



Behçet's Syndrome Society

**'Caring for those with a rare, complex and
lifelong disease'**



Annual Report 2012



Behçet's Syndrome Society

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Medical Panel



Name: Colin G Barnes (Chair of the Medical Advisory Panel)
Qualifications/Post Nominals: BSc, MBBS, FRCP
Where qualified: University of London (The London Hospital Medical College)
Year of initial qualification: 1961
Currently practising at: Retired – formerly Clinical Director for Rheumatology, The Royal London Hospital
Special interests: Clinical rheumatology; Behçet's syndrome



Name: Clive B Archer
Job title: Cons Dermatologist & Hon Clinical Snr Lecturer
Qualifications/ Post Nominals: BScMD, PhD, MSc Med Ed (Lond), FRCP Edin, FRCP (Lond)
Where qualified: Guy's Hospital Medical School, University of London
Year of initial qualification: 1978
Currently practising at: Bristol Dermatology Centre, University Hospitals Bristol NHS Foundation Trust, Bristol
Special interests: Clinical interests in inflammatory skin diseases, benign and malignant skin tumours, immuno-bullous diseases; research interests in immuno-pharmacology, cell regulatory mechanisms and medical education



Name: Adnan Al-Araji
Job title: Consultant Neurologist
Qualifications/Post Nominals: MB ChB, FRCP, FRCP (Glasg.)
Where qualified: Baghdad, Iraq
Year of initial qualification: 1977
Currently practising at: University Hospital of North Staffordshire, Stoke-on-Trent
Special interests: Neuro-Behçet's disease, multiple sclerosis and other inflammatory diseases of the central nervous system



Name: Reuben C S Ayres
Job title: Consultant Gastroenterologist
Qualifications/Post Nominals: BM, DM, FRCP
Where qualified: Southampton
Year of initial qualification: 1982
Currently practising at: Royal Devon & Exeter Foundation Trust
Special interests: Colorectal cancer, inflammatory bowel disease



Name: Paul Brogan
Job title: Senior Lecturer in Paediatric Vasculitis
Qualifications/Post Nominals: BSc(Hon), MBChB(Hon), MRCPCH, MSc, PhD
Where qualified: Manchester Medical School
Year of initial qualification: 1993
Currently practising at: Great Ormond St Hospital, London
Special interests: Vasculitis, vascular inflammation in the young



Name: Dr Andrew de Burgh-Thomas
Job title: Consultant in Genitourinary Medicine
Qualifications/Post Nominals: BSc, MBBS, MRCP, Dip GUM, Dip HIV
Where qualified: University of London
Year of initial qualification: 1994
Currently practising at: Gloucester Royal Hospital, Cheltenham General Hospital and Bristol Southmead Hospital
Member of: British Association of Sexual Health and HIV, British Medical Association, Royal College of Physicians
Special interests: HIV and genital dermatology



Name: Farida Fortune CBE
Qualifications/Post Nominals: BDS, MBBS, FRCS, FRCP, FDSRCS, FGDP, DipEdTMD, PhD
Job title: Dean for Dentistry; Director, Clinical Academic Unit
Where qualified: University College London
Year of initial qualification: Dentistry 1975; Medicine 1980
Currently practicing at: Dental Institute, Barts and The London NHS Trust
Special interests: Oral manifestations of systemic disease including immune related/autoinflammatory conditions such as Behçet's disease, Sjogren's syndrome, orofacial granulomatous and oral Crohn's disease, pemphigus and pemphigoid. Clinical research in inflammatory mucosal disease. Undergraduate and postgraduate dental and medical education, specialising in teaching the medical support subjects for dentistry.



Name: Dorian O Haskard
Job title: Professor of Medicine/Honorary Consultant Rheumatologist
Qualifications/Post Nominals: DM FRCP FMedSci
Where qualified: University of London
Year of initial qualification: 1977
Currently practising at: Imperial College London/Hammersmith Hospital
Special interests: Vascular inflammation



Name: Desmond Kidd
Job title: Consultant Neurologist
Qualifications/Post Nominals: MD FRCP
Where qualified: Ireland
Year of initial qualification: 1986
Currently practising at: Royal Free Hospital, London
Special interests: Neurological complications of inflammatory diseases, particularly Behçet's syndrome, sarcoidosis and histiocytosis; neuro-ophthalmology



Name: Sue Lightman
Job title: Professor of Clinical Ophthalmology/Consultant Ophthalmologist
Qualifications/Post Nominals: FRCP FRCOphth PhD FMedSci
Where qualified: University of London
Year of initial qualification: 1975
Currently practising at: Moorfields Eye Hospital
Special interests: Uveitis in adults and children, infective eye disease, ocular inflammation of all types associated with systemic disease



Name: Robert J Moots
Job title: Professor of Rheumatology/Consultant Rheumatologist
Qualifications/Post Nominals: BSc (Hons), MB BS (Hons), PhD, FRCP
Where qualified: Imperial College, London
Year of initial qualification: 1985
Currently practising at: University Hospital Aintree, University of Liverpool
Special interests: Clinical and basic science, Behçet's disease, systemic vasculitis, Raynaud's and scleroderma, rheumatoid arthritis, immunotherapy of rheumatic diseases



Name: Philip Ian Murray
Job title: Professor of Ophthalmology, University of Birmingham
Qualifications/Post Nominals: MBBS, DO(RCS), PhD, FRCP, FRCS, FRCOphth
Where qualified: St George's Hospital Medical School, University of London
Year of initial qualification: 1978
Currently practising at: Birmingham and Midland Eye Centre, City Hospital, Sandwell and West Birmingham Hospitals NHS Trust
Special interests: Scleritis; all types of uveitis including Behçet's disease, HIV-related eye disease, cataract surgery in uveitis patients.
Laboratory: The eye has evolved many mechanisms to prevent significant inflammation, which can lead to visual impairment. I am investigating why in patients with uveitis, the eye cannot control the inflammation. Jazz!



Name: Catherine Nelson-Piercy
Job title: Consultant Obstetric Physician
Qualifications/ Post Nominals: MBBSMA, FRCP, FRCOG
Where qualified: Cambridge University and St Bartholomew's Hospital
Year of initial qualification: 1986
Currently practising at: Guy's and St Thomas' Hospitals Foundation Trust and Queen Charlotte's Hospital, Imperial College Healthcare Trust
Special interests: Medical problems in pregnancy, particularly connective tissue diseases, thromboembolism, cardiac and renal disease



Name: Dr Jane Setterfield
Job title: Senior Lecturer/Consultant Dermatologist
Qualifications/Post Nominals: BDS, DCH, DRCOG, MD, FRCP
Where qualified: University College Hospital, London
Year of initial qualification: Dentistry 1980, Medicine 1987
Currently practising at: Guy's Hospital and St Mary's, Paddington, London
Member of: British Association of Dermatology, British Association of Oral Medicine, British Society for Investigative Dermatology, BMA
Special interests: Oral medicine, immunobullous disease, autoimmune disease and vulval dermatology



Name: Graham Wallace
Job title: Senior Lecturer
Qualifications/Post Nominals: BSc Immunology, PhD
Where qualified: University of London
Year of initial qualification: 1985 (PhD)
Currently practising at: School of Immunity and Infection, University of Birmingham
Special interests: Ocular immunology, Behçet's disease, immunogenetics, innate immunity

Foreword from the Chair of Trustees

I can say with great confidence that 2012 will be long remembered in the lives of Behçet's patients as a landmark year. We discovered our bid for Centres of Excellence in London, Birmingham and Liverpool had been successful in February and this step change in care will see patients visiting a centre where all the consultants they need to manage their illness will be available together, providing a more holistic picture of care and also ending the countless trips to various hospitals whilst dealing with this debilitating illness. This best practice model is already practiced in Turkey where Behçet's is more prevalent.

Obviously, the Centres aren't local for everyone and to ensure appropriate care, the Centres will establish relationships with local hospitals so that after registering with a Centre, the treatment can be delivered locally. The amount of effort from the Society in particular the Director, Kathryn and myself cannot be underestimated and I would personally like to thank everyone involved. This has been by far the largest project we've ever undertaken and it's great that we've been successful, but unfortunately it's not "mission accomplished" just yet!

The Centres are only available to patients in England following the devolution of the NHS within the UK, so in tandem with getting the Centres operating to the model we envisaged, we're also planning to lobby the Scottish, Welsh and Northern Irish parliaments to improve the care of their Behçet's patients.

To support the award of the contract from the National Specialist Commissioning Group, we have established a subsidiary company limited by guarantee called "Behçet's Patients Centres." This will ensure the risk to the Society of this contract is minimised. We have a Board of

Directors which will always include 2 trustees in addition to external talent. The initial Board will be chaired by myself with the Directors including Kathryn Proudlock (Vice Chair), Mike Rawlins & Dr Kaushik Chaudhuri. Alan Lane the Society's Treasurer will become Financial Officer for the Company. The company will also be responsible for the employment of 3 healthcare support workers whose recruitment is underway.

We haven't just focused on the Centres this year though. We continue to work with Prof Sue Lightman at Moorfields Hospital and we're eagerly awaiting the results of the Alpha interferon trial to assess whether the drug can have long lasting, positive effects on patients. We continue to work with Dr Nicky Ambrose and Prof Dorian Haskard at Hammersmith Hospital in their research to assess whether all Behçet's patients react to certain chemicals in the same way with an eye on whether this could start to form the basis of a test for Behçet's.

Following the launch of our new website last year, we have continued to develop it. We can now accept online subscriptions along with online donations from our own website without having to use intermediary sites. This has had a positive effect on the numbers of members joining online and further enhancements are planned for FY12/13.

We hope that the online donations will help with our fundraising which has not matched expectations this year. Individuals have continued to raise money on our behalf and we are grateful to everyone who has abseiled, parachuted from a plane, done a car boot or sold cakes etc on our behalf. The Society organised events have not been seen the same success as in recent years and we need to

understand why and what we can do differently in future years.

The decision to trial teleconference meetings rather than physical meetings for the Trustees has been a great success. It has the benefits of reducing both travel expenditure and time for the Trustees, whilst still allowing productive meetings to take place. We are looking into alternative providers of this facility now the proof of concept is complete.

This year has seen changes to the trustees. Matt Shea has stepped down owing to the demands of work and I'd like to thank him for all his support over the past few years. Joining the trustees have been John Henson who has taken over the coordination of the helpline; Fran Horne who continues to raise funds through the sale of handmade cards and Norah Martyn who has joined the Grant Aid committee. I'd like to welcome all the new trustees and look forward to working with them in the future.

I'm sure future years will feel very different with the Society working closely with the Behçet's Patients Centres Ltd and as the Centres have

also been on our Mission & Vision statement, now we've achieved this, we will revisit what the Society's aims are going forward. One thing that won't change is that we will ensure that patients throughout the UK remain at the centre of everything we do.



Jan Mather Sep 2012

Director's Report

Many years, directors report change, progress or consolidation, seldom do they report all three. This year saw change; a three day week to save costs in a difficult economic environment for the initial part of the year followed by a change back to full time working when we'd secured the contract, reduced travel to meetings and a tight budget to make ends meet, which perhaps also covers the heading consolidation.

However during this time the work that went into the success of the three centres of excellence continued at a pace. It did seem that once the bid was in all we would have to do was wait but an increase in questions and queries, did encourage us to think we might actually get the project, so effort then went into what happens when we do. Those sentences cover both change and progress but certainly do not do those topics justice.

Change for the diagnosis and care of patients in England will be dramatic over the coming months and years, a step change it is being called, if we can achieve a halving of our average diagnostic period (currently 10 to 12 years) it will be a major leap forward. If we can manage major flares much better, it will greatly reduce trauma for patients and families and mean that Behçet's Disease has the focus it should have had years ago.

Rare diseases are in fact gaining headlines in the media at last; the UK is working on a meaningful Rare Disease Plan (as required by our EU membership) and already Rare Disease centres are being discussed as a way forward. We are relieved to be ahead of this work, unsure that being one of many rare diseases treated in a new centre would have been the best way forward for our patients.

Patients and their family and friends form the total focus for the Society and I have had the privilege of dealing with many of you during this past year. Our email queries have continued to increase, in excess of 150 this year, with enquires from all around the world as well as in the UK. Many of these are referred to our medical panel who under the chairmanship of Dr Colin Barnes continue to give their time freely to answer our questions.

I know also that our helpline has been busy with queries and this when combined with the information continually accessed on our website means we can be proud of the all-round information service we offer to patients in this country and worldwide. Last year we had some difficulty managing our online forum (mainly due to its success) but a change to a joint system with Health Unlocked means we have a working forum without the headache of managing the operating system. There are currently 300 or so members, some of who use the forum everyday a valuable service the Society is pleased to be able to provide.

The schedule for Newsletter production continues unabated, as soon as one edition is out the next is planned and it is thanks to members, supporters and clinicians for the new articles we continue to get; without them it would be a much smaller edition each time. The website too, attracts lots of visits and both newsletter and website continue to receive good comments from users and we strive to maintain the standard. Thanks are given elsewhere to the helpline volunteers who give the continued cover we have offered to patients for some time, a group of people whose service is much appreciated by all who use it.

Our support group network has expanded and contracted again this year, new group's struggle to start and some struggle to continue. In Scotland we are piloting a virtual support group, which may catch-on elsewhere. The idea being that to cover the whole of Scotland with patients spread very thinly is difficult, if not impossible, but by using the internet, email and telephone (perhaps video) conferencing, they hope to keep in contact and discuss different items as they occur, we will report in the newsletter how they get on.



Chris Phillips Sept 2012

The work goes on, the centres will develop in England and our support workers will no doubt come up with new areas of work for us to attend to. In Scotland, Wales and Northern Ireland a campaign to get them included in the new centres, or perhaps new centres of their own, will occupy the minds of patients and the Society and we look forward to getting them parity of care; it is after all the National Health Service. Work continues in monitoring advances in Europe and other countries, the International Conference in Japan was reported in a recent newsletter and you need to gear up for the next one in 2014 in Paris, slightly easier to get to.

I have made some good friends over these past years, patients, family and supporters and I look forward to making more in the months ahead. Fundraising, centre development and monitoring, new support groups, the control of orphan drugs, prescription charges, benefits advice and well, just the rising tide of admin, will challenge us and I for one look forward to that challenge.

Behçet's Syndrome Society Vision and Mission

The sentence used by the society to encapsulate the organisation is :-

Caring for those with a rare, complex and lifelong disease.

The Society will care for all those associated with Behçet's Disease, whether members, enquirers or those yet undiagnosed.

The Society's ultimate aim is to find a cure for Behçet's Disease but in the meantime it will strive to obtain the best care for all Behçet's Disease patients. This includes helping them obtain the quickest diagnosis possible, quick referral to a specialist consultant as near as possible to the person's home and finally enabling them to gain the best drug regime to alleviate their symptoms.

Mission

The Behçet's Syndrome Society aims to raise sufficient funding to support research into Behçet's Disease with the overall goal of finding a cure. Along this path it is hoped to find the most appropriate drug regime to relieve the many symptoms of Behçet's.

The Society wishes to:-

- Reduce diagnosis times for Behçet's Disease patients from years to months thus avoiding much discomfort, suffering and anguish as well as preserving vital organs and tissue.
- Provide nationwide centres of excellence reducing patient travel times and the need to see specialists at different times in different locations.
- Provide support staff for newly diagnosed patients
- Provide direct assistance with Disability Living Allowance claims and tribunals. Lobbying Government on behalf of Behçet's disease patients for a uniform approach to DLA awards and removal of the so called 'postcode lottery' for drug supply.
- Provide an NHS approved Behçet's database for GP's and nurses that will be invaluable for information and research.
- Provide an interactive website with a patient forum for members to gain information and support
- Provide a network of patient support groups to give local contact for new patients and mutual support and advice for those with long term needs, and their carers.
- Organise professional fundraising to gain substantial funds for the mission list, in particular to fund research, information and expansion of services.
- Raise the profile of the Society, by gaining media respect and offering effective articles that will appeal to a wide range of publications
- Gain influential patrons from the medical, political and celebrity world to help improve and raise the charity's profile
- Expand the membership and increase membership value. In addition seek appropriate fees for members' services
- Gain commercial sponsorship to help fund research

Fundraising Update

In over 30 years in sector, again I must record that fundraising has never been harder. Clearly this reflects the economic situation of the nation but I think it also reflects the growing disparity between large and small charities. I have long been worried by the buying power of the top 100 charities in the UK. They can afford expensive advertising campaigns including TV and radio and they are moving ahead as any brand does in the public's mind. This leaves the medium sized charities and the small charities (us) running behind in their wake, never to catch up but to at least try to close the gap.

Many rare diseases such as ourselves are also restricted by both the spelling and pronunciation of our names and in the public's eyes we are just another charity they have never heard of. It is not however all doom and gloom luckily we have members and member's families who are willing to help by devoting time and money to raising our profile and raising money. It would seem that this year we have failed to put on a national event that caught anyone's imagination for we had hoped short and long walks on the South Downs would have encouraged people to take part, but clearly we missed the mood of patients and families in the South of the country. The London Tube event is still to take place so perhaps people are saving themselves we hope so.

Thanks of course continue to go to the band of regular helpers, those who do car boot sales in all weathers, those that encourage friends to do runs, walks, cycles of various lengths, all this effort adds to the fundraising income of the Society and quite frankly we could not continue without it.

We have links with various organisations that operate events such as abseiling, parachute jumping, walking, cycling in UK and abroad and we have reported participants' efforts throughout the year. Just saying thank

you to someone who throws themselves off a building or from an aeroplane does not seem quite enough but the money raised by these supporters reflects the awe in which they are held by their own friends and family. What we can say as well as thank you, is please encourage others, the thrill, the adrenaline rush, whatever you call it, is supposed to be amazing and most people want to do it again, our message is please don't stop them and use them as an example to others.

There are many aspects of fundraising that large charities use that are also not open to us, corporate fundraising, sponsorship, charity balls and glitzy events, that is not for want of trying but goes back to profile and awareness that sadly we do not have.

I have said thank you throughout this section and will say it again, THANK YOU, for money in lieu of flowers at funerals and family celebrations, for those who have collecting boxes, for those that do daring (and not so daring) things on our on our behalf, for those that buy and sell Christmas cards and wrist bands, for those who send extra donations with their subscriptions etc etc, we cannot continue our service without you, so please continue to help when and where you can, it is highly valued and much appreciated by patients known and unknown who benefit from our work.

Chris Phillips

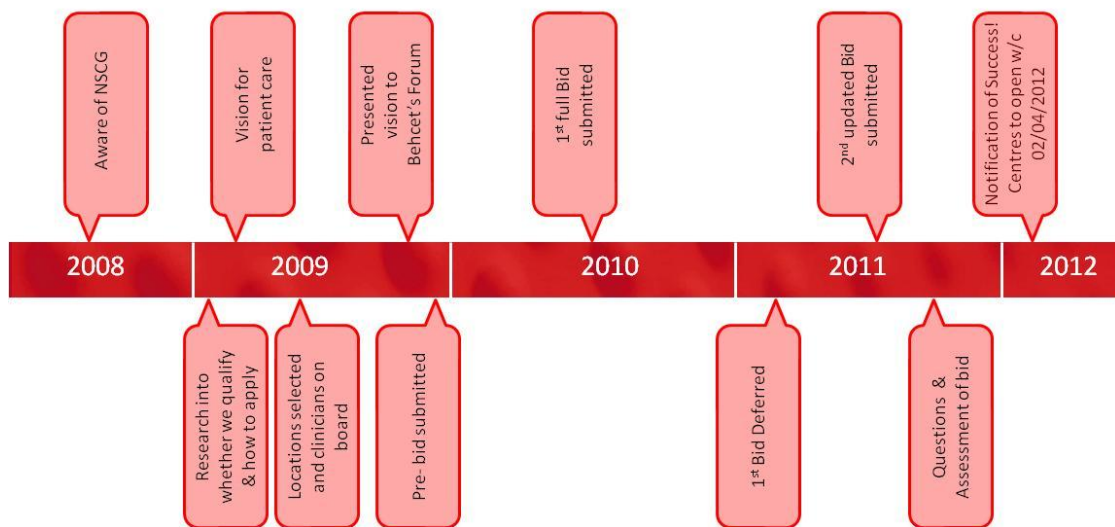


National Commissioning & Centres of Excellence

The National Specialist Commissioning Group (NSCG) have been tasked with commissioning services for complex rare diseases in England. The Society became interested in this service back in 2008 and has been actively working to

establish centres for Behçet's since that time. As previously mentioned, the Centres opened in April 2012 and will continue to evolve into the service we envisaged.

A potted history of the bid process



The Governance of the Company

The Behçet's Patients Centres (BPC) charitable company limited by guarantee has been established as a subsidiary of the Behçet's Syndrome Society. This will ensure any risk associated with the contract will be minimised to the Society.

As a company, a Board of Directors has been established with the articles stating that 2 of the Directors must always be on the Board of Trustees from the Society to ensure the patient focus is retained.

The initial Board includes:

Jan Mather – Chair of Trustees and of the Board of Directors

Kathryn Proudlock – Vice Chair of Trustees and Director

Dr Kaushik Chaudhuri – consultant Rheumatology and Director

Mike Rawlins – self-employed consultant and Vice Chair of Directors.

Alan Lane – Treasurer of the Society will take the role of Financial Officer for the company.

Chris Phillips the Director of the Society will remain employed full time by the Society but will be recharged to the company to work on the Centres for 2 days per week.

The Patient's experience

The aim of the Centres is to provide holistic care for Behçet's patients in a 'one-stop shop'. This is the best practice model currently employed in Turkey where Behçet's is more prevalent.

The patients will sign up with one of the Centres in London, Birmingham or Liverpool and on arrival, will see a specialist nurse who will triage their needs for that appointment. The patient will then see an Ophthalmologist, a Rheumatologist and an Oral specialist. There will also be strong relationships with other specialists such as Neurologists, Dermatologists, Gynaecologists etc. These consultants will discuss the patient care and any changes in medication together. Furthermore, each of the centres will follow the same drugs pathway which will be led by the symptoms of the patient and the medications already used. This will ensure the most appropriate drug regime will be used for all patients.

The Behçet's Patients Centres will provide a Support Worker at each Centre who will provide non medical care to the patients. They will organise support groups to alleviate isolation; provide signposting through the benefits system and help patients explain their illness to both family and employers. The Birmingham support worker has been offered a contract and is due to start during September 2012. Her name is Janine Davies. Support workers for London and Liverpool are still being recruited.

The Centres will work with other hospitals throughout England to ensure that once a patient has registered at a Centre, ongoing care can be provided by a more local hospital. This will reduce travel time for

patients and improve knowledge and treatment of Behçet's throughout England.

The Centres are currently only available to patients in England. This is because the devolved NHS groups in Scotland, Northern Ireland and Wales have opted not to utilise the English centres. As a Society, we will work to lobby these groups to ensure patients throughout the UK receive the same high level of care.

The Centres are in their infancy at present. Once established, the leading clinicians will be responsible for organising training courses to raise awareness of the condition. They will also provide a focus for research into Behçet's Syndrome.

The initial contract is for 3 years, although finances were submitted for a 5 year contract. The service from both the medical professionals and from the BPC will be monitored and assessed on an ongoing basis with a full review on an annual basis.

Sub-committees

The governance of the Society will need further review when the Centres of Excellence are fully established.

We have trialled a new way of operating the Society using teleconferences which has been successful. We will continue to have 2 face to face trustee meetings per annum with one linked to the AGM in October. The remaining meetings have all taken place over a tcon.

Papers are circulated before the meeting with discussion occurring on the tcon together with any votes. Further research will be conducted to find alternative providers of the tcon facility.

Although the subcommittee structure is no longer in effect, there remains a key trustee responsible for each of the areas who can call on other trustees and volunteers for support as required.

Sub Committee

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<div style="border: 1px solid red; width: 30px; height: 60px; display: inline-block; margin-right: 10px;"></div> Support Chris	<div style="border: 1px solid red; width: 30px; height: 60px; display: inline-block; margin-right: 10px;"></div> AGM/Conferenc Sarah	<div style="border: 1px solid red; width: 30px; height: 60px; display: inline-block; margin-right: 10px;"></div> Yout Amanda Moselev	<div style="border: 1px solid red; width: 30px; height: 60px; display: inline-block; margin-right: 10px;"></div> National Commissionin Chris Phillips / Jan Mather / Kathrvn
<div style="border: 1px solid red; width: 30px; height: 60px; display: inline-block; margin-right: 10px;"></div> Helpline John	<div style="border: 1px solid red; width: 30px; height: 60px; display: inline-block; margin-right: 10px;"></div> Websit Alan	<div style="border: 1px solid red; width: 30px; height: 60px; display: inline-block; margin-right: 10px;"></div> Grant Alison	

Finance

This group is tasked with maintaining a sound financial basis for the Society to proceed. A full report is provided later in this document.

Benefits

This group has been working towards helping our members with the benefits systems whilst acknowledging this is a complex area. The new Support Workers will take a lead in this area going forward and keep the trustees up to date with any changes.

Research

This group aims to work alongside our Medical Advisory Panel and other

medics to promote research into Behçet's. We continue to work with

Moorfields Hospital with the Alpha-interferon trial along with Dr Nicky Ambrose and Prof Dorian Haskard at the Hammersmith Hospital in London.

Newsletter

This group aims to continue communicating what the Society is doing and sharing information and advice amongst our members. We will continue to provide 4 newsletters per year. We have had some success with encouraging our members to receive their newsletter electronically to reduce our printing costs. Judi Durant continues to coordinate the newsletter on the Society's behalf.

AGM / Conferences

This group ensures that an AGM is held on an annual basis providing members the opportunity to meet with other patients and hear from medics. This year's AGM was held in October in Gloucester with presentations by Dr Nicky Ambrose, Dr Colin Barnes and Dr Andrew de Burgh Thomas. It was attended by over 60 people from across the country. Next year's AGM is planned for Peterborough in October.

Youth

The youth group have an active Facebook site for young members to keep in touch with each other. We will be undertaking grant applications in order to undertake a survey of our young members. If we are successful with our grant applications, we also hope to run an outing for our young people to socialise with each other in addition to hearing from medics.

Website

Solve the Web won the tender to host and recreate our website. We now have the facility for online donations and membership which has been very successful in gaining new members. Further updates will take place to our website through FY12/13 to accommodate the Centres.

Grant Aid

This group considers applications for grants from members suffering from severe financial hardship as a result of their Behçet's Syndrome. The upper limit for any individual grant is £750. This year there have been 3 successful applications.

National Commissioning

This group will no longer operate going forward as they have been superseded by the Board of Directors for the BPC.

Helplines

This group continues to ensure that the helpline volunteers have appropriate rotas, but also have the opportunity to talk through any upsetting calls. Reports are produced from each call received and stored securely for 6 months by the lead of this group.

Support Groups

There are currently support groups in Liverpool, Northern Ireland, Cambridge, Suffolk and Portsmouth. A further 'virtual' group will be formed in Scotland. The support workers will be responsible for the establishment and coordination of these groups going forward.



Report on Financial Statement 2011-12

Significant changes this year

This was a relatively stable year in terms of financial management. The changes made during the previous year, moving the Society's main banking to CAF Bank Ltd and adopting Paxton Computers Ltd software for financial processing have bedded in well and provided an efficient service with clear and timely reports.

The Trustees agreed in March 2012 to place the sum of £10k in a 90-day notice deposit account at 1.7% interest with Scottish Widows (for which CAF Bank were agents) in order to achieve a higher rate of interest on funds that were unlikely to be touched in the near future. Although rates of interest generally are low at present, this has provided a much higher return than was available in our ordinary deposit account.

The success of the Society in achieving an NHS National Commission grant to support three Behçet's Patients Centres has led to the formation of a separate company (Behçet's Patients Centres Ltd) in order to ensure that the Society's funds were not placed at risk by any unexpected problems that might emerge regarding this new venture. The Trustees agreed to meet some initial costs of the company pending its receipt of the first instalment of funds due from the NHS. These were repaid to the Society in full by the end of September.

The Trustees appointed Critchleys LLP (Abingdon office) to be the Society's Independent Examiners of Accounts for 2011-12.

Financial Year 2011-12

For several years up to 2010, the Society had had an operating deficit, as a result of which its reserves were steadily diminishing. It was necessary for the Trustees to take action to reduce costs and as a result a small surplus was reported in 2010-11. The out-turn for 2011-12 also shows an operating surplus of just over £10k, with the General Fund

now standing at £33k. The Trustees aim to maintain a surplus at around this level in order to ensure that the work of the Society would not be put in jeopardy by any unexpected problems that might occur in the future.

Although membership subscriptions have held up very well, in common with other charities the Society has experienced a significant drop in donation income this year, being around 30% less than had been budgeted. Fundraising showed an even larger drop, being almost 40% down on the total that had been anticipated. A number of advertised events failed to attract much interest, though several that did take place were highly successful, particularly where Trustees themselves had organized the events and recruited sponsors.

Fortunately the overall drop of 16% in income from the budgeted total was almost exactly matched by a similar reduction in expenditure. Cautious estimates had been made in budgeting with the result that expenditure on travel and subsistence, printing and publicity, web site costs and AGM expenditure were all much less than had been expected.

The accounts include expenditure totalling £4.2k that had been incurred in setting up and providing temporary funding for the Behçet's Patients Centres. The corresponding amount of income was due to the Society at the end of our financial year in August and is therefore shown in the Income and Expenditure account, as well as being included under 'Debtors' on the Balance Sheet. The company received the first instalment of its grant from the NHS in mid-September enabling the loan from the Society to be repaid in full at that time.

A few specific donations have again been made to our Research Fund, which stands at around £9k. No expenditure has been incurred from this fund this year, but Trustees are considering ways in

which this sum might be used to support research in the future.

Membership

In previous years membership subscriptions were generally paid by cheque or by standing order to one of our old bank accounts (Barclays or Santander). From September 2011 the Society has also used CAF Fundraising to process membership subscriptions by direct debit, or by credit/debit card payments, both from paper forms and also from our web site. This gives us greater certainty as to who has paid and the ability to vary subscription rates in the future without the need to ask members to revise their standing orders. By the end of the year, some 90 direct debit instructions had been received and 20 credit/debit card subscriptions.

We are delighted to welcome around 20 new members each month, almost all of whom now join the Society through our web site and, unless exempt, pay their subscriptions by electronic means. On 1 September 2012 the Society had 605 full members, 4 junior members and 46 associate members. Not included in these figures were people whose subscriptions were more than a year in arrears, from whom we hope to hear in the near future. It is now our policy to remove from our database names of contributors with whom we have had no contact for two years.

Summary

It is important to state that the work of the Society is completely dependent upon its subscription income and the many generous donations made by members and supporters, as it currently receives no grants from Government or other sources. Despite the difficult financial circumstances being experienced nationally, the Trustees are optimistic that the Society will continue to have a strong financial position and be able to support its members and to promote services for Behçet's patients and their carers in the United Kingdom.



*Alan Lane Honorary Treasurer
Sept 2012*

Statement of Financial Activities for year ended 31 Aug 2012

	General Fund	Research Fund	Total 2012	Total 2011	
	£	£	£	£	
Incoming resources					
Donations	24 060	185	24 245	36 865	
Subscriptions	13 432		13 432	12 970	
Gift Aid tax reclaimed	5 005	17	5 022	5 365	
Grants received	0		0	2 500	
Fundraising activities	6 112		6 112	11 996	
Sales of goods	1 454		1 454	1 082	
Interest	96	18	114	10	
Charitable activities income	552		552	0	Note 6
Other	4 213		4 213	35	Note 8
Total incoming resources	54 924	220	55 144	70 823	
Resources expended					
Fundraising / trading costs	10 182		10 182	19 435	Note 7
Grants to individuals	599		599	715	
Subscriptions to other organizations	491		491	67	
Helpline costs	619		619	644	
Charitable support staff costs	3 606		3 606	6 712	Note 7
Travel and subsistence	451		451	1 908	
Insurance	353		353	500	
Administrative staff costs	7 212		7 212	10 374	Note 7
Telephone charges	565		565	879	
Printing, postage, stationery and materials	861		861	1 290	
Newsletter	7 256		7 256	7 109	
Web site and publicity	1 295		1 295	5 925	
Public relations staff costs	3 606		3 606	3 657	Note 7
AGM and conference	1 908		1 908	0	Note 6
Governance costs	1 397		1 397	1 187	
Other	4 169		4 169	0	Note 8
Total resources expended	44 570	0	44 570	60 402	
Net movement in funds for the year	10 354	220	10 574	10 421	
Fund balance brought forward at 1 Sep 2011	23 044	9 018	32 062	21 641	
Fund balance carried forward at 31 Aug 2012	33 398	9 238	42 636	32 062	

Balance Sheet as at 31 August 2012

	General Fund	Research Fund	Total 2012	Total 2011
	£	£	£	£
Current Assets				
Stock in hand	403		403	700
Debtors	4 169		4 169	0
Recoverable Gift Aid	4 816	17	4 833	2 650
Deposit Accounts	25 844	8 956	34 800	26 689
Current Accounts	1 065	265	1 330	2 981
Petty Cash	300		300	300
Total current assets	36 597	9 238	45 835	33 320
Current Liabilities				
Creditors	2		2	0
Advance subscriptions	1 729		1 729	200
Accrued expenses	1 468		1 468	1 058
Total current liabilities	3 199	0	3 199	1 258
Total net assets	33 398	9 238	42 636	32 062
TOTAL FUNDS	33 398	9 238	42 636	32 062

Note 8

The financial statements were approved by the trustees on 12 October 2012

Signed

Alan Lane
Treasurer

Date 12 October 2012

Notes forming part of the financial statements for the year ended 31 Aug 2012

1. Basis of accounting

The financial statements have been prepared under the historical cost convention and in accordance with the Statement of Recommended Practice for Charities "Accounting and Reporting by Charities" 2005, the Charities Act 1993 and applicable accounting standards.

2. Income

- (a) All income is included in the financial statements without netting off expenditure.
- (b) Donations and fundraising income are treated as General Fund unless they are specifically designated by the donor for the Research Fund.

3. Resources Expended

Resources expended are recognised in the year to which they relate. Irrecoverable VAT is included in the relevant heading.

4. Stock

Stock consists of purchased items which are intended for resale and is stated at the lower of cost and net realisable value

5. Fund

- (a) The General Fund comprises funds that the trustees are free to use in accordance with the charitable objects.
- (b) The Research Fund was opened in 1995 and is specifically intended to provide for financial grants to be given to research projects in the UK concerned with the study of Behçet's Disease.

Analysis of net assets between funds

	Unrestricted Funds £	Restricted Funds £	Total £
Net current assets	<u>33 398</u>	<u>9 238</u>	<u>42 636</u>
Total	<u>33 398</u>	<u>9 238</u>	<u>42 636</u>

6. Annual General Meeting

The AGM for 2010 formed part of the international conference held in the UK that year and did not fall within the 2010-11 accounting period. Therefore the income and expenditure relating to the AGM in October 2011 have no corresponding entries for the previous year.

7. Salary costs

Year ending 31 August	2012 £	2011 £
Wages and salaries	22 100	30 940
National Insurance contributions	<u>2 050</u>	<u>3 294</u>
	<u>24 150</u>	<u>34 234</u>

The charity employed 1 person during the year (2011: 1 person). There are no employees earning above £60,000 (2011: none)

The Director's salary and on-costs are apportioned between the activities that he undertakes for the Society.

No trustee, nor any persons connected with them, have received any remuneration during the year.

Four trustees received expenses for travel and subsistence costs amounting to £225 (2011: £181) during the year.

8. Behçet's Patients Centres Ltd

These items relate, or mainly relate, to expenditure incurred in setting up the new company and to the corresponding income that was due to the Society on 31 August 2012 and that was repaid in full by 30 September 2012.

BEHÇET'S SYNDROME SOCIETY
INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE BEHÇET'S SYNDROME SOCIETY
FOR THE YEAR ENDED 31 AUGUST 2012

I report on the accounts of the Behçet's Syndrome Society for the year ended 31 August 2012, which are set out on pages 18 to 20.

Respective responsibilities of trustees and examiner

The Charity's Trustees are responsible for the preparation of the accounts. The Charity's Trustees consider that an audit is not required for this year (under section 144(2) of the Charities Act 2011 (the 2011 Act), and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 Act, as amended
- to follow the procedures laid down in the General Directions given by the Charity Commissioner under section 145(5)(b) of the 2011 Act ; and
- to state whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with the General Directions given by the Charity Commissioner. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and the seeking of explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and, consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out below:

Independent examiner's statement

In connection with my examination, no matter has come to our attention:

1. which gives me reasonable cause to believe that in any material respect the requirements:
 - to keep accounting records in accordance with section 130 of the 2011 Act; and
 - to prepare accounts which accord with the accounting records and to comply with the accounting requirements of the 2011 Act have not been met; or
2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Caroline Webster FCA
Critchleys LLP

Avalon House
Marcham Road
Abingdon
Oxon
OX14 1UD

Date 2 October 2012

Report of the Trustees for the year ended 31 August 2012

The trustees present their report along with the financial statements of the charity for the year ended 31 August 2012. The financial statements have been prepared in accordance with the accounting policies set out in this report and comply with the charity's trust deed and applicable law.

Constitution and objects

The Behçet's Syndrome Society is constituted under a trust deed dated 11 October 2008 and is a registered charity No.326679.

The object of the charity is to relieve and mitigate the distress of persons suffering from Behçet's Disease by:-

- promoting the study of the cause and treatment of the disease and allied conditions.
- gathering and publishing information useful to sufferers and the general public
- co-operating with the medical, allied professions and other societies with similar aims.
- providing financial assistance to relieve poverty among Behçet's Patients.

Organisation

The trustees who have served during the year and since the year-end are set out on page 23. Trustees are elected at any time during the year and the trustees are presented to the members at the Annual General Meeting.

The trustees act as a management committee and meet quarterly to administer the business of the society. All trustees are unpaid volunteers working on behalf of the Society in their own time.

Trustees' responsibilities in relation to the financial statements

Law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the charity's financial activities during the year and of its financial position at the end of the year. In preparing those financial statements, 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 and statements of recommended practice have been followed subject to any departures disclosed and explained in the financial statements and
- prepare the financial statements on a 'going concern' basis unless it is inappropriate to presume that the charity will continue in business

The trustees are responsible for keeping accounting records which disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements 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. The trustees confirm that they have complied with the duty in s4 Charities Act 2006 to have due regard to guidance published by the Charity Commission.

Approved by the Trustees and signed on their behalf by

Jan Mather, Chair

Kathryn Proudlock , Vice Chair

Staff and Trustees

Director

Chris Phillips

Trustees

Jan Mather (Chair)
Kathryn Proudlock (Vice-Chair)
Alison Pemberton (Hon Secretary)
Alan Lane (Hon Treasurer)
Sarah Graves
John Henson
Fran Horne
Aaron McPeake
Norah Martyn
Kirsty Millard
Amanda Moseley

Stepped down from Trustees

Matt Shea

Website / Newsletter editor

Clare Griffiths

Helpline co-ordinator

John Henson

Helpline volunteers

Alan Booth
Linda Lavis
Niki Weigner
Rachel McHugh

Medical Panel

Dr Colin Barnes
Dr Adnan Al-Araji
Dr Clive Archer
Dr Reuben Ayres
Dr Paul Brogan
Dr Andrew de Burgh-Thomas
Prof Farida Fortune
Prof Dorian Haskard
Dr Desmond Kidd
Prof Sue Lightman
Prof Rob Moots
Prof Phil Murray
Dr Catherine Nelson-Piercy
Dr Jane Setterfield
Dr Graham Wallace

Patron

Lord Evans of Watford

Bank Details

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Independent Examiner

Critchleys LLP,
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OX114 1UD

Registered Office Address

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15 The Daedings
Deddington
BANBURY
OX15 0RT

Administration Office

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Helpline Tel: 0845 130 7329

Email: info@behcetsdisease.org.uk
www.behcets.org.uk

Registered Charity No: 326679