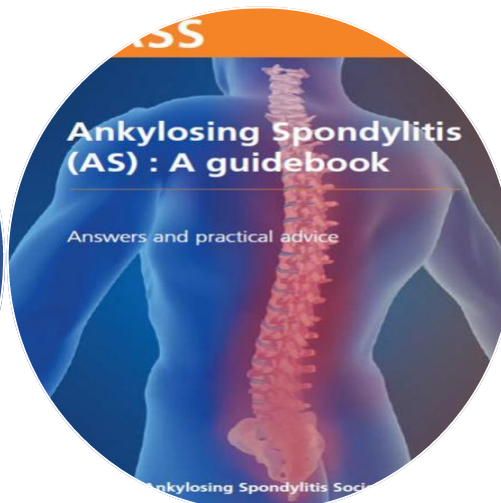


NASS

National Ankylosing Spondylitis Society



Raising
awareness of
AS & related
conditions



Supporting
and funding
research



Information
and support
for patients &
their families



Report and Accounts
for the year ended 31 December 2011

RCN 272258 SC 041347



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Trustees

The Trustees of the Society are

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 (appointed June 2011)
Peter Wheatley-Price
Professor Paul Wordsworth

Co-opted Members

James O'Leary (co-opted September 2011)
Dr Raj Sengupta

Director Jane Skerrett (Resigned May 2011)
Debbie Cook (Appointed June 2011)

Auditors Felton Pumphrey, 1 The Green, Richmond TW9 1PL

Bankers Barclays Bank, Calverley Road Branch, Tunbridge Wells, TN1 2UZ

Solicitors Russell-Cooke, 2 Putney Hill, London SW15 6AB

Chairman's Report

2011 has been a year of achievement for NASS, so much that I can only give a flavour of the top elements, so my apologies if not all can be included.

The start of the year focussed on the recruitment of a new Director, following the resignation of Jane Skerrett who I would like to thank for her hard work and professionalisation of NASS in her five years as NASS Director. Debbie Cook our new Director joined NASS at the beginning of June with the aim of raising further the profile of ankylosing spondylitis (AS) and NASS. I'm pleased to say that at the end of the year NASS's good profile is rising within relevant parts of the NHS, the medical profession, and in Parliament.



On a wider front, NASS has embraced social media, developing a NASS Facebook page, joining Twitter and with Debbie providing weekly blogs on the NASS website. All this activity, our excellent website and the online apps mentioned later specifically cater for younger people with AS, though everyone is encouraged to engage, enjoy, and benefit!

World Arthritis Day on 12th October 2011 marked the launch of the NASS Back to Action App on the iPad/iPhone platform which had seen some 1500 downloads by the end of the year. This success will be followed up in 2012 with a version for the majority of other (android) hand-held devices.

World Arthritis Day also marked the launch of *Stretch for NASS*, aimed at strengthening relationships between our branches and NASS headquarters and the provision of a support fund for branches which might need financial help from time to time.

The trustees' commitment to our branches had seen the creation of a full time branch development officer post in 2010 and this year Maddy Randall provided the Council of Management with a series of reports, giving a complete strategic picture of the opportunities and challenges presented to our branch network. We now have a 3-year programme to develop the network which includes several branch development conferences taking place across the country in 2012.

The NASS telephone helpline was launched in September 2011 with some concern that demand may outweigh our resources, but this has averaged out at approximately 60% of the information officer's time. Well done to Sally, the NASS team that support her and the medical trustees who give unstinting advice and support!

We always try to have medical information and research focussed on AS, and this year we approved the funding of a research post at Oxford, specifically focussing on AS. Meanwhile, it was great news to see the NICE approval of golimumab during the year, offering a third anti TNF option for people with AS.

For the last 3 years the trustees have set a negative budget, aiming to increase the level of representation, profile and service given by NASS and hoping for a longer term rise in fundraising and donations in recognition. In fact, our contributors and fundraisers out performed and 2011 has been the first year that we ended with a deficit. So, THANK YOU again to everyone who helps to chip in and raise awareness in any way. NASS is getting better and better – and we couldn't do it without your help.

So, I wish to thank all our volunteers. Thanks to those volunteers who came into the office to help with specific tasks – Sally Vinter, Amiee Matthews, Heidi James, Lindy Storer, Becky Storer and Hugh Crawshaw. Our branch network of over 80 branches could not function without the dedicated Chairmen, Treasurers, Fundraisers and other volunteers to whom we are extremely grateful. Thanks must also go to the physiotherapists who supervise the branches weekly, helping NASS members stay as active and flexible as possible.

I wish to thank all of the NASS trustees who undertake many duties on behalf of NASS in addition to the 4 or 5 council meetings they attend every year. Special thanks must also go to the NASS Executive who give up additional time every month to serve NASS; myself, Simon Frost (Treasurer), Claire Harris and Professor Paul Wordsworth [and, more recently, Steve Dean].

2012 is already shaping up to be a very exciting year with work on-going on our key priorities. The profile of NASS and AS is indeed rising.



Hedley Hamilton
Chairman

30 May 2012

Director's Report on the year

I joined NASS in June 2011 and I will therefore focus on the work of the Charity from then onwards to the end of 2011 in this report. Much of the early part of the year was taken up with the appointment of a new Director. I would like to pay tribute to Jane Skerrett the previous Director for the work she did for NASS during the period she was Director at NASS.



I first joined NASS as a member in 1997 after being referred to the Burton-on-Trent NASS group by my then rheumatologist. I only kept up my membership for the first year though for many reasons, some of which I am sure would still resonate with young people today. I have a background in leadership, change, democracy and communications, having spent 22 years in local government. I became interested in the charitable sector when studying for a Master's at the University of Warwick between 2006 and 2009. It was my early experience of NASS that attracted me to this worthwhile position, eager to be able to lead an organisation which served all of its members and the broad range of their requirements.

I made a commitment to our members at the June 2011 Annual General Meeting to raise the profile of ankylosing spondylitis amongst the general public - something I believe is essential. People with ankylosing spondylitis, often an invisible condition, deserve to have all of their symptoms understood fully.

It became apparent early into my appointment that the organisation needed to raise its profile generally and communications then became a real focus for the organisation. Reaching young people is a critical issue for the organisation, and to my mind required immediate attention given the average age of disease onset. Consequently, the organisation quickly embarked upon a social media journey in the summer of 2011. Mechanisms were also put in place to ensure that we maximised our media exposure with the limited resources available.

I have been privileged to meet so many of our members during these first few months. I want NASS members to be fully informed about what I am doing on their behalf and so early on into my appointment I started to blog for the first time ever. I update my blog on the NASS website regularly so that everybody with access to the internet can track what I'm up to. NASS is your charity and it is hugely important to me that you are connected to it in as many ways as possible.

Campaigning

Prescription charges

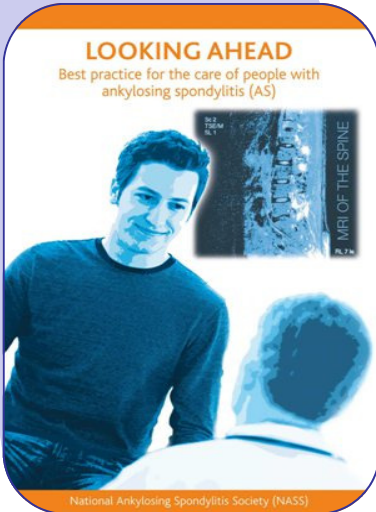
NASS has continued with its membership of the Prescription Charges Coalition (PCC). This is a group of major charities including organisations such as Asthma UK and the British Heart Foundation.

In the current economic and political climate the PCC recognise that they are unlikely to make any headway in their demands for free prescriptions for people with long term conditions. This is despite free prescriptions now being available for all those living in Scotland, Wales and Northern Ireland.

Instead the PCC has concentrated on raising awareness of the pre-payment prescription certificate. The year started with a survey around awareness of the pre-payment certificate. A link to the survey was placed on the NASS website and on the website of all the other charities involved in the PCC.

The PCC then arranged a series of workshops with the Department of Health to discuss how the pre-payment certificate could best be promoted to people with long term conditions. NASS attended all the workshops with the Department of Health and gave extensive input into the process over the course of the year.

The Looking Ahead report / GP awareness



Looking Ahead was launched at the April 2010 British Society for Rheumatology conference followed by a Parliamentary event in July 2010. On joining NASS I was keen to ensure that such an excellent document, outlining the best practice of care for people with ankylosing spondylitis, was distributed and embedded as widely as possible.

It quickly became apparent that an education programme, focussed on primary care was needed in an attempt to tackle the delay in diagnosis, currently averaging 7 - 10 years. There was also a real need to campaign for better care based on the *Looking Ahead* document. In September 2011 the Council of Management agreed the NASS priorities for 2012 and GP awareness was at the forefront. It was agreed to recruit a temporary Campaigns Officer to work on this project and promote education, based on *Looking Ahead*. Recruitment commenced at the end of December 2011 for a post-holder to join NASS in January 2012.

Sign up for Change

The Sign up for Change petition was launched by the outgoing Director in May 2011. NASS has been running the Sign up for Change petition throughout the year, calling on the Government to recognise the inequalities of healthcare and access to treatment that is currently experienced by people with AS. We know that centres of excellence exist but sadly these centres are limited in number and too few patients are receiving optimum care as a result. This petition accompanies our other campaigning work, particularly in relation to the diagnosis, treatment and management of issues identified in the Looking Ahead Report. The Sign up for Change petition will likely continue to run until sufficient signatures are collected to present to Parliament.

World AS Day

The first Saturday in May has been designated World AS Day by the AS International Federation (ASIF). To mark this day NASS organised the return of NASS en Masse, the 5k and 10k sponsored walk and run, to the new location of Manchester's Heaton Park and to London's Richmond Park over the weekend of 7/8th May 2011. Around 200 participants signed up to walk, run and help out between the two venues raising over £21,000 for NASS in sponsorship.



It was a fabulous atmosphere at both venues despite the inclement conditions in Manchester. We are grateful to NASS member and trustee, John Boyle and his family for their help and support before, during and after the event in Manchester and for securing the first-ever billboard poster for NASS.

We were delighted to be joined in Richmond Park by local MP Zac Goldsmith who set the walkers and runners on their way. Participants came from as far as Devon and Norfolk. I was also there (it was 3 weeks before my official start date) with my husband and two daughters to witness first-hand the fantastic support shown to NASS by its dedicated friends and supporters.



World Arthritis Day

On 12 October 2011 NASS marked World Arthritis Day and its theme 'Move to Improve' with a new campaign called *Stretch for NASS* to promote the benefit of exercise for people with AS, to raise awareness of the NASS branches and collect donations towards the new Branch Development Fund. This new initiative aims to provide a platform for branches to support other branches and importantly to develop improved relationships between NASS Headquarters and our branch network. The event itself furnished NASS with some fantastic, positive images of branches taking part and importantly, having fun whilst exercising and these images have been useful in publicising the great work that is being undertaken weekly throughout our branch network. More than 500 NASS members, branch members, friends and family stretched for NASS as individuals or as part of the 30 branches that took part in the Stretch for NASS campaign and raised over £1,400 for the new fund.

The Branch Development Fund is intended to help branches with limited funds engage in activities that will help with awareness raising, recruiting new members and providing AS specific training for physiotherapists.

Stretch for NASS will return in 2012 to continue promoting the branch network and raising the profile of AS and exercise.

Back to Action



The NASS **Back to Action** App was also launched on the I-platform for World Arthritis Day. Based on the Back to Action book, the App was aimed at people with AS who wanted to exercise safely at home or in a gym. A grant of £2,000 was secured to publicise the App and a further grant of £2,000 was also secured to print a copy of the book and distribute it to every rheumatology department in the country. NASS received much publicity for its innovation in the production of the App. It was declared App of the Week in the Guardian Online and was quoted by Dr Roger Henderson, media medic and health

columnist, as a brilliant app for people with AS on social media platforms. It also generated publicity for the NASS website having been selected Website of the Day in Miriam Stoppard's Health Focus in the Daily Mirror. By the end of the year the App had received many 5-star reviews and had been downloaded over 1500 times. Calls for an android version of the App received from many NASS supporters have been actioned and production is in hand.

Health and Social Care Bill

NASS spent much time following the debate surrounding the proposed introduction of this Bill. In December 2011 I took part in a Department of Health and ARUK stakeholder event to discuss Personal Health Budgets. Around this time, I also agreed to become a signatory to a letter co-ordinated by National Voices emphasising the importance of shared decision-making and asking the Government to prioritise 'patient involvement' in the proposed Health and Social Care Bill. This letter was submitted to The Times and was published early in the New Year.

Through membership of the Arthritis and Musculoskeletal Alliance (ARMA) and National Voices, NASS strengthens its ability to campaign on wider issues at all levels of government.

Education and Assistance

New resources

NASS Patient Guidebook

The Guidebook for Patients 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. It is an important document introducing newly diagnosed patients both to ankylosing spondylitis and to NASS. During 2011 NASS gave out 5,000 guidebooks.

The guidebook has been revised regularly since its first introduction but had been in its present format since 2006, aside from a few minor revisions at the end of 2010. With the expert guidance of Dr Richard Jacoby, Professor Paul Wordsworth and Claire Harris, the guidebook was completely updated towards the end of 2011.

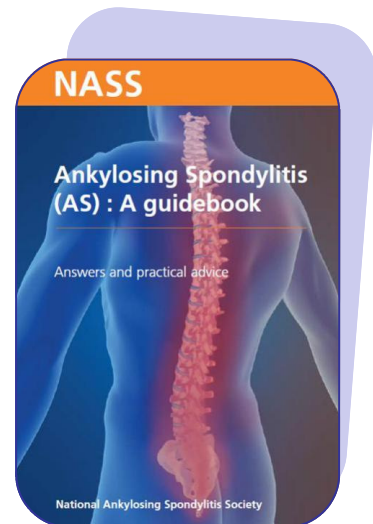
In particular, we added in the NASS Helpline details so that newly diagnosed patients can quickly see who to call for information and support. We also added in a cut out information page, specifically designed to provide information to friends, family and employers. This particular addition was as a result of many NASS members advising how they find it difficult to explain their AS to others, particularly at work.

Benefits and work guides

State benefits are a major issue for many people with AS. People not able to work may have been claiming Incapacity Benefit for quite some years. They are now all being moved across to the Employment and Support Allowance (ESA) which has much stricter criteria. Many people have been in contact with NASS, either because they are about to start this process or because they have been turned down for ESA, perhaps unfairly, and told they must go onto Jobseekers' Allowance and start looking for work.

NASS has tried to help people by taking out a professional subscription to the Government's Benefits and Work website which has allowed us to download a whole range of practical guides to claiming or appealing these 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.

We also regularly write supporting letters to the Department for Work and Pensions for individuals with AS.



On-going support and information

- **NASS Helpline**

Our information officer, Sally Dickinson, has been available to take patient enquiries throughout 2011. An official Helpline was launched in September 2011 to make it clear that this service was available to all. The formal NASS Helpline has been welcomed greatly by NASS supporters and praised a great deal by those who have used it. The Helpline is now advertised in all our publications and on every page of the website.

Since January 2011 the information officer has taken more than 1,000 enquiries. These are fairly evenly balanced between telephone and email enquiries, although the trend is towards email. Only a small minority make contact via letter but the information officer will commonly follow up a telephone call with information in the post.

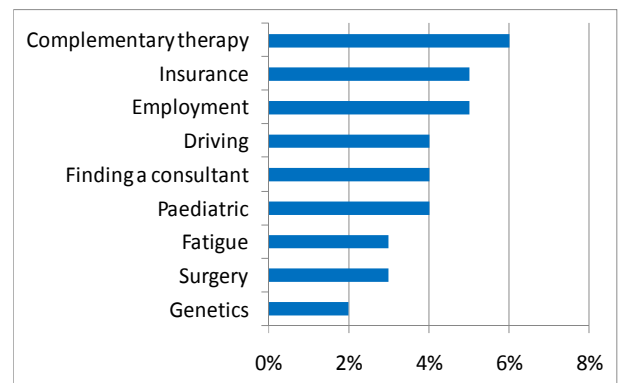
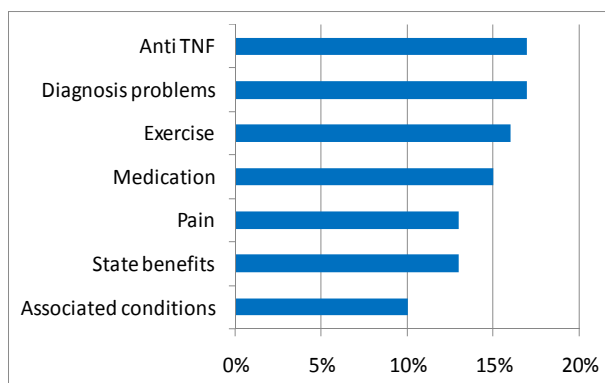
We have set Helpline hours between 0900 and 1200. This is working very well, with the majority of people making contact during those hours. NASS Members are also able to call during the afternoon as a particular benefit of membership. This system aims to free-up some of the afternoon for the information officer to work on other information resources.

Over time we have moved towards greater personalisation of the Helpline. Sally is named as the information officer on the website and her photograph is also on the Helpline page. Generally this is not recommended practice, but the NASS team felt this might encourage people to call and for members to feel more connected to NASS. We are pleased that to date we have not had any problems with inappropriate calls or excessive repeat calls.

It is good practice for Helpline workers to have the opportunity to 'unload' to another staff member after difficult or emotional calls. It is important that the member of staff who takes on this role is non-judgemental and familiar with the role. Jill Hamilton, Membership and Fundraising Assistant, has been identified as an appropriate person for this role which she has been fulfilling since mid 2011.

Diagnosis remains a major issue for people calling the Helpline but the Helpline also deals with a whole range of enquiries around managing AS, exercise and practical issues around living with AS. It is noticeable that NASS is getting more and more contact from people who have just been diagnosed with AS by their rheumatology department and have been given NASS contact details to find out more information. We hope this group grows further in 2012 with the introduction of the new guidebook which contains contact details for the Helpline inside the front cover.

Reasons for calling the helpline (2011)



In October 2011 Sally Dickinson attended a course on managing emotional content in calls run by the Helplines Association. This was a very useful course as it covered the best ways of managing callers who are very emotional as well as highlighting best practice for risk management for Helpline workers.

In November 2011 Sally also attended a course on Employment and Support Allowance. This provided Sally with greater knowledge about this complex benefit and enabled her to provide better advice.

- **NASS website**

The NASS website was redeveloped and launched at the end of 2010. It has now become the main method of communication to promote NASS and its objectives in providing information and support for people affected by AS, raising awareness of AS and campaigning for better services. We have seen a steady increase in visitors to the site with more than 47,000 unique visitors throughout 2011 viewing more than 350,000 pages.

The website hosts a Members only section where members can login to the forum and enjoy special member benefits such as the discount MedicAlert offer and archive of AS News. The NASS Near You section hosts a page for every branch of NASS allowing visitors to see at a glance where and when the branch meet for physiotherapy and hydrotherapy, how to get there and how to get in touch. These pages have proved to be a great success and are a great resource for the NASS team.

The exercise section of the website is also a popular section covering every aspect of exercise that anyone with AS would need and provides links to free resources including the Back to Action exercise programme. The About AS section offers people with AS as much information as they need on their journey from diagnosis through to treatments and managing and living with AS. The website is continually reviewed and updated.

- **Forum**

The NASS forum is a resource for members with AS to seek information, experience and opinion from other people in the same situation as themselves. Following promotion in AS News and an introduction in the new member packs, the forum has seen an increase in traffic with new threads and posts on a wide variety of topics on a daily basis. The forum is considered an important feature of membership and is appreciated and valued by those who use the forum with regularity.

- **NASS Patient Conference**

The NASS Patient Conference & AGM was held at the Mountbatten Centre in Portsmouth on 18 June 2011. The conference was attended by more than 150 NASS members, trustees, health professionals and guests who were treated to a series of presentations by leading health professionals on the latest findings in genetic research, the latest news on biologics, coping with fatigue, the importance of exercise and driving with AS. We are extremely grateful to all the speakers for giving up their time including Professor Paul Wordsworth, Dr Karl Gaffney, Professor Sarah Hewlett, Claire Jeffries and Claire Harris. We are also extremely grateful to the Portsmouth NHS Trust's Department of Rheumatology for hosting the event and providing a number of health professionals for the participative round table discussions as well as the exhibition stands involving other patient organisations, information and services associated with arthritis.

It is hoped, finance permitting, to hold a patient conference each year in future to educate, inform and keep members up to date with the latest research into, treatments for and management of AS. It is hoped that a free annual patient conference will also be valued by members and become one of the many reasons to continue to support NASS by remaining a NASS Member.

Spondyloarthritis Knowledge and Learning Network (SParkLe)



In November 2011 I was invited to speak at the first SParkLe event in Leeds. This was a two-day event attended by some 40-50 rheumatologists. I was able to present an update on the work of NASS and recent new initiatives. This event was thoroughly worthwhile; many health professionals clearly hadn't appreciated that there was so much going on at NASS and expressed an interest in starting new branches at their hospitals and also engaging more in our work. As a result I was asked to speak at the next scheduled SParkLe event in March 2012 in Bristol.

Medical Matters

The National Institute for Health and Clinical Excellence (NICE)

Golimumab

NASS has continued to be involved in NICE consultations for the introduction of new high cost drugs for ankylosing spondylitis. The initial Technology Appraisal Committee meeting for golimumab (Simponi) on 17 November 2010 was cancelled because errors were discovered in the submitted analyses that could not be rectified before the meeting. This meant that the manufacturer of golimumab decided to withdraw their submission and the appraisal was rescheduled for 18 May 2011. Jane Skerrett and Ben Hoare attended the meeting in the role of patient experts and I was able to attend as a public observer (as this was before my official start date as Director). Dr Helena Marzo-Ortega and Dr Karl Gaffney attended as medical experts.

In June 2011 NICE provisionally recommended the use of golimumab (Simponi) in ankylosing spondylitis and in August 2011 this guidance was officially confirmed. This was great news for AS patients as it means both greater choice and that there is now a third option for people with AS. NASS is very grateful to the rheumatology consultants and NASS members who supported the golimumab application to NICE .

Review of the British Society for Rheumatology (BSR) guidelines on the use of anti TNF drugs

The current BSR guidelines were issued in 2004. The NASS Director, together with a member of NASS sits on the review committee which is chaired by Dr Andrew Keat. Work on the review of these guidelines continued throughout 2011.

Physiotherapy

Physiotherapists play a vital role in helping our branch members to access regular land-based physiotherapy and aquatic physiotherapy. NASS branch members across the UK are privileged to work with over 120 individual physiotherapists each week helping people with AS to learn to self-manage their long term condition. We owe them all an enormous debt for all their hard work and professionalism.



NASS was able to promote amongst its NASS branches a specialist training course for physiotherapists in November 2011 in Portsmouth, carried out by two members of AStretch, Karen Irons and Claire Jeffries. This was extremely well attended and NASS paid for a number of physiotherapists working with NASS branches to attend.

Branches

By the end of 2011 more than 800 members and over 120 physiotherapists have had a dialogue with NASS through the programme of branch visits started in 2010. For the first time in the history of NASS, there was a clear picture emerging of how the branches operate, what is working, what the main issues are and how challenges have been overcome in the past.

A 3-year programme of work was scheduled to support and grow the branch network. Maddy Randall, Branch Development Officer was able to deliver a full report on this programme to the NASS trustees in September 2011 where it was agreed that this 3-year programme would become a key priority for NASS 2012 – 2015. This 3-year programme of work commenced immediately and remains a real focus for NASS. A positive theme from this work is that the branches very much welcome the prospect of better communication and a stronger connection with NASS and with other branches. As part of the programme a series of branch development conferences were agreed in 2011 and are planned for 2012 and 2013 to address the issues and challenges facing branches today. These conferences will provide support and guidance to branches on membership, safety and public awareness of ankylosing spondylitis.

During the latter half of 2011, I made a conscious effort to visit as many branches as possible, to both support the work of the Branch Development Officer but also to communicate first-hand how valued the branch network is by NASS and to try to secure better connections between the branches and NASS Headquarters. These visits have been welcomed and will be continued in 2012 and beyond as an on-going part of the day-to-day business of the organisation. Between July and December 2011 I visited branches in Burton-on-Trent, Hull, Swansea, Derby and Leicester and in October 2011 I was delighted to be the guest speaker at the Norwich branch Annual General Meeting.

The NASS branch network continued to grow in 2011 with two new branches opening up in Frimley Park, Surrey and Leicester and the downward trend in the number of branches closing had been stopped. NASS had 83 active branches at the end of 2011 with great prospects for more opening in 2012.

Members

Subscription rates remained unchanged in 2011; £6 unwaged, £20 ordinary membership, £25 overseas membership. 286 members joined NASS in 2011. At the end of 2010 NASS had 5,721 members and at the end of 2011, NASS had 6,008 members.



Royal National Hospital for Rheumatic Diseases (RNHRD), Bath

I was appointed to the RNHRD Board of Governors at the latter end of 2011 to represent NASS. NASS was founded in 1976 at the RNHRD and so it holds a special place in our history. As part of my new governor duties I have met with the Chairman of the RNHRD and I have had the opportunity to meet with patients on the AS course at 'the Min'.

Ankylosing Spondylitis International Federation (ASIF)

In November 2011 I attended the ASIF conference held in Izmir, Turkey. During the two-day event I was asked to give a presentation on the work of ASIF and NASS alongside Professor Paul Wordsworth and Claire Harris, all of us representing work which was on-going in the UK. During the conference I was elected to the ASIF Executive.

In July 2011 I was asked by ASIF to become actively engaged in the work of their ASleep project. This project seeks to give hotels accreditation for providing the facilities that would make a hotel stay more comfortable for a person with AS such as pillow choice, mattress choice, adjustable bed height, and walk-in shower. Work is on-going with this project and a strong brand has been developed. It is hoped that by engaging with hotels in this work that the profile of the condition will be raised generally.

Research

Arthritis Research UK

The Director and another NASS member are members 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 areas where research would be of particular interest and concern to patients. NASS has a section on its website which allows members to suggest research topics.

Genetic Research Programme, Oxford

NASS has been providing support for many years on the work into the genetics of AS carried out at the Nuffield Orthopaedic Centre (NOC) in Oxford. One of the important ways we have supported this work is by recruiting NASS members to provide the genetic samples without which this vital work cannot take place. In April 2011 we sent out a mailing to 400 new members asking them to contribute a saliva sample. Recruitment is also still ongoing through the NASS website and with all new NASS members.

In July 2011 Nature Genetics published a clinical paper on the interaction between ERAP1 and HLA-B27 in ankylosing spondylitis. The study is regarded as a breakthrough in the understanding of the genetics underlying ankylosing spondylitis. It was a collaboration between the Australo-Anglo-American Spondyloarthritis Consortium and the Wellcome Trust Case Control Consortium and compared the genomes of 3,023 cases against those of 8,779 healthy controls. This research would not have been possible without all those NASS members who donated their blood and saliva samples to the team at Oxford over the years.



In April 2011 NASS awarded a grant of £62,000 over 3 years to support the employment of a post-doctoral research assistant in bioinformatics to work on the identification and validation of genes involved in ankylosing spondylitis.

University of Swansea

Fatigue is a major problem for people with any inflammatory painful condition and currently there are no drugs which combat fatigue. For people with multiple sclerosis it has been shown that mindfulness therapy helps to reduce fatigue. This is a method of coping with the pain and fatigue and is normally done in a class with others, however, people with AS are often young with family and work commitments and may find it difficult to attend regular courses. For this reason the University of Swansea is looking at distance delivered mindfulness compared to usual treatment methods. In conjunction with the Welsh Arthritis Research Network (WARN) team at Swansea University, we are applying to the Arthritis Research UK and in Wales the National Institute for Social Care and Health Research to examine mindfulness for people living with AS.

The Fatigue in Ankylosing Spondylitis Trial (FAST) study seeks to compare distance delivery (home-based) mindfulness and distance delivery physiotherapy compared to usual treatment for people with AS. The Mindfulness Intervention Delivery for Ankylosing Spondylitis (MIDAS) trial seeks to compare the different deliver methods of mindfulness interventions such as the traditional mindfulness course (2.5 hours for 8 weeks duration) with home based mindfulness (weekly phone support for 45 minutes over 8 weeks).

Both the FAST and MIDAS trials are primarily concerned with examining different ways of reducing fatigue levels in people living with AS. This is something which NASS members ask to be addressed and therefore I am a co-applicant for both trials. In addition other aspects of AS will be examined and compared, including pain levels, psychological well-being, sleep quality and activity levels.

Ultimately we are looking at effective ways of helping people with AS to combat fatigue. We will find out whether we have been successful at securing these research funds early next year.

NASS also regularly publicises the study of people with AS living in Wales. The University of Swansea ran an AS information afternoon in March 2011 which NASS members reported that they found invaluable.

Conferences

NASS had a stall at the British Society for Rheumatology (BSR) conference in April 2011 and at the European League Against Rheumatism (EULAR) conference in May 2011. The stand at EULAR was an ASIF stand and along with information from NASS, featured materials from member societies throughout Europe. The attendees were drawn from throughout Europe and we were able to supply many with materials from their home country as well as contact details for their home organisation. As a number of ASIF members attended the conference it was a great opportunity for me to meet important members of ASIF.

I also attended the AS Clinical Practice two-day event held at the Queen Alexander hospital in Portsmouth in June 2011 and the 5th New Perspectives in Research and Management in AS two-day event in Birmingham in September 2011.

Income

NASS needs to raise every penny it spends each year: we receive no government or statutory funding. NASS is enormously grateful to the individuals, charitable trusts, members and donors for all they do for NASS.

Legacies

We are grateful to all those who have generously left a gift in their will to NASS. They have not only helped to secure a future for NASS so we may continue to provide information and support for people affected by AS both now and in the future but by doing so have acknowledged their faith in and loyalty to NASS.

This year we owe a special thank you to:

Adam Crawford
Jacqueline Levy
John Moore
P F Smith
W Price

Trusts & Companies

We are also grateful to the charitable trusts and grant making organisations for supporting our work throughout the year including:

Alys & Graham Ferguson Trust
Bernadette Charitable Trust
C M Keyser Charitable Trust
G C Gibson Charitable Settlement
G C Gibson Charitable Trust
John Coates Charitable Trust
Longview Trust
Norman Collinson Charitable Trust
PF Charitable Trust
Stella Symons Charitable Trust

Summers & May Charitable Settlement
The Albert Hunt Trust
The George John and Sheilah Livanos Charitable Trust
The Joicey Trust
The Mary Homfray Charitable Trust
The Orr Mackintosh Foundation
The Simon Gibson Charitable Trust
The Sovereign Health Care Charitable Trust
The Vivienne and Sam Cohen Charitable Trust

Working with the Pharmaceutical Industry

In September 2011 NASS agreed its Ethical Statement and Code of Conduct policy which spells out clearly how NASS will work with the pharmaceutical industry. I am of the view that so long as NASS works within the parameters set by this policy and is clear about its priorities, that working with colleagues in industry can be very beneficial. NASS can achieve so much more with this support. During my first 6 months as NASS Director I developed good working relationships with Abbot UK, MSD, Pfizer and UCB representatives. In September 2011 I visited the UCB offices and in December 2011 I visited the MSD offices, both visits to talk about the work of NASS. NASS facilitates involving NASS members to talk to pharmaceutical company staff to better enhance their understanding of AS and how their work can be developed to address the needs of an AS patient.

I would like to thank colleagues from these companies who have welcomed me into the role and quickly developed a positive working relationship and ideas for working together.

I am particularly grateful to Abbott UK for supporting our work throughout the year.

Staff

In addition to my role, NASS has the following team members; Ingrid van der Weide (Assistant Director), Madeline Randall (Branch Development Officer), Sally Dickinson (Information Officer and Helpline) and Jill Hamilton (Membership and Fundraising Assistant). I would like to thank all of the NASS team for their hard work in 2011. Most of all, I would like to thank them for welcoming me to NASS and for supporting me in my role as Director. NASS is fortunate to have such a skilled, dedicated team, each and every one sharing my passion to raise the profile of ankylosing spondylitis. Since I have been Director, the team and others advise me that we have increased both the pace and the profile of NASS. This has required the team to work very differently and they have each risen to the challenge very well, each one of them an asset to the organisation. Each has coped with an increased workload, has contributed to the work of NASS with new ideas whilst at the same time maintaining excellent relations with our members. They work effectively as a team and this enables us to have a profile which is much greater than would be expected of an organisation with a total of 5 members of staff. The whole team can look back on our achievements in 2011 with great pride.

The team have all received social media training in December 2011 in preparation for our key objectives in 2012.

We also welcome Sophie Matthew, our new temporary Campaigns Officer, who joined us early in 2012 and wish to thank Stephanie de Salvo Hall, our book-keeper, who has been coming in once a month for the last 5 years to keep our accounts up to date.



From left to right: Ingrid van der Weide, Maddy Randall, Sally Dickinson, Sophie Matthew and Jill Hamilton

Thank you all

I would like to formally acknowledge and thank the previous Director, Jane Skerrett for all she did for the AS community.

I would also like to put on record my sincere thanks to the whole AS community who have made me feel very welcome in the role as your Director. I would like to thank all the NASS Trustees for their hard work and support and the NASS Executive body who take on an additional commitment for NASS. I am particularly grateful to the Council of Management for making me feel so welcome; NASS is an incredible organisation to be a part of. I would particularly like to thank the NASS Medical Advisory Board for their continued support; Dr Andrew Keat, Dr Raj Sengupta, Dr Karl Gaffney, Dr Richard Jacoby, Dr Andrei Calin, Claire Harris, Dr Ramanan, Professor Paul Wordsworth. My thanks also go to Claire Harris, Claire Jeffries and Dr Tim Jones for their contribution and hard work on the Back to Action App launch. I am very grateful to have met and worked alongside some inspirational patients, members, health professionals and trustees during my first 6 months in the role. I have felt incredibly privileged to represent the AS community in this role: *thank you*.

The future

In September 2011, the NASS Council of Management agreed three key 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* and engaging young people through social media.

In raising the profile of AS and engaging with hard to reach audiences NASS now engages positively in social media activity with particular emphasis on Facebook and Twitter. Following the production of a social media strategy NASS uses these mediums to inform, engage and support people affected by AS. They are also used to signpost to relevant information and resources and celebrate the achievements and success of our work and that of our supporters. There has been a steady increase in reactions and in response to this activity measured by the volume of retweets, likes, and conversations. Social media is helping to build a positive AS community. It has also been a great success in broadcasting latest news and events such as media activity, campaigning activity and fundraising events.

Work is already well underway to roll-out the branch development conferences and our GP awareness project has started to make a significant impact in terms of reaching GPs with *Looking Ahead*.

I look back on 2011 and what was achieved with pride, and I hope that our members will agree with that viewpoint. 2012 is shaping up to be a very exciting and productive year with NASS taking on more and more initiatives. There is much to do for the ankylosing spondylitis community. I can assure you of my personal commitment and the commitment of the NASS Team and Council of Management in the challenge to seek improved services and a better understanding of AS. NASS will work to support people with ankylosing spondylitis to the best of our ability, actively engaging with our members as effectively as possible.



Debbie Cook
Director

30 May 2012

Trustees' Report

The Trustees present their report and accounts for the year ended 31 December 2011, prepared in accordance with current statutory requirements and in accordance with the Charity Commission Statement of Recommended Practice.

1. REFERENCE AND ADMINISTRATIVE DETAILS

a. Name, address and registration

The name of the charity is the National Ankylosing Spondylitis Society and its address is Unit 0.2, One Victoria Villas, Richmond, Surrey TW9 2GW. The charity is registered with the Charity Commissioners for England and Wales, registration number 272258, and with the Office of the Scottish Charity Regulator, registration number 041347.

b. Trustees

The Trustees who served during the year were:

Honorary Officers

| | |
|-------------------|-------------|
| Hedley S Hamilton | (Chairman) |
| Simon H Frost | (Treasurer) |

Ordinary Members

| | |
|----------------------------|---|
| John Boyle | |
| Brian Bowman MA | (resigned 18 June 2011) |
| Stephen Dean | |
| Eric N C Eustance FCMA MCT | |
| Dr Karl Gaffney | |
| Claire Harris | |
| Ben Hoare | |
| Dr Richard Jacoby MD FRCP | |
| Dr Andrew Keat | (previously co-opted, appointed 18 June 2011) |
| David W Lavington | (resigned 18 June 2011) |
| Juliette Leach | (resigned 18 June 2011) |
| Ruth Miller | |
| Grant Poiner | (appointed 18 June 2011) |
| Peter Wheatley-Price | |
| Professor Paul Wordsworth | (previously co-opted, appointed 18 June 2011) |

Co-opted Members

| | |
|-------------------------|---|
| Dr Andrei Calin MD FRCP | (resigned 18 June 2011, appointed Vice President) |
| Dr Raj Sengupta | (co-opted 18 June 2011) |
| James O'Leary | (co-opted 24 September 2011) |

2. STRUCTURE, GOVERNANCE AND MANAGEMENT

a. Constitution

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

b. Appointment of Trustees

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

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

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

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

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

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

c. Management

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

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

None of the Trustees received any remuneration during the year. Twelve 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.

4. ACHIEVEMENTS AND PERFORMANCE

a. Risk

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

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

b. Subscriptions

The Society charges subscriptions to its members at national and branch level. In addition the Society operates a local branch model for group exercise and most of the attendees are national members. At national level this income is used to fund the charitable activities of the Society and to defray the costs of running the Society. At branch level the income is used almost wholly to provide to members physiotherapy treatment over and above that available to them from the NHS.

The Society has approximately 6,000 members at national level and around 1,000 attendees per week at branches. The Trustees actively encourage all those with AS and related conditions to join the Society.

c. Branch network

The Society has 85 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 period two new branches (Frimley and Leicester) opened and 3 closed down (Barnstaple, Morecambe and Wrexham).

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 | (2010 - £5,000) |
| Schering Plough | £0 | (2010 - £5,000) |
| Wyeth | £0 | (2010 - £ 0) |

Grants totalling £34,000 were received for specific projects.

e. Expenditure on Research

The Society incurred total costs of £51,343 (2010 - £ 22,092) on research activities during the year which included support costs of £20,267 (2010 - £19,577).

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 £25,076 (2010 - £62,421) on campaigning activities during the year which included support costs of £17,733 (2010 - £17,380). Direct costs included £1,192 (2010 - £31,831) spent on Standards of Care.

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 despite the reduction in 2011 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 £189,064 (2010 - £183,417) on education and support activities during the period which included support costs of £136,800 (2010 - £133,645).

In addition the Society incurred branch costs of £165,862 (2010 - £163,076) in support of these activities.

The Trustees have now employed additional staff to continue 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 (previously the Long Term Conditions Alliance (LTCA)).

The Society has also worked closely with the National Rheumatoid Arthritis Society (NRAS) and values the constructive co-operation between the 2 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.

5. FINANCIAL REVIEW

a. Reserves

In 2005 the Society invested part of its reserves in acquiring a long term leasehold (999 years) office building in order to facilitate the activities of the Society. Free Reserves, defined as the balance of unrestricted funds less the amount invested in the office building, are maintained at a level sufficient to meet all anticipated outgoings of the Society for the next 12 months and currently amount to circa £398,000 (2010- £420,000).

In recent years the Society has expanded its charitable activities with expenditure growing from £280,000 in 2008 to £432,000 in 2011. 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 2012 is expected to exceed income by a substantial margin and the Society's Free Reserves will consequently be reduced.

In addition the Society is likely to continue to enter into strategic longer term commitments for funding research activities and must therefore maintain reserves sufficient to meet these commitments.

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 12 months. Although Free Reserves slightly exceed this level at present it is likely that this position will be normalised over the next two years.

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 last year their intention to review this policy during 2009. However the effect of the current economic recession and related downturn in investment performance has delayed this review which will now take place in 2012 or at such time as economic stability returns.

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

c. Summary of financial performance

As a whole, the Society reported a deficit of income over expenditure of £23,271 (2010 - surplus of £8,020). A deficit of £33,649 (2010 – surplus of £9,113) arose centrally and a surplus of £9,867 (2010 - deficit of £123) 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.

During the year the Society made grants from unrestricted funds for research of £30,000 (2010 - nil) and from the Fergus Rogers Fund for welfare of £894 (2010 - £1,000).

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

Charity law 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 its financial activities for that year. In preparing those accounts, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and 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 which 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. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

7. AUDITORS

Felton Pumphrey, Chartered Accountants were appointed as the charity's auditors during the year and have expressed their willingness to continue in that capacity.

Signed on behalf of the Trustees



H S HAMILTON
Chairman

Richmond
May 2012

Auditors' Report to the Trustees

We have audited the financial statements of The National Ankylosing Spondylitis Society for the year ended 31 December 2011 set out on pages 26 to 33. 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 section 44 (1c) of the Charities and Investment (Scotland) Act 2005. 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, (set out on page 24), the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view.

The trustees have elected for the financial statements to be audited in accordance with the Charities Act 2011 rather than the Companies Act 2006. Accordingly, we have been appointed as auditor under section 144 of the Charities Act 2011 and section 44(1) of the Charities and Trustee Investment (Scotland) Act 2005 and report to you in accordance with regulations made under those Acts. Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charitable company'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' Annual 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 charitable company's affairs as at 31 December 2011 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 Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Matters on which we are required to report by exception

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

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

Felton Pumphrey

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

Date: *10 August 2012*

STATEMENT OF FINANCIAL ACTIVITIES

For the year ended 31 December 2011

| | Note | Restricted Funds | | | | Total Year ended 31 Dec 2011 £ | Total Year ended 31 Dec 2010 £ |
|--|------|---------------------------|----------------------|----------------------------------|-------------------------------|---|---|
| | | Unrestricted Fund £ | Branch Funds £ | Branch Developpt Fund £ | Fergus Rogers Fund £ | | |
| Incoming resources | | | | | | | |
| Incoming resources from generated funds | | | | | | | |
| Voluntary income | 2 | 236,359 | 166,690 | - | - | 403,049 | 392,179 |
| Activities for generating funds | 3 | 92,909 | 16,227 | 1,435 | - | 110,571 | 148,444 |
| Investment income | 4 | 1,089 | 131 | - | - | 1,220 | 1,312 |
| Incoming resources from charitable activities | | - | - | - | - | - | - |
| Total incoming resources | | 330,357 | 183,048 | 1,435 | - | 514,840 | 541,935 |
| Resources expended | | | | | | | |
| Costs of generating funds | 5 | 94,037 | 1,702 | - | - | 95,739 | 94,360 |
| Charitable activities | 6 | 265,483 | 165,862 | - | 924 | 432,269 | 432,006 |
| Governance costs | 7 | 9,904 | - | - | - | 9,904 | 7,205 |
| Other resources expended | | - | - | - | - | - | - |
| Total resources expended | | 369,424 | 167,564 | - | 924 | 537,912 | 533,571 |
| Net incoming (outgoing) resources before transfers | | (39,067) | 15,484 | 1,435 | (924) | (23,072) | 8,364 |
| Gross transfers between Funds | | 5,617 | (5,617) | - | - | - | - |
| Net incoming (outgoing) resources before other recognised gains or losses | | (33,450) | 9,867 | 1,435 | (924) | (23,072) | 8,364 |
| Gains (losses) on revaluation of investments | | (199) | - | - | - | (199) | (344) |
| Net movement in funds for the year | | (33,649) | 9,867 | 1,435 | (924) | (23,271) | 8,020 |
| Funds brought forward | | 753,798 | 183,901 | - | 5,699 | 943,398 | 935,378 |
| Total Funds carried forward | 18 | 720,149 | 193,768 | 1,435 | 4,775 | 920,127 | 943,398 |

The notes on pages 28 to 34 form part of these accounts.

BALANCE SHEET

31 December 2011

| | Note | 31 December 2011 £ | 31 December 2010 £ |
|-------------------------------------|------|--------------------------|--------------------------|
| FIXED ASSETS | | | |
| Tangible assets | 9 | 322,373 | 332,409 |
| Investments | 10 | 60,484 | 60,683 |
| Total Fixed Assets | | 382,857 | 393,092 |
| CURRENT ASSETS | | | |
| Debtors and prepayments | 11 | 8,694 | 5,158 |
| Cash at bank and in hand | 12 | 560,198 | 558,337 |
| Total current asset | | 568,892 | 563,495 |
| CREDITORS | | | |
| Amounts falling due within one year | 13 | 31,622 | 13,189 |
| NET CURRENT ASSETS | | 537,270 | 550,306 |
| TOTAL NET ASSETS | | 920,127 | 943,398 |
| CHARITABLE FUNDS | | | |
| Unrestricted funds | 14 | 720,149 | 753,798 |
| Branch funds | 15 | 193,768 | 183,901 |
| Branch development fund | 16 | 1,435 | - |
| Fergus Rogers fund | 17 | 4,775 | 5,699 |
| TOTAL CHARITABLE FUNDS | 18 | 920,127 | 943,398 |

The accounts set out on pages 26 to 34 were approved by the Trustees on 12 May 2012.



H S Hamilton
Chairman



S H Frost
Treasurer

NOTES TO THE ACCOUNTS

For the year ended 31 December 2011

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 2011, 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 fees 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 2011 £ | Year to 31 Dec 2010 £ |
|--------------------------------|-----------------------------|-----------------------------|
| Unrestricted funds | | |
| Subscriptions | 79,617 | 81,158 |
| Donations and grants | 132,382 | 63,475 |
| Legacies | 24,360 | 102,140 |
| Total | <u>236,359</u> | <u>246,773</u> |
| Branch funds | | |
| Subscriptions | 146,176 | 135,122 |
| Donations | 20,514 | 10,254 |
| Total | <u>166,690</u> | <u>145,376</u> |
| Branch Development Fund | | |
| Donations | - | - |
| Total | <u>-</u> | <u>-</u> |
| Fergus Rogers Fund | | |
| Donations | - | 30 |
| Total | <u>-</u> | <u>30</u> |
| Total voluntary income | <u><u>403,049</u></u> | <u><u>392,179</u></u> |

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 2011 £ | Year to 31 Dec 2010 £ |
|--|-----------------------------|-----------------------------|
| Unrestricted funds | | |
| Annual draw | 9,961 | 11,080 |
| Fund-raising events | 71,764 | 69,506 |
| Research participation | 4,053 | 41,880 |
| Other income | 7,131 | 3,843 |
| Total | <u>92,909</u> | <u>126,309</u> |
| Branch funds | | |
| Fundraising events | 9,344 | 11,140 |
| Other Income | 6,883 | 10,995 |
| Total | <u>16,227</u> | <u>22,135</u> |
| Branch Development Fund | | |
| Fundraising events | 1,435 | - |
| Total | <u>1,435</u> | <u>-</u> |
| Fergus Rogers Fund | | |
| Fundraising events | - | - |
| Total | <u>-</u> | <u>-</u> |
| Total income from activities for generating funds | <u><u>110,571</u></u> | <u><u>148,444</u></u> |

4. INVESTMENT INCOME

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

| | Year to 31 Dec 2011 £ | Year to 31 Dec 2010 £ |
|--------------------------------|-----------------------------|-----------------------------|
| Unrestricted funds | | |
| Dividends received | 43 | 41 |
| Interest received | 1,046 | 1,095 |
| Total | <u>1,089</u> | <u>1,136</u> |
| Branch funds | | |
| Interest received | 131 | 176 |
| Total | <u>131</u> | <u>176</u> |
| Branch Development Fund | | |
| Interest received | - | - |
| Total | <u>-</u> | <u>-</u> |
| Fergus Rogers Fund | | |
| Interest received | - | - |
| Total | <u>-</u> | <u>-</u> |
| Total investment income | <u>1,220</u> | <u>1,312</u> |

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 2011 £ | Year to 31 Dec 2010 £ |
|--|-----------------------------|-----------------------------|
| Unrestricted funds | | |
| Annual draw prizes and expenses | 2,200 | 2,586 |
| Fundraising expenses | 10,498 | 7,944 |
| CAF administration charges | 2,806 | 4,016 |
| Support costs (note 8) | 78,533 | 77,111 |
| Total | <u>94,037</u> | <u>91,657</u> |
| Branch funds | | |
| Fundraising expenses | 1,702 | 2,703 |
| Total | <u>1,702</u> | <u>2,703</u> |
| Fergus Rogers Fund | | |
| Fundraising expenses | - | - |
| Total | <u>-</u> | <u>-</u> |
| Total costs of generating funds | <u>95,739</u> | <u>94,360</u> |

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 2011 £ | Year to 31 Dec 2010 £ |
|--|-------------|-----------------------------|-----------------------------|
| Unrestricted funds | | | |
| Research | [note 6(b)] | 51,343 | 22,092 |
| Campaigning | [note 6(c)] | 25,076 | 62,421 |
| Education and support | [note 6(d)] | 189,064 | 183,417 |
| Total | | <u>265,483</u> | <u>267,930</u> |
| Branch funds | | | |
| Research | | - | - |
| Campaigning | | - | - |
| Education and support | [note 6(e)] | 165,862 | 163,076 |
| Total | | <u>165,862</u> | <u>163,076</u> |
| Branch development fund | | | |
| Grants Made | | - | - |
| Total | | <u>-</u> | <u>-</u> |
| Fergus Rogers Fund | | | |
| Welfare – grants made | | 894 | 1,000 |
| Total | | <u>894</u> | <u>1,000</u> |
| Total resources expended on charitable activities | | <u>432,239</u> | <u>432,006</u> |

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

| | | Year to 31 Dec 2011 £ | Year to 31 Dec 2010 £ |
|-----------------------------------|--|-----------------------------|-----------------------------|
| Grants for research | | 30,000 | - |
| AS News | | 880 | 749 |
| Website and database development | | 196 | 1,766 |
| Support costs (note 8) | | 20,267 | 19,577 |
| Total research expenditure | | <u>51,343</u> | <u>22,092</u> |

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

| | | Year to 31 Dec 2011 £ | Year to 31 Dec 2010 £ |
|--------------------------------------|--|-----------------------------|-----------------------------|
| Advertising and campaigning | | 1,746 | 4,046 |
| AS News | | 2,639 | 2,247 |
| Website and database development | | 592 | 5,299 |
| Standards of care | | 1,192 | 31,831 |
| Other direct expenses | | 1,174 | 1,618 |
| Support costs (note 8) | | 17,733 | 17,380 |
| Total campaigning expenditure | | <u>25,076</u> | <u>62,421</u> |

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

| | Year to 31 Dec 2011 £ | Year to 31 Dec 2010 £ |
|--|-----------------------------|-----------------------------|
| AS News | 14,076 | 11,985 |
| Guide books and DVDs | 31,041 | 8,914 |
| Literature and brochures | 3,170 | 613 |
| Conference expenses | 828 | - |
| Website and database development | 3,149 | 28,260 |
| Support costs (note 8) | 136,800 | 133,645 |
| Total education & support expenditure | 189,064 | 183,417 |

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

| | Year to 31 Dec 2011 £ | Year to 31 Dec 2010 £ |
|---|-----------------------------|-----------------------------|
| Treatment by healthcare professionals | 131,355 | 125,135 |
| Hire of NHS facilities | 22,026 | 24,460 |
| Grants payable | 1,235 | 1,696 |
| Support costs (note 8) | 11,246 | 11,785 |
| Total branch education & support expenditure | 165,862 | 163,076 |

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 2011 £ | Year to 31 Dec 2010 £ |
|-------------------------------|-----------------------------|-----------------------------|
| Expenses paid to Trustees | 2,537 | 1,864 |
| Annual General Meeting costs | 2,667 | 1,846 |
| Independent examiner fees | - | - |
| Auditors' remuneration | 4,700 | 3,495 |
| Total governance costs | 9,904 | 7,205 |

The Trustees received no remuneration during the year (2010 – nil). [12] 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 2011 £ | Year to 31 Dec 2010 £ |
|-----------------------------------|-----------------------------|-----------------------------|
| Staff costs (note 8c) | 194,029 | 166,516 |
| Premises costs | 14,403 | 36,993 |
| Travel expenses | 9,291 | 7,112 |
| IT and Communications | 15,476 | 14,643 |
| Office costs | 13,458 | 13,265 |
| Insurance, legal and professional | 6,676 | 9,184 |
| Total support costs | 253,333 | 247,713 |

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 | 20,267 | 19,577 |
| Campaigning | 17,733 | 17,380 |
| Education and support | 136,800 | 133,645 |
| Fundraising activities | 78,533 | 77,111 |
| | 253,333 | 247,713 |

b) Branch support costs incurred in the year amounted to £11,246 (2010 - £11,785), and are wholly attributable to education and support.

c) Staff costs incurred during the year consisted of:

| | | |
|---------------------------------------|---------|---------|
| Wages and salaries | 168,174 | 146,064 |
| Social security contributions | 18,041 | 15,053 |
| Pension contributions | 3,281 | 3,098 |
| Recruitment, training and other costs | 4,533 | 2,301 |
| Total staff costs | 194,029 | 166,516 |

d) The average number of employees during the year was 5 (2010 – 5)

9. TANGIBLE FIXED ASSETS

| | Leasehold Buildings £ | Office Equipment £ | Total £ |
|---|-----------------------------|--------------------------|------------|
| Cost at 31 December 2010 | 351,000 | 17,396 | 368,396 |
| Additions in the year | - | 1,520 | 1,520 |
| Cost at 31 December 2011 | 351,000 | 18,916 | 369,916 |
| Depreciation at 31 December 2010 | 28,000 | 7,987 | 35,987 |
| Depreciation charge for the year | 7,020 | 4,536 | 11,556 |
| Depreciation at 31 December 2011 | 35,020 | 12,523 | 47,543 |
| Net book value at 31 December 2010 | 323,000 | 9,409 | 332,409 |
| Net book value at 31 December 2011 | 315,980 | 6,393 | 322,373 |

The leasehold building is held on 999 year lease with 992 years remaining.

10. INVESTMENTS

| | 31 Dec 2011 £ | 31 Dec 2010 £ |
|------------------------------|------------------|------------------|
| Bronze statues, at valuation | 60,000 | 60,000 |
| Listed shares, at valuation | 484 | 683 |
| | 60,484 | 60,683 |

The bronze statues, by Elizabeth Frink, were acquired at a cost of £2,156 in 2009. These were revalued in December 2009 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 reduction in value of £199 (2010 - £344) during the year has been reflected in the Statement of Financial Activity.

11. DEBTORS AND PREPAYMENTS

| | 31 Dec 2011 £ | 31 Dec 2010 £ |
|----------------|------------------|------------------|
| Prepayments | 4,694 | 4,988 |
| Sundry debtors | 4,000 | 170 |
| | 8,694 | 5,158 |

12. CASH AT BANK AND IN HAND

| | 31 Dec 2011 £ | 31 Dec 2010 £ |
|---|------------------|------------------|
| Deposit account balances held centrally | 331,682 | 353,829 |
| Deposit account balances held by branches | 190,029 | 180,125 |
| Current account balances | 34,715 | 20,607 |
| Cash in hand | 3,772 | 3,776 |
| | <u>560,198</u> | <u>558,337</u> |

13. CREDITORS: Amounts falling due within one year

| | 31 Dec 2011 £ | 31 Dec 2010 £ |
|------------------|------------------|------------------|
| Sundry creditors | 10,296 | 10,689 |
| Deferred income | - | - |
| Accrued expenses | 21,326 | 2,500 |
| | <u>31,622</u> | <u>13,189</u> |

There are no creditors falling due after more than one year (2010 – 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 £1,100 (2010 - £860) were paid to branches from Unrestricted Funds and donations totalling £6,717 (2010 - £2,891) were made by branches to Unrestricted Funds.

16. BRANCH DEVELOPMENT FUND

The Branch Development Fund was established in 2011. Monies held in the Branch Development Fund have been raised to support the Society's continuing branch operations with a view to assisting the financial position of branches with temporary financial difficulties and with establishing new branches. It is the Society's intention that monies are also contributed to this Fund by way of grants from branches and from balances held by branches which have closed.

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 £894 (2010 – £1,000) was expended on welfare.

18. RECONCILIATION OF CHARITABLE FUNDS

| | Unrestricted Fund £ | Branch Funds £ | Branch Dev Fund £ | Fergus Rogers Fund £ | Total Funds £ |
|-------------------------------|---------------------------|----------------------|-------------------------|-------------------------------|------------------|
| Tangible assets | 322,373 | - | - | - | 322,373 |
| Investments | 60,484 | - | - | - | 60,484 |
| Debtors and prepayments | 8,694 | - | - | - | 8,694 |
| Cash at bank and in hand | 361,655 | 193,768 | 1,435 | 4,775 | 560,198 |
| Less creditors | (31,622) | - | - | - | (31,622) |
| Total charitable funds | <u>721,584</u> | <u>193,768</u> | <u>1,435</u> | <u>4,775</u> | <u>920,127</u> |

National Ankylosing Spondylitis Society

Unit 0.2, One Victoria Villas
Richmond Surrey TW1 4SB

T: 020 8948 9117 E: admin@nass.co.uk W: www.nass.co.uk