NASS

National Ankylosing Spondylitis Society

Report and Accounts for the year ended 31 December 2010

Registered Charity Number 272258 Scottish Charity Registration Number 041347

Contents

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Chairman’s Report

2010 has been a year of achievement for NASS and has included a number of important milestones including the new website and the publication of the Looking Ahead report.

Staff and Volunteers

None of this would have been possible without the hard work of the staff and volunteers and I would like to thank them all.

In 2010 we said goodbye to our first ever branch officer, Steve Devlin. Steve made an excellent start on this new role and began the programme of branch visits. He left in July to join Hounslow Council. Maddy Randall took over the role in August 2010 and has built on Steve’s valuable work in visiting and supporting existing branches and working to develop new ones. Sally Dickinson joined us in January 2010 as information officer and has been closely involved in working on the website and expanding the NASS information resources.

NASS is also able to benefit from the support of a number of volunteers to whom we owe a great debt: thank you all. These include everyone who helps with one of the 83 active NASS branches whether they are the branch contact, treasurer, or help with administration and fundraising. We are also very grateful to all the physiotherapists who supervise the branch exercise sessions and play the vital role of providing the sessions which help NASS members to stay as fit, active and flexible as possible. Without them NASS branches simply could not exist.

We are also grateful to those volunteers who come in to the head office to assist with administrative tasks: they include Becky and Lindy Storer, Sally Vintner, and Christine Wheeler.

We are also grateful to the NASS members who provide advice and input on particular topics that NASS is working on including most importantly this year the website, but who also participate in research meetings, attend public meetings and provide support and information to other people with AS.

Trustees

I would like to thank all the NASS Trustees for their work during the year which extends beyond attending the 4 Council meetings as they are consulted throughout the year. I would also like to give particular thanks to those trustees who serve on the Executive Committee.

Executive Committee

The Executive Committee has continued to be an effective introduction to improve the management of the organisation: those serving on this Committee during 2010 were the Chairman, Treasurer and Director, ex officio, and Claire Harris, David Lavington and Professor Wordsworth.

Hedley Hamilton
Chairman

May 2011

Director's Report on the year

Campaigning

The Looking Ahead report

This report was the culmination of work which started at the end of 2008 when a group of rheumatologists and other health professionals met at the American rheumatology conference and decided there was a need to produce a document which identified the barriers to the prompt diagnosis and best treatment and management of AS in the UK.

I was asked to be involved in early 2009 and NASS then facilitated work on the report and its launch at the British Society for Rheumatology (BSR) conference in April 2010 and in Parliament in July 2010. The report, which is a first for the UK, focuses on 7 propositions which identify the problems that people with AS face and how these can be resolved in the light of modern knowledge – in particular better use of MRI scans for diagnosis - and access to the new treatments.

The launch at the BSR was a great success with over 100 people attending: the then President of the BSR, Professor Deborah Bax launched the event which also included speeches by Dr Andrew Keat, one of the Looking Ahead contributors, and Paul Curry, a member of NASS, who gave a very personal view of what the reality is for an individual experiencing some of the problems identified in the Looking Ahead report.

The launch in Parliament was a drop in event hosted by Andrew George MP, who himself has AS: a number of NASS members from different parts of the UK were invited and they in turn invited their MPs. We had an excellent turnout on the day with over 30 MPs attending or expressing an interest in knowing more about AS and the challenges that patients face. An early day motion based on the findings of the report was launched in June 2010.

The Looking Ahead report's findings have been used at a number of events in the UK subsequently, organised by both industry and the NHS. One hospital audited its services for people with AS against the Looking Ahead recommendations and this is a most welcome development. The report was also the focus of an editorial in Rheumatology in April 2011.

The recommendations will provide a good basis for any clinical guidelines on AS or a set of quality standards and patients can also use them to benchmark their own experience. The recommendations are not an end in themselves but form the basis for NASS campaigning for better services in the future.

Prescription charges

NASS is a member of the Prescription Charges Coalition (PCC), a group of major charities including organisations such as The Stroke Association, Diabetes UK and the British Heart Foundation. The Coalition had been making some headway before the May election in calling for Gordon Brown to implement his promise, made at the Labour Party Conference in 2008, for free prescriptions for people with long term conditions. The PCC was also asking him to implement the recommendations of the Gilmore review which also backed this proposal.

However once the coalition government was in place this issue was put back to October 2010 pending the outcome of the Comprehensive Spending Review. It was subsequently rejected on grounds of cost. The PCC is continuing to press the government on this issue and is also encouraging its members to highlight the pre payment certificate which is a means of reducing the costs of prescriptions. It remains a matter of great concern to NASS that England is becoming the only country in the UK where patients with long term conditions pay for prescriptions.

World AS Day

The first Saturday after 1 May has been designated World AS Day by the AS International Federation (ASIF). In 2009 a number of member countries held an event to celebrate World AS day and in 2010 NASS initiated a sponsored run, called NASS en Masse (NEM), on the weekend of World AS day to raise money and awareness of AS. The first NEM took place in Richmond Park on the outskirts of London on 9 May and was a huge success with over 160 people taking part. They raised the magnificent total of £25k. A smaller NEM, organised by NASS member Helen Matthews, also took place from Craigellachie to Aberlour and back, in Aberdeenshire.

Plans for 2011 include holding NEM at an out of London venue and placing more emphasis on raising awareness of AS and the needs of people with AS. I would like to give very special thanks to the following top NEM fundraisers: Mark Holloway and family; Nigel Inkster; Rachel Leung; Danny McFarlane; Christine Wheeler and Anke Wittenberg.

Education and Assistance

Providing information for patients, those who suspect they have AS, patients' families and health professionals is a core NASS activity. In 2010 NASS developed a number of new resources.

Back to Action

This project arose from my concerns that we were taking a lot of calls at NASS from people who were newly diagnosed, heard the phrase "exercise is good for people with AS" and then exercised inappropriately with the possible risk of injury. A small survey of our members confirmed that this was indeed the case. After discussions with Dr Tim Jones, consultant in rheumatology and rehabilitation, and Claire Harris and Claire Jeffries, both physiotherapists working in the NHS, the Back to Action project was born. NASS was able to work with staff at the Defence Medical Rehabilitation Centre (DMRC) Headley Court and to use their gym as the venue in which to take photographs for the project. The pack gives wide ranging advice on exercise, including how put together a programme to use in the gym and what other exercises and sports are suitable for people with AS. It is a UK first.

The pack was finally published in October 2010 and has been in great demand: over 250 were sold by the end of 2010. We are hoping to complete an online version of Back to Action in 2011 which will have expanded features and some interactive aspects.

NASS is very grateful to everyone who worked on this project and especially to the Commanding Officer at the DMRC Headley Court, Colonel Jerry Tuck.

Getting it right

AS remains a condition which is not well known or well understood. As a result of this NASS can have an important role in correcting wrong information on AS, used by official agencies, which can often give rise to major problems for individuals. Three examples of this in 2010 are: NHS Choices; the Driver and Vehicle Licensing Agency (DVLA); and the Department of Work and Pensions (DWP).

NHS Choices

In May 2010 NASS checked the information on ankylosing spondylitis (AS) held on the NHS Choices website. We noticed there was a video clip featuring a consultant orthopaedic surgeon talking very generally about back pain. No information on AS or on the problems of diagnosis were given in the clip.

NASS took the view that:

- As someone with suspected AS would need to see a rheumatologist it was misleading to feature an orthopaedic surgeon
- Information on AS and on how AS is diagnosed should be given in the clip
- The general information provided on back pain implied AS might resolve by itself in time

In May 2010 we emailed the team at NHS Choices highlighting these reasons for concern and offering our assistance in putting together a more appropriate clip. We were quickly contacted by the editor of the Health A-Z section of NHS Choices who wrote:

“You are quite right - the video is totally inappropriate for the AS topic, so it has been removed.”

We suggested Dr Andrew Keat would be an ideal specialist to be interviewed on this topic and a 4 minute clip featuring Dr Keat discussing AS and the challenges of diagnosis now appears on the overview page.

DVLA

In July 2010 we received a call from a NASS member in Swindon who expressed concern that NASS were currently not doing enough to alert members to the new information on driving and AS.
We checked the Directgov website which stated that:

“The law requires you to tell the Driver and Vehicle Licensing Agency (DVLA) about any condition that may affect your ability to drive safely. If you are involved in an accident and it is found that your health was a contributing factor, you may be prosecuted and your insurance may not be valid.

Ankylosing spondylitis is a condition that you need to tell the DVLA about.”

We were concerned by this apparent change in policy from the DVLA which would mean that everyone with a diagnosis of AS, no matter how mild their symptoms, would need to contact the DVLA. Eventually, after some conflicting advice from the DVLA, we were able to clear this up and get the website corrected to the right position which is as stated below by the DVLA spokesman:

“I can confirm that Ankylosing Spondylitis (AS) is NOT a condition that needs to be notified to the Agency irrespective of the severity of the condition. It is a medical condition that DVLA will only need to be notified of if it is felt likely to affect the licence holder’s ability to drive. Typically for those with the condition AS this would be if the driver required adaptations to the car, usually extra mirrors or automatic transmission.

Please accept my apologies for any confusion in the advice that was previously provided and I hope that this has helped to clarify the position.”

Department of Work and Pensions (DWP)

A NASS member contacted us in December 2010 with a query on the information on AS in the Employment Support Allowance (ESA) Handbook, the guidelines produced by the DWP for doctors performing medicals on behalf of the DWP but employed by Atos Healthcare. The information in the ESA Handbook stated that:

“Degenerative disease of the lumbar and lower thoracic vertebrae / intervertebral discs limits forward flexion and extension but rarely affects lateral flexion or rotation. Ankylosing spondylitis on the other hand, limits lateral flexion and rotation but not forward flexion or extension. Equal limitation in all planes of movement suggests purposeful exaggeration of disability.”

NASS checked this information with some of our medical advisors and all agreed it was incorrect.

We decided to challenge this issue with the DWP as we believed people with AS could be turned down for ESA because they were suspected of exaggerating their condition at their medical. We did eventually get this corrected and had an apology from the DWP Minister, Chris Grayling:

“I have asked my officials and Atos Healthcare to investigate the issue you raised. They have acknowledged that the statement in the ESA Handbook is incorrect and will ensure that it is corrected as soon as possible.”

New website

The NASS website was due for a complete overhaul: although the content had expanded the look and feel of the site had remained the same since its inception in the 90s. Producing the new site was a major task for a small organisation like NASS but the site was launched to great acclaim in November 2010. It now has a modern look and the information it contains has been re ordered to reflect the patient journey from pre diagnosis to getting a diagnosis and then living with AS. There is a great deal more new information for patients on the site as well as a NASS near you section to find your nearest NASS branch and what they can offer; a new exercise section; a section for health professionals and expanded shop and fundraising pages. The NASS website will continue to evolve and develop over time to reflect its role as our key method of communicating with our members, prospective members and supporters.

I would like to thank Ken Burrell, NASS member and our webmaster since the site first came into being. Ken has done tireless service on the site and we owe him a great debt of thanks. I am happy to report that he is still involved with the site as a moderator of the forum.

New resources

We have produced a number of new fact sheets in 2010: 2 on uveitis – one for patients and one for health professionals, both drafted by Professor Sue Lightman and her staff from Moorfields Eye Hospital in London. We have also produced one on anaesthesia and AS written by consultant anaesthetist Dr Robert Caranza from the Derby Hospitals Foundation Trust and one on inflammatory back pain (often the precursor to AS) by Dr Karl Gaffney, consultant rheumatologist.

A new feature for 2010 is the start of a library of patient experiences written by patients for patients. The first of these is on what it is like to attend the inpatient course at the Royal National Hospital for Rheumatic Diseases in Bath. This has proved very popular. A further patient experience is that of a NASS member who had a minor accident which resulted in a fracture of the spine – people with AS may have fragile spines. This points out what to be aware of even after a relatively minor accident and how to make sure you get the best care and follow up.

All these items are available from the website and in hard copy as we are well aware that there are still people who cannot access information on the web.

Ongoing support and information

The information officer's main tasks are editing and producing our twice yearly journal, AS News, and responding to patient enquiries. Since the installation of our new database in July 2010 we are now able to log more easily information about these enquiries. Over the 5 months July-December 2010 we had 336 patient enquiries: 59% came by email, 22% by phone and 19% by letter. Enquiries from members were 52% of the total and the ratio of enquirers was 60% male to 40% female. The main topics were anti TNF (17%), problems with diagnosis (17%) and exercise and physiotherapy (16%). The trend is for an increase in such enquiries: there were 450 enquiries during the first 4 months of 2011 alone.

The information officer also did some casework for 15 people claiming Disability Living Allowance (DLA): the booklet on benefits in general and DLA in particular continue to be in demand. In 2010 NASS also sent out over 5,000 copies of our free guidebook, A Positive Response to AS, to health professionals and hospitals.

Patient Conferences

There was no conference in 2010: the next patient conference will take place in June 2011 in Portsmouth.

Research

Research done by NASS

Working with ankylosing spondylitis, report published February 2010

This report, with an introduction by Dame Carol Black, the National Director for Health and Work, was based on a survey on work sent out to 1,000 NASS members at the end of 2009. There were a number of key issues it identified: over half of the respondents with severe AS described work as the area most affected by their condition. Despite this only a third had received useful advice from either their healthcare professional or employer on coping with their condition at work and half reported that their GP or rheumatologist had never discussed work issues with them.

The report identified that effective treatment makes the difference for most people to staying in work and worrying less about workplace issues. The report identified a number of actions which could be taken by government, health professionals, employers and people with AS to improve the situation and the actions identified in the report remain important. Sadly one of the actions, the appointment of a National Clinical Director for musculoskeletal disorders (MSDs), was making progress and had the full support of the whole MSD community but was then lost in the upheaval of the May 2010 elections.

NASS Patient and Unit Survey

Lack of data on AS remains an issue: this survey was a start on helping to fill this information gap.

The survey was made up of 2 parts: 2,000 non health care professional members of NASS were sent a questionnaire asking about their experiences of diagnosis, treatment and access to therapies and a separate questionnaire was sent to a consultant rheumatologist in every acute NHS trust in the UK asking about services offered to patients with AS.

The aim of the survey was to look at provision of services for people with AS in the UK and was the first study of its kind. Some of the key findings from patients were that nearly one third of AS patients in the UK are not seen in secondary care; diagnostic delay remains a problem and despite NICE approval, anti TNF drugs continue to be rationed.

This first finding was one I did not anticipate. If nearly one third of patients in the survey are not seen in secondary care they may be unaware of the new anti TNF treatments available for AS, are certainly not being considered for them and are not receiving any long term monitoring of their condition. These 2 surveys, taken together, provide valuable ammunition for NASS in arguing that services for people with AS continue to be patchy and inadequate and desperately need to improve.

An article on the survey findings was accepted by Rheumatology for publication in early 2011. I would like to thank Dr Louise Hamilton and Dr Karl Gaffney of the rheumatology department, Norfolk and Norwich University Hospital, Norwich for carrying out the hospital survey and their work on the subsequent report and article: without their input this important work would not have been possible.

Research in other institutions

Arthritis Research UK

The Director and 2 members of NASS are members of the Arthritis Research UK Clinical Studies Group on Spondyloarthropathies (CSG on SpA). This initiative was started in December 2007 by Arthritis Research UK (then the Arthritis Research Campaign); the committee meets regularly during the year and met 3 times in 2010. The aims of the CSG on SpA, among others, 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. In March the CSG organised a day at Loughborough University to bring together researchers, clinicians and patients to focus on developing a set of research priorities in SpA. A number of NASS members attended including the Chairman, David Blythe, Mo Cowpe, Matt Homfray and the Director: feedback from the members who did attend was overwhelmingly positive. Members thought it was a genuine opportunity to have input into the final set of priorities.

Assessment of SpondyloArthritis International Society (ASAS)

NASS members were asked to assist in validating the new Health Index which ASAS is working on. We sent out a link to the survey along with an explanation of the background to the research. ASAS reported that 664 NASS members responded: far more than any other individual country. In fact NASS members made up more than 40% of the responses achieved across the whole of Australia, Canada, the UK and the USA.

Nuffield Orthopaedic Centre (NOC), Oxford

NASS has for many years provided support for the work on the genetics of AS carried out at the Nuffield Orthopaedic Centre (NOC) in Oxford. This has been done through our small research grant programme but most importantly of all by recruiting NASS members to provide the genetic samples without which this vital work cannot take place. In August we sent out a mailing to 235 new members to ask them to contribute a genetic sample. This no longer involves a blood sample but a saliva sample so it is an easier process in which to involve people. Recruitment to this programme is also ongoing through the NASS website.

Research into the genetics of AS is bearing fruit and our knowledge of the genetics is developing fast: current thinking is that there are a large number of genes implicated in AS. NASS will continue to do all it can to support this important work which holds out the hope of new treatments and the ultimate goal of a cure for AS. The contribution that NASS has made in the UK to making this work possible is freely acknowledged by Professor Wordsworth at NOC.

In June 2009 NASS also gave a grant of £15,000 for a DPhil student, David Harvey, to work on the role of ERAP1/ARTS1 in AS in the University of Oxford. David has been working very successfully on his thesis and is aiming to submit it early in 2011. This work has been of fundamental importance to the understanding of one of the genetic reasons that some people are predisposed to develop AS and is reported on more fully on the NASS website.

Swansea University

Researchers in the School of Medicine in Swansea University, led by Dr Stefan Siebert and Dr Sinead Brophy, were awarded a £200,000 grant in 2008 by the Medical Research Council (MRC) to study AS and its effects on people with the condition who live in Wales. NASS regularly recruits for this study among our Welsh members and publicises events which the study may give rise to.

Registers

British Society for Rheumatology – AS Register (BSR – ASR)

As I have already mentioned one of the issues that arises time and again in relation to AS is a lack of data. It is heartening for NASS as an organisation that this is an area that is now being given a great deal more attention. NASS contributed a small grant at the end of 2009 to enable the recruitment of an individual to work on setting up the BSR – ASR and progress has been made in 2010. The register went out to tender in the summer of 2010 and I was involved in the selection process. The contract was given to the University of Aberdeen and the ARUK Epidemiology Unit at the University of Manchester. The primary purpose of the register will be to document the safety of biologic treatments by recording any adverse events but it will also be an opportunity to capture a wide range of other information on AS and its impact. This could include information on work; the psychological impact and impact on quality of life as well as information on the use people with AS make of the NHS and the cost of this: visits to GPs, inpatient admissions, surgery and so on. This data will give NASS valuable information as it will show the “hidden” costs of AS and how better management of AS may lead to a better use of resources. We are hopeful that the register will begin recruiting in 2011.

Scotland and Ireland Registry for AS (SIRAS)

SIRAS was set up in 2008 and is run by the University of Aberdeen. In 2010 NASS sent out information on SIRAS to all our members in the relevant areas including a special newsletter for members in Scotland. This helped to boost recruitment to the register and some centres which had been reluctant to recruit have started recruiting because patients have shown an interest in the register. NASS also recruited a patient representative to sit on the SIRAS Steering Committee and he has proved a very successful appointment.

Conferences

NASS had a stall at the British Society for Rheumatology (BSR) conference in April 2010 in Birmingham as usual but this year there were a number of NASS inputs to BSR. They included the launch of the Looking Ahead report; a presentation by the NASS Chairman at one of the pre conference symposia; a poster presentation on the findings of the NASS work survey; an oral presentation by the director on findings from the same survey and a presentation on the NASS exercise programme Back to Action by Dr Tim Jones, consultant in rheumatology and rehabilitation medicine.

During the year I also attended the biennial conference on Spondyloarthropathies in Gent; the Brussels Presidency Conference on MSK conditions in October and the PARE Conference in Berlin, on both occasions on behalf of the AS International Federation (ASIF).

Medical matters

The National Institute for Health and Clinical Excellence (NICE)

Golimumab

NASS was due to attend the NICE appraisal on golimumab (Simponi), a new anti TNF drug which has undergone trials in rheumatoid and psoriatic arthritis as well as AS. This was scheduled for November 2010 but the appraisal was postponed and has now been re scheduled for May 2011: a NASS representative, consultant rheumatologist and the NASS director will be representing NASS at the appraisal to make sure the patient voice is heard loud and clear.

Clinical guidelines

In May, after consultation with the BSR and the NASS trustees, I applied to NICE for clinical guidelines for AS. We have still not had a formal response from NICE but I remain hopeful that such guidelines will be given the go ahead in the not too distant future.

Review of the first NICE appraisal for anti TNF drugs

We are also still waiting to hear from NICE about their decision on whether or not to review the technology appraisal on adalimumab, etanercept, and infliximab which was published in May 2008. Fergus Rogers, Richard Bridgeman, Terry Orsler and I were all involved in this appraisal, the outcome of which did give AS patients access to 2 out of 3 of the anti TNF drugs and was such an important milestone for people with AS. We await the review decision from NICE with interest.

Review of the BSR guidelines on the use of anti TNF drugs

These are now due for revision as the current guidelines were completed in 2004. The NASS director, together with a member of NASS, sits on the review committee which is chaired by Dr Andrew Keat. Provisional work has begun on this and will be taken forward in 2011.

Physiotherapy

Physiotherapists play a vital role in helping people with AS to manage their condition effectively and are a key element in the multi disciplinary teams that support our members. NASS branches cannot function without the physiotherapists supervising the exercise sessions: we owe them all an enormous debt for all their hard work and professionalism.

NASS continues to work closely with AStretch, (the network of physiotherapists in the UK with a special interest in AS). AStretch held their biennial conference in November 2010 which I attended. It was an opportunity to present Back to Action and feedback from the audience was overwhelmingly positive.

Two members of AStretch, Karen Irons and Claire Jeffries, carried out 2 training courses for physiotherapists in 2010 in Edinburgh and Portsmouth. NASS paid the fees for a number of physiotherapists working with NASS branches to attend.

Branches

The NASS branches continue to serve an invaluable function by offering regular, supervised physiotherapy during the year and are a very important part of the work of NASS. There are currently 83 active branches. During 2010 the newly appointed branch officer, Steve Devlin, did further work on visiting branches to try and understand more about what they are doing, the challenges they face and how the NASS office can better support them. Steve wrote an interim report which was presented to the NASS trustees and members at the AGM and which was very much welcomed as a useful and informative document for the trustees. Steve stayed with NASS for a year and then left to join Hounslow Council.

We were delighted to welcome Maddy Randall to the role now renamed branch development officer in August. Maddy took up Steve's programme of visits and also began work on new materials to support branches including guidance on health and safety issues; fundraising and local promotion and awareness. By the end of 2010 a total of 73 branches had been visited and a final report on all the branches will be delivered in 2011.

NASS remains concerned about the challenges that branches face from changes in the provision of hydrotherapy pools, cut backs in physiotherapy posts, or further bureaucratic barriers put up to stop the classes taking place. We are also aware of the heavy burden that some branch officials carry and that we need to do everything possible to support those who are already volunteering by encouraging other branch members to take on branch roles and by identifying areas where the NASS office can help with services, information or advice.

A programme of activity for 2011 is planned to focus on a number of issues starting with health and safety and will involve bringing together groups of branches which are geographically close for meetings at which the NASS staff can explain the changes needed and how they can be implemented. These meetings will also be an opportunity for branches to exchange good practice and learn from the experience of others.

Members

One of the important changes of 2010 was raising the membership fee; this had stayed the same for over 13 years. The increase was approved by the members at the AGM in May and the increase was implemented in the second half of the year. The new subscriptions with the old levels in brackets are £6 unwaged (£3); ordinary membership £20 (£13) and £25 (£15) for overseas members. It continues to be a challenge to recruit and retain members but I am very pleased to report that we recruited 440 new members in 2010, an increase of 7.5% over an average of the previous 5 years.

Income

NASS needs to raise every penny it spends each year: we receive no government or statutory funding. We are enormously grateful to all the individuals, charitable trusts, members, and donors for all they do for NASS. It gave the NASS trustees and staff great pleasure to hold a reception for all our donors and supporters at the House of Commons on 1 December. It was an opportunity to thank them all and to show them a little of what NASS has achieved as an organisation in recent months, with their support. In spite of the appalling weather we had a very good turnout on the day and some truly heroic stories of people who had battled to be with us.

We are especially grateful to all those with AS who undertake some physical challenge or organise an event to raise money for us: this is an expanding group. We welcome their support for they not only raise money for NASS but raise awareness of AS. And they help to get across the vital message that AS is not a rare disease; that there are hundreds of people with AS in the UK and that with the right treatment and support from a good medical team, people with AS can live fulfilled and dynamic lives.

I would like to give special mention here to Jonathan Ball, Diane Faulkner, Emma Gilchrist, Rob Goss, Craig Gunn, Tom Homfray, Julie Lambert, Raj Mahapatra, Janni Nielsen, David Piper, Simon Ross, Paul Sheering and Alicia Ward. Thank you all for your dedication and generosity.

We are very grateful to Annie Swanston for the work she does in organising a golf day in memory of her late husband, Ian. Annie has raised over £50,000 for NASS as at the end of 2010, a magnificent achievement. Annie has recently re married and NASS was delighted to be able to congratulate Grahame on the occasion of their marriage in December 2010. We wish them both a wonderful future together.

Legacies

We continue to be grateful for all those generous individuals who have left NASS a gift in their will and who have helped to secure a future for NASS so that we can provide services for people with AS both now and in the years to come.

This year we owe this special debt to Shirley Livesey.

Trusts and Companies
We are also grateful for the support of the following charitable trusts and companies:

Bernadette Charitable Trust
Hospital Saturday Fund Charitable Trust
John Coates Charitable Trust
Longview Trust
Lord Leverhulme's Charitable Trust
Neville Milner Charitable Trust
Norman Collinson Charitable Trust
Patricia & Donald Shepherd Charitable Trust
PF Charitable Trust
Reuben Brothers Foundation
Simon Gibson Charitable Trust
Sir Julian Hodge Charitable Trust
Summers & May Charitable Settlement
The Arnold Burton 1998 Charitable Trust
The George John and Sheilah Livanos Charitable Trust
The Mary Homfray Charitable Trust
The Rest Harrow Trust
The Rofeh Trust
The Sovereign Health Care Charitable Trust
The Woolf Charitable Trust
Vivienne and Sam Cohen Charitable Trust

Abbott UK
Schering Plough now part of Merck Sharpe Dohme

Staff

There have been a number of changes this year. Sally Dickinson joined NASS in January as information officer and Maddy Randall arrived in August to take over from Steve Devlin.

We wish Steve well for the future: he has gone to work for Hounslow Council in charge of developing a network for families who have children with a disability which fits in very well with his background in youth work.

I would like to thank all the staff for their work in 2010. It has been a challenging year for NASS and we have achieved a number of important milestones during the course of it: I would like to thank Ingrid van der Weide for her work on the website and the new database – installing new technology can be a demanding and thankless task and I am grateful to Ingrid for her work on these projects and for running NASS en Masse so capably. Sally Dickinson has settled in well during the year as the information officer and is developing her knowledge of AS and rheumatology. I know that the information she provides is key to many of our callers, particularly people who are newly diagnosed, in helping them to feel they understand more about AS and have the knowledge to self manage their condition effectively. Jill Hamilton is responsible, among other tasks, for providing cheerful support for our volunteer fundraisers and is helping to expand this activity which is now developing as an important part of NASS fundraising. Our other new member of staff, Maddy Randall, has also settled in well and is getting round the NASS branches and working on supporting and expanding the network with efficiency and charm.

The whole team can look back on the year with great pride: any organisation succeeds as a team and it is the NASS team that has made 2010 such a productive and effective year.

Thank you all

I would like to put on the record our very particular thanks to all the Looking Ahead contributors (Trish Cornell, Dr Karl Gaffney, Dr Andrew Keat, Dr Kirsten MacKay, Dr Helena Marzo-Ortega, Liz van Rossen, and Professor Paul Wordsworth); to those people who worked on the Back to Action project (Headley court staff Rebecca Bull, Kate Connelly, Colin Suffield, Edward Wolfe and Dr Tim Jones, and NHS physiotherapists Claire Harris and Claire Jeffries) and to Andrew George MP for his unfailing support for the work of NASS in raising the profile of AS and for hosting our 2 Parliamentary events.

The future

The future looks very positive for NASS: we can build on the achievements of this year and substantially develop our information resources; support the branch network; expand the opportunities for our members to be involved and consulted through facilities like the e newsletter, introduced in 2011, and develop our campaigning work so that we can effectively represent the needs of our members.

This is my last annual report as I am leaving NASS at the end of May 2011. It has been a great privilege to serve NASS and its members and to be part of the welcoming and supportive rheumatology community in the UK. I shall miss you all but I leave the organisation in good heart and look forward to the future progress and achievements of NASS, but as an observer.

Jane Skerrett
Director

27 May 2011

Trustees' Report

The Trustees present their report and accounts for the year ended 31 December 2010, prepared in accordance with current statutory requirements and in accordance with the Charity Commission Statement of Recommended Practice.

Last year the Trustees amended the reporting date for the Society's accounts to coincide with calendar years. As a result the comparative figures shown in these accounts are for the 18 month period ending on 31 December 2009.

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 with registration number 272258 and with the Office of the Scottish Charity Regulator, registration number 041347.

b. Trustees

The Trustees who served during the period were:

Honorary Officers
Hedley S Hamilton (Chairman)
Simon H Frost (Treasurer)

Ordinary Members
John Boyle
Brian Bowman MA
Dr Anthony Clarke BSc MB FRCP (Resigned May 2010)
Stephen Dean
Eric N C Eustance FCMA MCT
Barbara J Foster (Resigned May 2010)
Dr Karl Gaffney (Appointed May 2010)
Claire Harris
Ben Hoare
Dr Richard Jacoby MD FRCP
David W Lavington
Juliette Leach
Ruth Miller (Appointed May 2010)
Peter Wheatley-Price

Co-opted Members
Dr Andrei Calin MD FRCP
Dr Andrew Keat (Appointed May 2010)
Dr Athimalaipet Ramanan
Professor Paul Wordsworth

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

2. STRUCTURE, GOVERNANCE AND MANAGEMENT

a. Constitution

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

b. Appointment of Trustees

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

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

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

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

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

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

c. Management

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

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

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

3. OBJECTIVES AND ACTIVITIES

a. Objectives

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

The Society's mission is threefold:

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

b. Public benefit

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

The Society provides public benefit in several ways:

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

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

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

c. Strategies adopted

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

(i) Research into ankylosing spondylitis and related conditions:

- to facilitate research through a variety of means including campaigning, cooperation with academic centres and with pharmaceutical companies, and PR;
- to encourage members of the Society to co-operate in research programmes;
- to set up a grants scheme for research;
- to communicate to members and the wider public the results of research using the most appropriate media, including AS news, websites and conferences.

(ii) Campaigning on behalf of people with ankylosing spondylitis and related conditions:

- to use a variety of means to increase awareness of these conditions among the public and within the healthcare profession, including such matters as early diagnosis and appropriate treatment;
- to use a variety of means to improve access to the latest available treatments and care, in particular through lobbying elected representatives, healthcare professionals and statutory bodies;
- to ensure that awareness of these conditions is raised with related charities and organisations so that concerted approaches can be made when appropriate including at international level.

(iii) Education of the public about ankylosing spondylitis and related conditions:

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

4. ACHIEVEMENTS AND PERFORMANCE

a. Risk

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

(i) Loss of funds: Funds are held with various first-tier banks on a short-term basis and as a result there is little risk of loss in the short to medium term.

(ii) Loss of income: The Society seeks to broaden and expand its income from all sources. Nevertheless the Society is dependent upon voluntary income, both at branch level and at national level, and aims to continue to increase its membership locally and nationally.

(iii) Loss of reputation: The Society seeks at all times to maintain its independent viewpoint. Assistance received from external bodies, such as members of the pharmaceutical industry, is strictly controlled so as to ensure that independence is not compromised.

b. Subscriptions

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

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

c. Branch network

The Society has 83 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 one new branch (Poole) opened and 3 closed down (Bradford, Chelmsford, and Huntingdon).

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	£5,000	(2009 - £35,000)
Pfizer Limited	£0	(2009 - £6,000)
Schering Plough	£5,000	(2009 – nil)
Wyeth	£0	(2009 - £20,000)

e. Expenditure on Research

The Society incurred total costs of £22,192 (2009 - £ 38,120) on research activities during the period which included support costs of £19,577 (2009 - £21,707).

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.

4. ACHIEVEMENTS AND PERFORMANCE - continued

f. Expenditure on Campaigning

The Society incurred total costs of £62,421 (2009 - £29,370) on campaigning activities during the period which included support costs of £17,380 (2009 - £18,993). Direct costs included £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 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 £183,417 (2009 - £199,473) on education and support activities during the period which included support costs of £133,645 (2009 - £146,520).

In addition the Society incurred branch costs of £163,076 (2009 - £246,873) 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 2011. They include further development of the information resources for patients and their families; the launch of the online guidance on exercise for people who are just diagnosed; the launch of the best practice guidelines as a result of the collaboration between a group of health professionals and NASS; 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 this is appropriate, so that we provide an effective voice for our 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 £420,000.

In recent years the Society has expanded its charitable activities with expenditure growing from £280,000 in 2008 to £432,000 in 2010. 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 2011 is expected to exceed income by a substantial margin and its Free Reserves will consequently be reduced.

In addition the Society has entered 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. Gift Aid

During 2009 the Society concluded negotiations with HMRC on Gift Aid claims made by a number of NASS branches during the years 2000 to 2008, where HMRC felt that part or all of the claims did not properly comply with Gift Aid regulations. This resulted in a formal settlement agreement under which the Society repaid part of the claims together with interest thereon, totalling £81,719. The Trustees agreed that this cost should not be borne by branches and this amount was charged to Unrestricted Funds in 2009.

In addition the Society has adopted revised procedures for claiming Gift Aid.

c. 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.

d. Summary of financial performance

As a whole, the Society reported a surplus of income over expenditure of £8,020 (2009 – deficit of £562). A surplus of £9,113 (2009 – surplus of £26,553) arose centrally and a deficit of £123 (2009 - deficit of £22,269) was incurred at branch level.

Voluntary income was particularly buoyant in the period 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.

d. Summary of financial performance - continued

Central expenditure has risen considerably in the period 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.

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 1993. 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.

H S HAMILTON
Chairman

Richmond
13 June 2011

Auditors' Report to the Trustees

We have audited the financial statements of The National Ankylosing Spondylitis Society for the year ended 31 December 2010 set out on pages 23 to 32. 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 43 of the Charities Act 1993 and regulations made under section 44 of that Act. 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 43 of the Charities Act 1993 and report to you in accordance with regulations made under section 44 of that Act. 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 2010 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 applicable to Smaller Entities; and

have been prepared in accordance with the requirements of the Charities Act 1993.

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 1993 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

sufficient accounting records have not been kept; or

the parent Charity 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: 3 August 2011

STATEMENT OF FINANCIAL ACTIVITIES

For the year ended 31 December 2010

	Note	Unrestricted Fund £	Restricted Funds Branch Funds £	Restricted Funds Fergus Rogers Fund £	Total Year ended 31 Dec 2010	Total 18 months to 31 Dec 2009
Incoming resources						
Incoming resources from generated funds						
Voluntary income	3	**246,773**	**145,376**	**30**	**392,179**	553,082
Activities for generating funds	4	**126,309**	**22,135**	**-**	**148,444**	88,316
Investment income	5	**1,136**	**176**	**-**	**1,312**	12,737
Incoming resources from charitable activities		**-**	**-**	**-**	**-**	-
Total incoming resources		**374,218**	**167,687**	**30**	**541,935**	654,135
Resources expended						
Costs of generating funds	6	**91,657**	**2,703**	**-**	**94,360**	103,120
Charitable activities	7	**267,930**	**163,076**	**1,000**	**432,006**	518,836
Governance costs	8	**7,205**	**-**	**-**	**7,205**	8,946
Other resources expended	10	**-**	**-**	**-**	**-**	81,719
Total resources expended		**366,792**	**165,779**	**1,000**	**533,571**	712,621
Net incoming (outgoing) resources before transfers		**7,426**	**1,908**	**(970)**	**8,364**	(58,486)
Gross transfers between Funds		**2,031**	**(2,031)**	**-**	**-**	-
Net incoming (outgoing) resources before other recognised gains or losses		**9,457**	**(123)**	**(970)**	**8,364**	(58,486)
Gains (losses) on revaluation of investments		**(344)**	**-**	**-**	**(344)**	57,924
Net movement in funds for the year		**9,113**	**(123)**	**(970)**	**8,020**	(562)
Reconciliation of Funds						
Total Funds brought forward As previously reported		**744,685**	**184,024**	**6,669**	**935,378**	729,647
Change in accounting policy	2	**-**	**-**	**-**	**-**	206,293
As restated		**744,685**	**184,024**	**6,669**	**935,378**	935,940
Movement for the year		**9,113**	**(123)**	**(970)**	**8,020**	(562)
Total Funds carried forward	19	**753,798**	**183,901**	**5,699**	**943,398**	935,378

The notes on pages 25 to 32 form part of these accounts.

BALANCE SHEET

31 December 2010

	Note	**31 December 2010**	31 December 2009
		£	£
FIXED ASSETS			
Tangible assets	11	**332,409**	364,767
Investments	12	**60,683**	61,027
Total Fixed Assets		**393,092**	425,794
CURRENT ASSETS			
Debtors and prepayments	13	**5,158**	5,425
Cash at bank and in hand	14	**558,337**	545,290
Total current assets		**563,495**	550,715
CREDITORS:			
Amounts falling due within one year	15	**13,189**	41,131
NET CURRENT ASSETS		**550,306**	509,584
TOTAL NET ASSETS		**943,398**	935,378
CHARITABLE FUNDS			
Fergus Rogers fund	16	**5,699**	6,669
Branch funds	17	**183,901**	184,024
Unrestricted funds	18	**753,798**	744,685
TOTAL CHARITABLE FUNDS	19	**943,398**	935,378

The accounts set out on pages 23 to 32 were approved by the Trustees on 13th June 2011.

H S Hamilton
Chairman

S H Frost
Treasurer

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) **G*rants 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. This represents a change in accounting policy in the previous period and the effect is summarised in Note 2 below.

(g) ***Fixed assets***: Depreciation is charged on the leasehold property over its expected useful life of 50 years from its acquisition in 2007.This represents a change in accounting policy as previously no depreciation was charged. The effect of the change in policy is not material and no adjustment has been made to comparative figures. 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. BRANCH ACCOUNTING

As stated in Note 1 the accounting policy for branch funds was changed in the previous accounting period. The comparative figures for the balance sheet have been restated and the effect is as follows:

	Year to 31 Dec 2010 £	18 months to 31 Dec 2009 £
Branch Funds as previously reported	**184,024**	-
Creditors: balances at branches	-	188,093
Creditors: branch deposits	-	2,642
Branch Funds at the start of the year	-	190,735
Additional Funds not previously reported	-	15,558
Restated balances at the start of the year	**184,024**	206,293

3. 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 2010 £	18 months to 31 Dec 2009 £
Fergus Rogers Fund		
Donations	**30**	10
Total	**30**	10
Branch funds		
Subscriptions	**135,122**	194,712
Donations	**10,254**	12,197
Total	**145,376**	206,909
Unrestricted funds		
Subscriptions	**81,158**	104,874
Donations and grants	**63,475**	187,014
Legacies	**102,140**	54,275
Total	**246,773**	346,163
Total voluntary income	**392,179**	553,082

4. 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 2010 £	18 months to 31 Dec 2009 £
Fergus Rogers Fund		
Fundraising events	**-**	-
Total	-	-
Branch funds		
Fundraising events	**11,140**	19,353
Other Income	**10,995**	6,518
Total	**22,135**	25,871
Unrestricted funds		
Annual draw	**11,080**	19,925
Fund-raising events	**69,506**	33,296
Research participation	**41,880**	5,711
Other income	**3,843**	3,513
Total	**126,309**	62,445
Total income from activities for generating funds	**148,444**	88,316

5. INVESTMENT INCOME

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

	Year to 31 Dec 2010 £	18 months to 31 Dec 2009 £
Fergus Rogers Fund		
Interest received	**-**	144
Total	**-**	144
Branch funds		
Interest received	**176**	1,924
Total	**176**	1,924
Unrestricted funds		
Dividends received	**41**	89
Interest received	**1,095**	10,580
Total	**1,136**	10,669
Total investment income	**1,312**	12,737

6. 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 2010 £	18 months to 31 Dec 2009 £
Fergus Rogers Fund		
Fundraising expenses	**-**	-
Total	-	-
Branch funds		
Fundraising expenses	**2,703**	3,936
Total	**2,703**	3,936
Unrestricted funds		
Annual draw prizes and expenses	**2,586**	5,188
Fundraising expenses	**7,944**	3,680
CAF administration charges	**4,016**	6,203
Support costs (note 9)	**77,111**	84,113
Total	**91,657**	99,184
Total costs of generating funds	**94,360**	103,120

7. 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 2010 £	18 months to 31 Dec 2009 £
Fergus Rogers Fund			
Welfare – grants made		**1,000**	5,000
Total		**1,000**	5,000
Branch funds			
Research		**-**	-
Campaigning		**-**	-
Education and support	[note 7(e)]	**163,076**	246,873
Total		**163,076**	246,873
Unrestricted funds			
Research	[note 7(b)]	**22,092**	38,120
Campaigning	[note 7(c)]	**62,421**	29,370
Education and support	[note 7(d)]	**183,417**	199,473
Total		**267,930**	266,963
Total resources expended on charitable activities		**432,006**	518,836

7. RESOURCES EXPENDED ON CHARITABLE ACTIVITIES - continued

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

	Year to 31 Dec 2010 £	18 months to 31 Dec 2009 £
Grants for research	**-**	15,000
AS News	**749**	1,413
Website and database development	**1,766**	-
Support costs (note 9)	**19,577**	21,707
Total research expenditure	**22,092**	38,120

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

	Year to 31 Dec 2010 £	18 months to 31 Dec 2009 £
Advertising and campaigning	**4,046**	3,324
AS News	**2,247**	4,241
Website and database development	**5,299**	-
Standards of care	**31,831**	-
Other direct expenses	**1,618**	2,812
Support costs (note 9)	**17,380**	18,993
Total campaigning expenditure	**62,421**	29,370

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

	Year to 31 Dec 2010 £	18 months to 31 Dec 2009 £
AS News	**11,985**	22,617
Guide books and DVDs	**8,914**	14,540
Literature and brochures	**613**	7,394
Conference expenses	**-**	8,402
Website and database development	**28,260**	-
Support costs (note 9)	**133,645**	146,520
Total education & support expenditure	**183,417**	199,473

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

	Year to 31 Dec 2010 £	18 months to 31 Dec 2009 £
Treatment by healthcare professionals	**125,135**	190,654
Hire of NHS facilities	**24,460**	28,363
Grants payable	**1,696**	6,372
Support costs (note 9)	**11,785**	21,484
Total branch education & support expenditure	**163,076**	246,873

8. 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 2010 £	18 months to 31 Dec 2009 £
Expenses paid to Trustees	**1,864**	4,440
Annual General Meeting costs	**1,846**	1,506
Independent examiner fees	**-**	3,000
Auditors' remuneration	**3,495**	-
Total governance costs	**7,205**	8,946

The Trustees received no remuneration during the year (2009 – nil). 14 Trustees claimed expenses during the year.

9. 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 2010 £	18 months to 31 Dec 2009 £
Staff costs (note 9c)	**166,516**	191,166
Premises costs	**36,993**	22,565
Travel expenses	**7,112**	10,147
IT and Communications	**14,643**	17,357
Office costs	**13,265**	19,923
Insurance, legal and professional	**9,184**	10,175
Total support costs	**247,713**	271,333

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	**19,577**	21,707
Campaigning	**17,380**	18,993
Education and support	**133,645**	146,520
Fundraising activities	**77,111**	84,113
	247,713	271,333

b) Branch support costs incurred in the year amounted to £11,785 (2009 - £21,484), and are wholly attributable to education and support.

c) Staff costs incurred during the period consisted of:

Wages and salaries	**146,064**	162,200
Social security contributions	**15,053**	16,945
Pension contributions	**3,098**	3,982
Recruitment and other costs	**2,301**	8,039
Total staff costs	**166,516**	191,166

d) The average number of employees during the period was 5 (2009 – 3)

10. OTHER RESOURCES EXPENDED

	Year to 31 Dec 2010 £	18 months to 31 Dec 2009 £
Gift Aid repaid	**-**	81,719

During the previous period negotiations were undertaken with HMRC in relation to Gift Aid claims made by 26 of the Society's branches between 2000 and 2008 which in large part did not fully comply with Gift Aid regulations. These negotiations resulted in a settlement agreement which was approved by the Trustees in July 2009. Together with interest the full amount repayable under the settlement was £81,719.

11. TANGIBLE FIXED ASSETS

	Leasehold Buildings £	**Office Equipment £**	**Total £**
Cost at 31 December 2009	351,000	17,396	368,396
Additions in the period	-	-	-
Cost at 31 December 2010	**351,000**	**17,396**	**368,396**
Depreciation at 31 December 2009	-	3,629	3,629
Depreciation charge for the period	28,000	4,358	32,358
Depreciation at 31 December 2010	**28,000**	**7,987**	**35,987**
Net book value at 31 December 2009	351,000	13,767	364,767
Net book value at 31 December 2010	**323,000**	**9,409**	**332,409**

The leasehold building is held on 999 year lease with 993 years remaining.

12. INVESTMENTS

	31 Dec 2010 £	31 Dec 2009 £
Bronze statues, at valuation	**60,000**	60,000
Listed shares, at valuation	**683**	1,027
	60,683	61,027

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 £344 during the year has been reflected in the Statement of Financial Activity.

13. DEBTORS AND PREPAYMENTS

	31 Dec 2010 £	31 Dec 2009 £
Prepayments	**4,988**	3,154
Sundry debtors	**170**	2,271
	5,158	5,425

14. CASH AT BANK AND IN HAND

	31 Dec 2010 **£**	31 Dec 2009 £
Deposit account balances held centrally	**353,829**	360,112
Deposit account balances held by branches	**180,125**	180,164
Current account balances	**20,607**	1,154
Cash in hand	**3,776**	3,860
	558,337	545,290

15. CREDITORS: Amounts falling due within one year

	31 Dec 2010 **£**	31 Dec 2009 £
Sundry creditors	**10,689**	16,651
Deferred income	**-**	21,480
Accrued expenses	**2,500**	3,000
	13,189	41,131

There are no creditors falling due after more than one year (2009 – nil).

16. 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 £1,000 (2009 – £5,000 on research) was expended on welfare.

17. 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 period grants totalling £860 (2009 - £1,550) were paid to branches from Unrestricted Funds and donations totalling £2,891 (2009 - £7,714) were made by branches to Unrestricted Funds.

18. 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.

19. RECONCILIATION OF CHARITABLE FUNDS

	Unrestricted Fund £	**Branch Funds £**	**Fergus Rogers Fund £**	**Total Funds £**
Tangible assets	332,409	-	-	332,409
Investments	60,683	-	-	60,683
Debtors and prepayments	5,158	-	-	5,158
Cash at bank and in hand	368,737	183,901	5,699	558,337
Less creditors	(13,189)	-	-	(13,189)
Total charitable funds	**753,798**	**183,901**	**5,699**	**943,398**

National Ankylosing Spondylitis Society
Unit 0.2 One Victoria Villas
Richmond Surrey TW9 2GW
Registered Charity No: 272258 • Scottish Registered Charity No: 041347