	**4,200**	3,281
Recruitment, training and other costs	**905**	4,533
Total staff costs	**217,329**	194,029

d) The number of employees whose emoluments exceeded £60,000 per annum was:

£60,000 to £70,000	**1**	-

e) The average number of employees during the year was 6 (2011 – 5). Pension contributions are made in respect of 1 employee.

9. TANGIBLE FIXED ASSET

	Leasehold Buildings £	**Office Equipment £**	**Total £**
Cost at 31 December 2011	351,000	18,916	369,916
Additions in the year	-	1,410	1,410
Cost at 31 December 2012	**351,000**	**20,326**	**371,326**
Depreciation at 31 December 2011	35,020	12,523	47,543
Depreciation charge for the year	7,020	3,484	10,504
Depreciation at 31 December 2012	**42,040**	**16,007**	**58,047**
Net book value at 31 December 2011	315,980	6,393	322,373
Net book value at 31 December 2012	**308,960**	**4,319**	**313,279**

The leasehold building is held on 999 year lease with 991 years remaining.

10. INVESTMENTS

	31 Dec 2012 £	31 Dec 2011 £
Bronze statues, at valuation	**60,000**	60,000
Listed shares, at valuation	**490**	484
	60,490	60,484

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 £6 (2011 - reduction of £199) during the year has been reflected in the Statement of Financial Activity.

11. DEBTORS AND PREPAYMENTS

	31 Dec 2012 **£**	31 Dec 2011 £
Prepayments	**4,701**	4,694
Sundry debtors	**391**	4,000
	5,092	8,694

12. CASH AT BANK AND IN HAND

	31 Dec 2012 **£**	31 Dec 2011 £
Deposit account balances held centrally	**282,570**	331,682
Deposit account balances held by branches	**181,278**	190,029
Current account balances	**10,583**	34,715
Cash in hand	**4,355**	3,772
	478,786	560,198

13. CREDITORS: Amounts falling due within one year

	31 Dec 2012 **£**	31 Dec 2011 £
Sundry creditors	**10,001**	10,296
Deferred income	**8,700**	-
Accrued expenses	**10,000**	21,326
	28,701	31,622

There are no creditors falling due after more than one year (2011 – 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 £600 (2011 - £1,100) were paid to branches from Unrestricted Funds and donations totalling £2,016 (2011 - £6,717) 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 £393 (2011 - £1,435) was raised 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 £350 (2011 – £894) was expended on welfare.

18. RECONCILIATION OF CHARITABLE FUNDS

	Unrestricted Fund £	**Branch Funds £**	**Branch Dev Fund £**	**Fergus Rogers Fund £**	**Total Funds £**
Tangible assets	313,279	-	-	-	313,279
Investments	60,490	-	-	-	60,490
Debtors and prepayments	5,092	-	-	-	5,092
Cash at bank and in hand	286,900	185,633	1,828	4,425	478,786
Less creditors	(28,701)	-	-	-	(28,701)
Total charitable funds	**637,060**	**185,633**	**1,828**	**4,425**	**828,946**