



# **Annual Report 2016**

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## Medical Advisory Panel



**Name:** Robert J Moots (Chair of Advisory Panel)  
**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:** 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:** Clive B Archer  
**Job title:** Cons Dermatologist & Hon Clinical Snr Lecturer  
**Qualifications/ Post Nominals:** BScMD, PhD, MSc Med Ed 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, immunobullous diseases; research interests in immunopharmacology, cell regulatory mechanisms and medical education



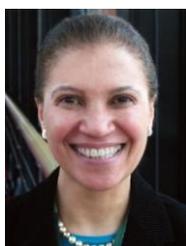
**Name:** Reuben C S Ayres  
**Job title:** Consultant Gastroenterologist  
**Qualifications/Post Nominals:** BM, DM, FRCP  
**Where qualified:** Southampton  
**Year of initial qualification:** 1982  
**Currently practising at:** Royal Devon & Exeter Foundation Trust  
**Special interests:** Colorectal 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:** 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:** Professor 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 practicing at:** School of Immunity and Infection, University of Birmingham  
**Special interests:** Ocular immunology, Behçet's disease, immunogenetics, innate immunity

# Chair's Report

This year has been a very busy one for all our trustees, volunteers and our new administrator. Through their hard work and tireless support the society has continued to take important steps forward and consolidated its success.

## Administrator

The society appointed Julie Collier to the part-time post of Administrator in October 2015. Without any administrative support the society had depended on all our volunteers to continue the work of the society. However, with Julie's appointment much of the day-to-day work has been taken on by her. She has had a positive impact on the running of the society and provides much needed support to the board and our helpline volunteers.

## Annual Conference

This year's Conference and Annual General Meeting took place at Friends' House, 271 Euston Road, London, on 17 October. The morning was taken up with the business of the society and the afternoon was dedicated to medical and scientific presentations on Behçets, its science, symptoms, treatments and its impact on the person. The event was very well attended and 43 people completed the feedback form provided. An impressive 95% of the completed forms indicated that the conference content was relevant and informative. There were a number of suggestions for items to be included in future conferences and they will be given careful consideration when organising future events.

## The Medical Advisory Panel

A major benefit of joining the BSS is the access members have to the Behçet's disease experts who make up our Medical Advisory Panel. This year the Panel has provided information on the effects of medication and breastfeeding, myeloma and Behçet's disease, inoculations, menopause, diet and many more. One of the excellent responses has appeared as an article in a recent newsletter. The replies to the questions put to the Panel are always prompt and comprehensive and take into account the severity and complexity of this chronic condition. Thus, on behalf of all our members, I thank Professor Moots and all the experts who make up the panel.

## Family Day

Our Family Day at Whitemoor Lakes was held On Saturday 12 March. The day was a resounding success. Thirty-eight people were able to make it including several families and both young people and adults with Behçet's disease.

In the morning they were split into two groups: One group were equipped with buoyancy aids and safety hats and whisked off to the lake for a canoeing session; the other group went climbing and abseiling.

Lunch provided a much earned break for all with an opportunity to carry on chatting and getting to know new people. After lunch there was group archery, with the final activity being a team game involving volunteers and lots of toilet paper; the result was lots of marvellous mummies!

A great Family Day out was had by all and we are looking to hold a similar event next year.

## BSS Helpline

This year we changed our Helpline number to 0345 130 7329 to reduce the cost of calls for those seeking support and advice.

The Helpline is available 9am to 6pm Monday to Friday, and 10am to 4pm Saturday and Sunday. Currently it is manned by three dedicated members but we are always looking to recruit new volunteers.

## Newsletter

There have been 4 issues of our newsletter this year which have provided information about Behçets and highlighted the energy, ingenuity and commitment of our volunteers, members and fund raisers throughout the country.

## Factsheet review

This year we commenced a review of all our factsheets which provide some of the best and most definitive of aspects of the condition, their treatment and possible side-effects. Once the review is completed the factsheets will appear on our website and be sent for printing to be included in future information packs.

## **Northern Ireland Mapping Project**

Following the meeting held at the Wellington Park Hotel, Belfast, in May 2014 to assess if people with Behçet's disease in Northern Ireland would be interested in forming a support group, a very successful group was established. In 2015, the Behçet's Syndrome Society UK agreed to fund a mapping project to get a clearer idea of how many people were living with the condition in the region. Subsequently questionnaires were sent to all 360 medical practices in the area. It sought to gather information about the number of cases as well as the age and gender profile. It was hoped that this information might help to justify improved services for people in Northern Ireland with the condition who are often on very toxic drugs.

In January 2016, 125 practices responded which found that there were 79 people with Behçet's disease in the practices. Based on this information, it is estimated that there are approximately 227 people in NI living with Behçet's disease. To find such a high figure was very surprising; it means that there is a higher incidence than the rest of the UK and other countries in Europe.

It revealed that some areas had more people with Behçet's disease than others. For example, 30 people were identified as having the condition in County Antrim, 21 in County Down, eight in County Derry/Londonderry, nine in County Tyrone and only one case in County Fermanagh.

The majority of cases were in the 19–40 age range and there were almost twice as many females as males identified with the condition.

This information has prompted great interest in looking at why the occurrences are so high in Northern Ireland. It would be helpful for service planning to look in more detail at how people are affected by the condition: e.g. how many people have vision problems, mobility problems or neurological problems?

It is hoped to do further research to look at the genetic markers of people diagnosed with Behçet's disease and their close relatives but before further research is undertaken it is important to raise awareness of Behçet's disease with GPs and dentists. It is also hoped to encourage people with Behçets to come forward to have their blood taken. To this end the next step in the process is to

hold a conference in Belfast on the 8th of October in the Wellington Park Hotel. Professor Moots from Liverpool, Dr Wallace from Birmingham and Dr Landy from Craigavon are among the speakers who will attend.

## **Rare Disease Day 2016 – Scotland**

The BSS continues to cooperate with other bodies interested in rare conditions and one of our trustees attended the Rare Disease UK reception to mark Rare Disease Day 2016 at the Scottish Parliament on 1st March. Alastair Kent CBE, Chairman of Genetic Alliance UK, talked about progress made since Scotland's rare disease plan ("It's not rare to have a rare disease – the Implementation Plan for Rare Diseases in Scotland") was published in July 2014. Although he said that there was still a lot to be done, he welcomed the commitment to change and the speed at which some of the changes are happening. The Scottish Medicines Consortium (SMC) has been able to improve access to some expensive medicines and therapies by approving the use of money from the New Medicines Fund. Patient and Clinical Engagement Committees, part of the SMC, have brought together clinicians, academics, patients with rare diseases and their carers when decisions are being made about whether new or expensive medicines can be authorised. It is not yet clear what part these responses play in decisions, but the willingness to involve patients is an important step forward.

Alastair Kent summed up by saying that new developments in medical research and technology, the greater involvement of the pharmaceutical industry and the resources being spent on rare diseases are all reasons for optimism.

Jamie Hepburn MSP, Minister for Sport, Health Improvement and Mental Health, said that the government had to learn from the experiences of patients and use them to improve the services offered. He then gave details of a further £6 million investment in the Scottish Genomes Partnership. Patients in the NHS in Scotland will now be able to benefit from advances in technology in human genome sequencing.

Professor Zosia Miedzybrodoka (Medical Genetics, University of Aberdeen) explained that this represented a significant step in a possible diagnosis for rare diseases. Some

Scottish families with rare inherited diseases would soon be offered the chance to be involved in the 100,000 Genomes Project in England. Sharing data from Scottish patients means that Scotland will now be a partner in a very large project that will help to improve the accuracy of information and provide opportunities for further research. It may, ultimately, also allow a much better understanding of the genetic causes of illnesses and lead to improvements in diagnosis and treatment, which could be more specific for each patient, directly helping patients and their families.

This was the busiest Rare Disease Scotland Day to date, with a real mix of patients, clinicians, pharmaceutical companies and MSPs. Rare diseases are clearly an area of increasing interest and it is important that BSS is represented in such developments.

#### **Recruitment of new volunteers**

This year we recruited Tony Wright to the Board of Trustees. He has been a helpline volunteer for some months and runs the London Support Group.

**Alan Booth**

**October 2016**

# Fundraising Activities

The Society relies heavily on the generous donations our members make and fundraising constitutes a large part of these. People are always finding new ways to raise money and this year has been no exception.

'Get Set Behcet's!' was devised by Laura Forrest and Rachael Humphreys. The aim was to spread the word Behcet's by challenging people to film their best tennis serve or hit a ball at a target. Over £1500 was raised.



Alan and Rachael Sime tied the knot in August and asked for donations instead of gifts. They raised £1780 which was split between the Society and EDS UK.

Joanne Sullivan cycled from London to Brighton and raised £425.



Richard Evans was made captain of Langland Bay Golf Club and nominated the Society as his charity for the year. A pantomime in December 2015 raised over £600.

Holistic therapist Bernie Douetil generously named the Society as her charity when she hosted a Christmas shopping event in November 2015. This raised £340.



Jan Mather and her Mum produced beautiful packs of Christmas cards which were a sell-out! They raised £1131 !

Gemma Partridge braved the freezing North Sea on Boxing day to take part in the annual Boxing day dip. She raised over £116 for the Society.



Heulwen Earl sold her own books to a second hand book store and

raised over £350. Nicole Devling raised over £400 when she undertook a sky dive.



Lottie Harris and her cousin Amy took part in the Gung-Ho race and raised £430.



David Scott took part in the London to Cambridge challenge which was to walk 100 km in a day. He raised over £400.



Deborah Gravestock has raised large sums of money in the past for the Society and recently received a cheque from her local church whose members made donations at their Lent supper.

Maddie Hyder, the 13-year-old daughter of the Birmingham Support Co-ordinator Rebecca, has been baking each week to raise money.



Malcolm Matthews continues to collect stamps from members and sell them. He has made frequent donations to the Society.



Andrea Hasketh held an event 'Breath for Behcet's' and she raised £87.

Andrew Minty took part in the JCP Swansea Marathon in June in support of the Langland Bay Golf Club fundraising campaign and raised £240.



Catherine Main jumped out of an aeroplane and raised over £250.



Ciara Kean raised £301 in sponsorship for her Hike in the Hollywood Hill challenge!

Drew Baker raised £140 in lieu of presents Christmas 2015.

Richard Evans of Langland Bay Golf Club organised a Captain's Charity Bike Ride and has raised £1445 to date.



In January 2016 **Lee Kearns, Fiona Bell and Emily McGovern** took on the crazy, chaotic roads of India to travel its (almost) full length - 3500 km - in a glorified lawnmower, in a whacky races style challenge. Yes, you did read that correctly. There wasn't a route, no mechanical support and basically no rules...just get to the finish line, somehow! The team knows as the Scottie Hotties raised £3200 in sponsorship with Gift Aid added. Truly amazing challenge! At the finish line they said "This is absolutely the best thing we've ever done."



At the finish line they said "This is absolutely the best thing we've ever done."



Anthony Martin went cycling and raised over £50 for the Society.

Mel Newland and her fantastic team took part in the South West Tough Mudder in August and £450 with gift aid.

Melvyn Berman had a special birthday and chose donations for the Society in Lieu of gifts and has raised over £600.



Joanne, Judi and Julie walked the 'Bridges for Behcet's' and raised £740.

Last, but by no means least, Dr Graham Wallace celebrated his 60<sup>th</sup> birthday in style! He held a Ceilidh for family and friends and raised £990 for the Society.

Our members and supporters continued to buy our Society merchandise, which helped us to raise funds and much needed awareness! We offered for sale, pens, wrist bands, t-shirts, bags, key rings and badges were also added to our virtual shop.



We also started to offer wedding favours, which included a donation card for guests, a badge, key ring or wrist band presented in an organza bag.

Many supporters have raised funds for the Society by looking after one of our collection tins and sending in the money when they are full. Each of the Behcet's Patient Centres has displayed one in their clinics.



**The Trustees would like to thank everyone who has raised money for the Society. Without these amazing efforts we could not continue to function.**

**Judi Scott**  
**Hon. Secretary**

# Report on Financial Statement 2015/16

## Secure position for further development

I am pleased to report that the Society's finances are currently stronger than they have been for at least ten years. As a result the Trustees are now in a position to consider a further expansion of the Society's work.

Although there were no large-scale fund-raising activities during the year, there have been many smaller activities bringing a steady income through Just Giving and other web sites. We are very grateful to all those whose efforts have made this possible. The Society also received one particularly generous donation of £5k during the year towards our Research Fund.

Five years ago, after a lot of hard work by the Trustees we were able to set up our related company, Behçet's Patients Centres (BPC), which shares the cost of producing newsletters and maintaining our web site. Last year we were able to make a large grant to support a research project at the University of Liverpool into the incidence of Behçet's among young people. Trustees are now looking into the possibility of supporting other activities or research in 2016/17.

The Society has not increased the level of its annual subscription for five years and, in view of its strong financial position, Trustees do not propose an increase this year. However there continues to be a gradual reduction in subscription income owing to the steadily increasing proportion of members who are exempt as they are in receipt of UK state benefits.

After ten months with no paid staff, we were delighted to welcome our new Administrator, Julie Collier, last October, who has already been responsible for a number of new initiatives as well as co-ordinating our administration and providing support to our members. Consequently, the staff cost elements of our accounts are greater than those of the previous year.

**The General Fund** received income of £45.7k, including £10.8k of subscriptions, £18.5k of donations, activities and sales of £9.1k and other income of £3.6k. The expenditure from this fund was £39.2k. There

was a surplus of £6.5k, giving accumulated reserves of £81.4k.

**The Research Fund** had a total income of £5.8k and no grants were made this year, as a result of which the accumulated reserve on this fund now stands at £12.4k.

## Membership

The Society's membership has also continued to grow. On 1 September 2016, we had 945 full members, compared with 848 on the corresponding date last year. In addition there were 8 junior members and 50 associate members (most of whom are medical professionals).

The total number of names on our database was 1050 on that date, compared with 1001 the previous year, of whom 855 are Behçet's patients. However these figures include a few members whose subscriptions were more than a year in arrears, from whom we hope to receive subscriptions very soon to avoid having to remove their names from our mailing list at our forthcoming annual review.

The number of members in receipt of UK state benefits, including retirement pensions was 617, compared with 558 the previous year. These are entitled to free membership but many make donations when they can, for which we are very grateful.

Subscriptions may be paid by direct debit, by one-off card through the web site or cheque payment through our office.

Around 300 members make a substantial addition to the Society's finances by Gift Aiding their subscriptions and we would very much encourage all those who pay UK Income Tax or Capital Gains Tax to consider doing so, by means of the declaration on the annual membership renewal form.

## Summary

Both the Society's financial and membership figures are in very good shape and Trustees are optimistic that the Society will continue to go from strength to strength.

**Alan Lane, Hon. Treasurer**

**October 2016**

## Statement of Financial Activities and Balance Sheet for the year ended 31 August 2016

	General Fund	Research Fund	Total 2016	Total 2015	
	£	£	£	£	
<b>Income and endowments</b>					
Donations	18 511	5 785	24 296	33 080	
Subscriptions	10 839		10 839	11 477	
Gift Aid tax reclaimed	3 569	30	3 599	3 532	
Fundraising activities	7 315		7 315	12 168	
Sales of goods	1 628		1 628	688	
Charitable activities income	199		199	299	
Investments	134	64	198	188	
Other	3 542		3 542	3 131	Note 6
<b>Total income and endowments</b>	<b>45 737</b>	<b>5 879</b>	<b>51 616</b>	<b>64 563</b>	
<b>Expenditure on charitable activities</b>					
Fundraising / trading costs	6 205		6 205	14 354	Note 8
Staff recruitment	151		151	0	
Grants to individuals	3 004		3 004	862	
Research grants	0		0	15 000	Note 5
Subscriptions to other organizations	390		390	226	
Helpline costs	285		285	55	
Charitable support staff costs	2 150		2 150	1 022	Note 8
Employment rebate	-1 545		-1 545	0	
Travel and subsistence	1 558		1 558	5 962	
Insurance	240		240	465	
Administrative staff costs	2 162		2 162	2 044	Note 8
Telephone charges	458		458	698	
Printing, postage, stationery and materials	1 343		1 343	2 014	
Equipment purchases	956		956	0	
Newsletter	7 734		7 734	7 671	
Web site and publicity	3 965		3 965	1 062	
Public relations staff costs	2 149		2 149	1 022	Note 8
AGM expenditure	6 109		6 109	3 372	
Governance costs	1 727		1 727	2 303	
Other	190		190	141	
<b>Total resources expended</b>	<b>39 231</b>	<b>0</b>	<b>39 231</b>	<b>58 273</b>	
<b>NET INCOME</b>					
	<b>6 506</b>	<b>5 879</b>	<b>12 385</b>	<b>6 290</b>	
Transfers between funds	0	0	0	0	
<b>Net movements in Funds after transfers</b>					
	<b>6 506</b>	<b>5 879</b>	<b>12 385</b>	<b>6 290</b>	
<b>RECONCILIATION OF FUNDS</b>					
Fund balances at 1 Sep 2015	74 916	6 546	81 462	75 172	
<b>Fund balance at 31 Aug 2016</b>	<b>81 422</b>	<b>12 425</b>	<b>93 847</b>	<b>81 462</b>	

<b>Balance Sheet as at 31 Aug 2016</b>	<b>General Fund</b>	<b>Research Fund</b>	<b>Total 2016</b>	<b>Total 2015</b>	
	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>	
<b>Current Assets</b>					
Stock in hand	1 307		1 307	1 332	<i>Note 9</i>
Prepayments	1 970		1 970	1 360	<i>Note 10</i>
Accrued income	427		427	340	<i>Note 11</i>
Recoverable Gift Aid	1 295	373	1 669	1 440	
Deposit Accounts	79 949	12 052	92 001	68 802	
Current Accounts	5 756		5 756	9 428	
Petty Cash	250		250	0	<i>Note 12</i>
<b>Total current assets</b>	<b>90 954</b>	<b>12 425</b>	<b>103 379</b>	<b>82 702</b>	
<b>Current Liabilities</b>					
Creditors	0		0	0	
Advance subscriptions	620		620	700	
Deferred income	8 360		8 360	0	<i>Note 13</i>
Accrued expenses	552		552	540	<i>Note 14</i>
<b>Total current liabilities</b>	<b>9 532</b>	<b>0</b>	<b>9 532</b>	<b>1 240</b>	
<b>Total net assets</b>	<b>81 422</b>	<b>12 425</b>	<b>93 847</b>	<b>81 462</b>	
<b>TOTAL FUNDS</b>	<b>81 422</b>	<b>12 425</b>	<b>93 847</b>	<b>81 462</b>	

**The financial statements were approved by the trustees on 11 October 2016**

Signed

Alan Lane  
Hon. Treasurer

Date: 11 October 2016

## Notes forming part of the financial statements for the year ended 31 Aug 2016

### 1. Basis of accounting

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Entities published on 16/07/14 and the Financial Reporting Standard for Smaller Entities (effective January 2015). Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

### 2. Income

All income is included in the financial statements without netting off expenditure.

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. Funds

The General Fund comprises funds that the trustees are free to use in accordance with the charitable objects.

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	81 422	12 425	93 847
Total	<u>81 422</u>	<u>12 425</u>	<u>93 847</u>

### 5. Research Fund

The Society has received a number of donations during the year to augment the Research Fund but has not made any grants from this fund during the year.

### 6. Other income

These items relate, or mainly relate, to contributions from Behçet's Patients Centres, the charitable company set up to support patients attending the three Centres of Excellence with funding from NHS England.

### 7. Salary costs

Year ending 31 August	2016 £	2015 £
Wages and salaries	10 423	5 710
National Insurance contributions	420	427
Employer's pension contributions	<u>51</u>	<u>0</u>
	10 894	6 137

The charity employed 1 person for part of the year (2015 1 person).

There are no employees earning above £60 000 (2015 none).

None of the trustees, nor any persons connected with them, has received any remuneration during the year. Six trustees received expenses for travel and subsistence costs amounting to £739 (2015: £4 154) during the year.

### 8. Director's Salary

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

### 9. Stock

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

### 10. Prepayments

Payments have been made in advance in connection with the Society's Annual General Meeting in Birmingham in London on 15 October 2016.

### 11. Accrued income

Sums due but not received by 31 August 2016 from Just Giving and HMRC.

### 12. Petty Cash

Expenses float held by Administrator.

### 13. Deferred Income

Advance subscriptions for 2016/17 received before 1 September 2016.

### 14. Accrued expenses

Provision for fees for independent examination of accounts.

**BEHÇET'S SYNDROME SOCIETY**  
**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE BEHÇET'S SYNDROME SOCIETY**  
**FOR THE YEAR ENDED 31 AUGUST 2016**

I report on the accounts of the Behçet's Syndrome Society for the year ended 31 August 2016, which are set out on pages 13 to 15.

**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**  
**Greyfriars Court**  
**OXFORD**  
**OX1 1BE**

**Date: 31 October 2016**

## Report of the Trustees for the year ended 31 August 2016

The trustees present their report along with the financial statements of the charity for the year ended 31 August 2016. 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 19. 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 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.

### Reserves

The trustees aim to maintain reserves at a level that lies approximately between the total income that the Society would expect in a six month period and that in a full financial year: currently the reserves are slightly higher than that so the Board will be looking into additional projects and services that can be undertaken for members in the year ahead.

### Risks and public benefits

The trustees do not consider that the Society faces any significant risks in the near future, but they are mindful that the level of subscriptions and donations has tended to drop recently as more members have become eligible for free membership from being in receipt of UK state benefits and will continue to monitor the situation closely.

The Trustees confirm that they have complied with the duty in section 17(5) of the Charities Act 2011 to have due regard to the guidance published by the Charity Commission.

**Approved by the Trustees and signed on their behalf by**

**Alan Booth, Chair**

**Gillian Millane, Vice-Chair**

**11 October 2016**

# Staff and Trustees

## Trustees

Alan Booth (Chair)  
Gillian Millane (Vice-Chair)  
Judi Scott (Hon Secretary)  
Alan Lane (Hon Treasurer)  
Rachael Humphreys  
Fionnuala McKinley  
Hazel McLachlan  
Tony Wright

## Administrator

Julie Collier

## Website / Newsletter editor

Clare Griffiths

## Helpline co-ordinator

vacancy

## Helpline volunteers

Alan Booth  
Fionnuala McKinley  
Tony Wright

## Medical Advisory Panel

Prof Rob Moots  
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 Phil Murray  
Dr Catherine Nelson-Piercy  
Dr Jane Setterfield  
Dr Graham Wallace

## Banks

CAF Bank Limited  
25 Kings Hill Avenue  
Kings Hill  
WEST MALLING  
ME19 4JQ

Barclays Bank plc  
1250 High Road, Whetstone  
London N20 0PB

## Independent Examiner of Accounts

Critchleys LLP  
Greyfriars Court  
OXFORD  
OX1 1BE

## Administration Office

Behçet's Syndrome Society  
Kemp House  
152-160 City Road  
LONDON  
EC1V 2NX

Office Tel: 0345 130 7328

Helpline Tel: 0345 130 7329

Email: [info@behcetsdisease.org.uk](mailto:info@behcetsdisease.org.uk)

Web: [www.behcets.org.uk](http://www.behcets.org.uk)

**Registered Charity No: 326679**