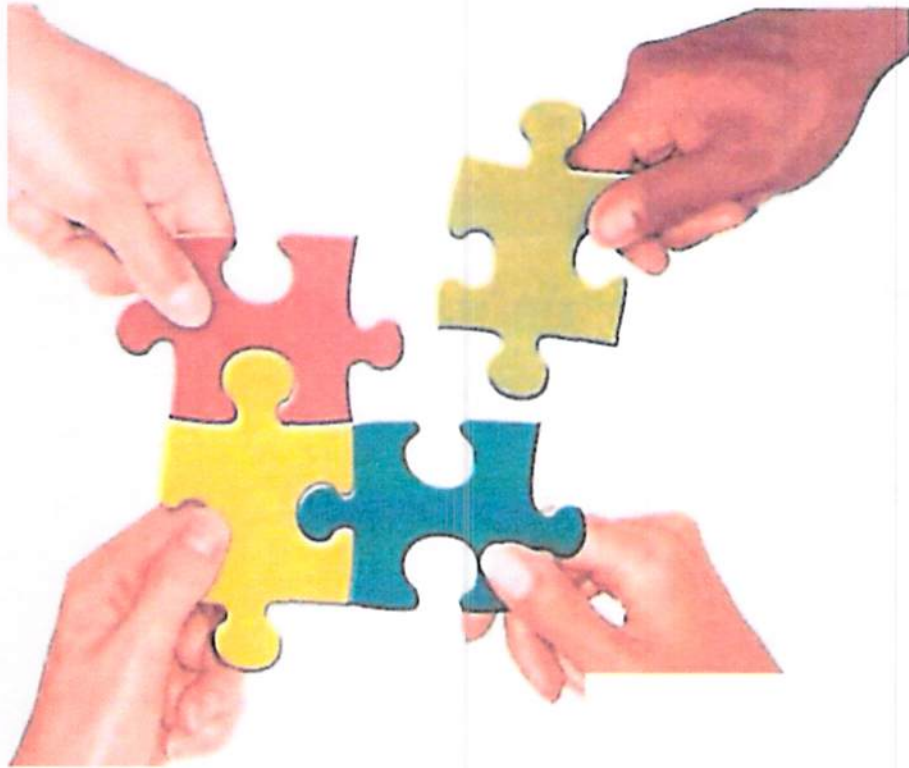




**Behçet's Syndrome Society**



# **Annual Report 2018**

Registered Charity No: 326679

## Contents

	Page
Medical Advisory Panel	3
Chair's Report	7
Fundraising Activities	11
Report of the Trustees	13
Staff and Trustees	15
Report on Financial Statement	16
Statement of Financial Activities	17
Balance Sheet	18
Notes to the Accounts	19
Independent Examiner's Report	20

## 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 (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



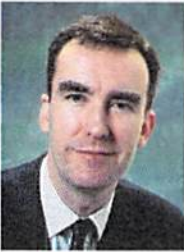
**Name:** Dr Andrew de Burgh-Thomas  
**Job title:** Consultant in Genitourinary Medicine  
**Qualifications/Post Nominals:** BSc, MBBS, MRCP, Dip GUM, Dip HIV  
**Where qualified:** University of London  
**Year of initial qualification:** 1994  
**Currently practising at:** Gloucester Royal Hospital, 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

## Overview

Stability of the Board has been an excellent platform on which to build for the future. We seek to encourage additional trustees to offer added depth in numbers and experience. I can report a highly successful year allowing the Society to grow from strength to strength and further support its members. Whilst we have not fully developed the Helpline into a fully robust and enduring conduit we are working towards this. The Annual General Meeting and Conference in Manchester was a success with excellent Medical Presentations. A worthwhile Families Day in Exeter took place, though lower than hoped numbers attended. A number of generous individuals have boosted our funds, and a couple of legacies feature on the horizon, notwithstanding the marvellous fundraising initiatives which continue to be apparent, which will all assist the Board in expanding our remit to support patients. The Society has become Affiliate members of the Rare Autoimmune Rheumatic Diseases Alliance (RAIRDA), which is a forum established to bring together clinical and patient organisations, and other key stakeholders, in order to improve care for people living with rare autoimmune rheumatic diseases. After 35 years the Society is to change its name to Behçet's UK, with accompanying rebranding of our logo.

## Governance

We have had a stable Board for the last year, which has been most beneficial. The trustees do an amazing job, voluntarily, and they are now addressing policy initiatives to refine our already proper management. The Treasurer has now taken steps to ensure he might not become a 'single point of failure' and our overall philosophy is to engineer our processes and procedures, including succession planning, in an orderly manner that are fit for purpose and longevity. A more systemic approach to the whole Society is becoming evident, to build on all the previous hard work of many individuals. We aim to build a structure with a President and Patrons, together with an Advisory Panel for our Research Strategy - to help judge bids professionally - and possibly a Financial Advisory Board, particularly if some potential legacies come to fruition. A Fund-Raising

Strategy will be produced and we have signed up to the Government-sponsored Fundraising Regulator.

## Annual Conference

The Annual General Meeting and Conference took place at the Manchester Conference Centre on 14 October 2017 and was attended by more than 70 people, a similar figure to 2016. Over 100 had actually signed up to attend, but quite a number of members pulled out on the day, which is sometimes unavoidable because of the unpredictability of Behçet's and flares. The AGM was more formally presented, and this year witnessed the instigation of the Judith Buckle Award. Heidi Goodway, daughter of Behçet's Syndrome Society (BSS) founder Judith Buckle, was presented with a crystal plaque and a bouquet of flowers as the first recipient. The medical presentations, sponsored this year by the Liverpool National Behçet's Syndrome Centre of Excellence first saw a brief given by the then new trustee Mark Friston, a patient at the Liverpool Centre, speaking about his journey with Behçet's disease (BD). John Mather, the Behçet's Patient Centre Operations Manager, reminded everyone that the BPC was a charitable company limited by guarantee contracted by the NHS to work with both the Centres of Excellence and closely with the BSS. He offered an update of a highly successful year. Professor Rob Moots, Clinical Lead at the Liverpool Centre, focused on the budget that the Centres of Excellence have been allocated for the use of high-cost biologic drugs, which ideally need biomarkers to determine which drug a particular patient is more likely to respond to well. The BioBehçet's clinical trial is a head-to-head study of interferon and infliximab in BD to help inform an optimal way forward. Dr Graham Wallace of the University of Birmingham briefed on Microbiomes and BD. Dr Róisín Cunningham, Clinical psychologist at the Liverpool Centre, briefed on Psychology in BD, and highlighted there is one clinical psychologist at each of the three centres. The day finished with a question and answer session with the medical speakers including Professor Farida Fortune.

## **The 18<sup>th</sup> International Conference on Behçet's Disease 2018**

I attended this event on behalf of the Society, and indeed have been accepted as an Associate Member. This important biennial event took place in Rotterdam, Holland between 13-15 September 2018. Most regrettably, the accompanying Patients Conference was cancelled at short notice, owing to a withdrawal of sufficient sponsorship. In consequence the Society incurred some nugatory costs having awarded a number of bursaries for our patient members to attend, as we have done historically; since Professor Shigeaki Ohno and Mr N. Nishida, a patient from Japan living with the disease, worked together to set up the first International Patient Conference in 2000. The Vice-Chair, Richard West, raised a formal note of concern which was taken at the International Society for Behçet's Disease (ISBD) Council Meeting, from which there are early indications that plans will be developed to involve Behçet's Patient organisations more directly in the planning of this important aspect in future. How it will be funded will remain an issue. Two themes were highlighted by the ISBD President, Professor Dorian Haskard, in his concluding remarks. First that research into Behçet's is going to benefit from being based on a molecular footing [the whole accelerating Genome initiative] and improvement in patient care is being witnessed by the use of biologic treatment. Moreover, 'big data' is going to assist with research in combatting Behçet's.

### **The Behçet's Forum Meeting**

The Behçet's Forum did not meet during the 2017 Conference, again regrettably, but members of our Medical Advisory Panel are reviewing how this important initiative can be re-vitalised. Clinicians and researchers in the UK are, basically, overstretched so the timing and location of where it meets needs careful consideration; and some Terms of Reference need to be developed.

### **2018 Heberden Round – British Rheumatology Society**

The British Society for Rheumatology (BSR) was formed in 1997, and the Heberden Round remains a fundamental pillar of the society's protocols. This year, Professor Robert Moots, who chairs our Medical Advisory Panel, was honoured by being invited to present the 2018 Heberden Round – in which he charted the

course of his experience with Behçet's disease using five case studies. The presentation was hugely poignant, which will have undoubtedly touched a nerve, both with his contemporaries and colleagues and with those starting out in their early careers in rheumatology, regarding the humane 'gold standard' that he has set. It has also given incredible visibility to our cause, which will undoubtedly 'ripple' throughout the rheumatology profession in the UK. At the end of his talk, Professor Rob listed and thanked a myriad of individuals who have helped him in his amazing medical and personal journey, including the Behçet's Syndrome Society and of course his fellow Centres of Excellence Heads, Professor Farida Fortune CBE and Dr Deva Situnayake.

### **Behçet's Families Day – Exeter**

A highly successful Family Day, was held at Haven Banks Outdoor Education Centre Exeter. Numbers were less than had been hoped, but the date had to be changed, partly due to the slight turmoil created by a change in Administrators, which undoubtedly affected matters. Gemma Darlow is congratulated on 'bringing it all together' which made for such a successful event.

### **Newsletter**

Clare Griffith maintains her pivotal role and provides an outstanding service for this essential function; issued quarterly. It remains fundamental to gathering and publishing information useful to those suffering with BD. Clare recently attended the International Conference for Behçet's Disease 2018 to write-up proceedings.

### **BSS Medical Factsheets**

We have nearly achieved the aim of routinely updating our Behçet's Medical Factsheets annually. As noted last year, this is vital to ensure they remain current, but also important, in perceptual terms, to ensure confidence in the information the Society provides is seen as current and up to date. Version numbers are being introduced to ensure version control. We have identified an issue that sometimes individuals both in Primary and Secondary care take scant notice of these well-informed, authoritative, information sheets, so the Board intends to seek advice from NHS England as to how we could add an NHS logo on them so that 'everyone is obliged to take notice of them'.



Behçet's is a rare disease, and most clinicians may only see one patient across their working life.

### **Local Support Groups**

An additional Local Support Group was initiated in Plymouth this year, and we are taking initiatives to encourage additional and complementary facilities to support patients.

### **Fundraising and Membership**

As noted last year, members, family and friends continue to surprise us with exciting and innovative ways to support the Society. Amazing fund-raising activities have accumulated in the region of £11.6k to boost our funds this year. A fuller report follows, but we again thank everyone for such a brilliant effort. A most generous individual, Mrs Virginia Yee, has pledged a considerable sum to support our Research Strategy, for which we are most grateful, and this will allow us to pursue this initiative in earnest. Membership remains buoyant, with 1186 names on our database, and I would urge members to encourage further additions to our 'community' in future years.

### **Administrator and Administrative Assistant**

Julie Collier continued to provide excellent service, but handed her notice in when family commitments had to take priority. However she kindly volunteered to continue to help manage the Helpline. A new Administrator and Assistant Administrator have been appointed; Gemma Darlow and Deborah Cardinal. We are fortunate to have secured two excellent individuals: this now gives us some staff time on every working day of the week and thus progress initiatives, rather than just 'padding to keep up'; the invidious situation Julie Collier found herself in. As stated in my 2017 report, the benefit to the society of these posts remains both evident and fundamental; without which administrative support for the society would be solely dependent on volunteers afflicted with Behçet's.

### **BSS Helpline**

Our Helpline continues to be a most important, but intractable issue. Ideally, and indeed historically, it would be manned by patients, who thus have empathy with those that are seeking help. However this is an additional strain on what they have already been going

through with Behçet's. How we overcome this we are not sure but we will continue to try to provide an optimal service. We are fortunate that, even though she was unable to continue her role as Administrator, Julie Collier volunteered to continue with managing the Helpline function, for which we are most grateful. The Board continues to look at this requirement carefully.

### **Rare Autoimmune Rheumatic Diseases Alliance (RAIRDA)**

A significant initiative has now come to fruition; BSS becoming Affiliate members of RAIRDA, which is a forum established to bring together clinical and patient organisations, and other key stakeholders, in order to improve care for people living with rare autoimmune rheumatic diseases.

The alliance Members are: British Society of Rheumatology, LUPAS UK, SCLERODERMA & RAYNAUD'S UK, VASCULITIS UK, British Sjögren's Syndrome Association (BSSA). We will remain Affiliate member for a period of one year after which we can decide whether to become full members.

RAIRDA has three aims:

1. To raise the profile of the needs of people living with rare autoimmune diseases and their access to timely effective treatment.
2. To promote the implementation of best practice care and pathways.
3. To increase knowledge about patient care through better data.

These chime closely with those that the BSS has striven to achieve since its formation in 1983.

This is great news, as we move forward, to raise comprehensive awareness of Behçet's amongst all clinicians within NHS primary, secondary and tertiary care. One of the first outputs will be to produce a NICE-accredited guideline, sponsored by the British Society of Rheumatology and British Association of Dermatologists, to encourage better awareness and more consistent approaches to treatment of Behçet's.

### **Communications Strategy**

It has been my aim to prepare a Communications Strategy, and whilst I have still to articulate this yet, initiatives are being put in place to address our endeavours in a systemic manner.

## **The Society – change in name**

After a full year of stability within the Board, several initiatives are being progressed to lead the Society into the next stage of its development, to better support its members in accordance with its Constitution. A prime goal of the Society for some time now has been to reduce time to diagnosis for patients, which can still take up to 10 years. Within the medical profession, both in the UK and internationally, there is no consensus amongst clinicians as to whether to describe Behçet's as a syndrome, a disease or both. In 2010 at the London International Conference (UK hosted), an abstract was presented of a Medline search for all literature up until that point, noting that over 80% of the publications used the term Behçet's Disease in their title rather than the term syndrome. Behçet's Disease is the term used by NHS Choices, and the International Society for Behçet's Disease has clearly stated the name as Behçet's Disease for decades now and has requested unification of the term for a long time. In short, the term Syndrome in the Society's name does not add clarity to the debate (though it can legitimately be used by clinicians). This makes it difficult for the Society to offer a clear message to raise awareness to the wider public (and indeed GPs) and ultimately potentially affects fundraising.

More consistency across our Behçet's Medical Factsheets has been implemented, the policy being to refer in a consistent manner to both syndrome and disease at the outset (for those few clinicians who want to use/mention syndrome) and then just use Behçet's thereafter. This has found favour with UK clinicians. Moreover, inequity remains in the referral process for patients and Society members residing in Scotland, Wales and Northern Ireland, in that they do not benefit from having a national Centre of Excellence.

Renaming the Society 'Behçet's UK' sends a clear message that the Society exists for the benefit of all members in the UK – the very intention when the Society was formed by Judith Buckle in 1983. Behçet's UK is a more 'snappy' title, which cannot be abbreviated, again providing more harmony/consistency.

Thus, in accordance with the Constitution of the Behçet's Syndrome Society, dated 11 October 2008, after research and consultation amongst the Trustees, it has been agreed to

change the name of the Society to Behçet's UK. The Constitution will be revised to this effect.

In parallel, it is the intention of the trustees to consult members at the AGM about refreshing the logo design. As some patient members have suggested, and the trustees are keen to promote, a more friendly, supportive and welcoming image of the Society is needed in its publications and literature and on the website. This chimes with how most other charities nowadays promote and present their cause/business. Behçet's UK needs to model best practice.

## **Conclusion**

I must end by thanking everyone who makes this Society the great institution that it is; with the aim of supporting our Patient Members. This starts with your trustees, the admin staff, Helpline, Local Support Group leads, and Clare Griffith. It includes carers and supportive family members, all the staff at the National Centres of Excellence led by the Clinical Leads, Professor Rob Moots, Dr Deva Situnayake and Professor Farida Fortune CBE, supported by Jan Mather's team in Behçet's Patient Support.

I will also flag up the fact that a number of researchers and research students, who our clinical leads employ or encourage, are earnestly seeking to help us for which we are most grateful. I have made it my business to meet these individuals and it may not be readily apparent to members that there is a lot going on in the background to crack the Behçet's problem. Finally, and most importantly, the Patient Members, who valiantly 'soldier-on' whilst afflicted by this nasty thing termed Behçet's. Whilst you all 'soldier-on', so will the rest of us; to support you to the best of our abilities.

**Tony Thornburn OBE**

**October 2018**

## Fundraising Activities

The Society depends upon the fantastic endeavours of those members, their friends, families and other supporters who continue to undertake new and exciting forms of fundraising.

Whether it's running a marathon, holding a cake stall, selling second-hand books, taking a dip in the North Sea (on Boxing Day!), taking a skydive from a plane, completing a Tough Mudder challenge, to name just a few, their fundraising efforts are the lifeblood of the Society.

This year has been no exception.



Naomi Hogan and her mother raised over £580 when they made a tandem skydive from 12 000 feet.



Andrea Vigor began making and selling cards to friends and family and at local church fêtes in aid of the Society. She raised £210 last year.

Every year Newton village in Mid- Glamorgan holds a music festival, and in 2017 John Williams persuaded the organisers to include the Society as one of their three charities. Not only did the event provide funds, it also raised the profile of the Society.



Gemma Partridge took the very chilly plunge again when she swam in the North Sea on Boxing Day. She raised over £260 for the Society.

Paul Weston hopes to raise £10 000 for the Society by the end of 2018. He has already reached the wonderful amount of over £6000 towards this target by holding musical events and setting up a JustGiving page.

Jenni Cupples ran the Belfast Marathon and raised over £500.

Chris Sundborg organised a football match in memory of his cousin Lee Pearcey and raised over £2000.

Andi Hesketh's daughter Robyn and niece Kim completed a Tough Mudder challenge and have raised over £700.

Hannah Grivell is holding a 'Great British Bake Along' raising funds in memory of her sister Ruth. Hopefully there will be a lot of cakes baked to reach her target of £500!

Malcom Matthews continues to collect and sell postage stamps to raise funds.

Jan Mather and her mother produced and sold their beautiful Christmas cards and raised over £1000. These will be on sale again this year.

The income received from fundraising enables the Society to provide funds for ongoing research into the condition and grants to members who are in need, to finance the Society's presence at conferences and conventions around the country, and to facilitate the annual Conference and AGM.

The Trustees would like to say a huge thank you to everyone who has raised funds for the Society. Your efforts and generosity are much appreciated. What would we do without you?

**Judi Scott (Hon. Secretary)**

## Weston Music presents May Bank Holiday Mania Charity Event

**Monday 28th May 2018**

With **The Westons & Friends...**

Billy Bubba King    Amy Morgan

Steve Hanks

Kenny Jr    Texas Tornados

**Disco & Tuition with ..**

Cheryl Carter & Luke Craig

Doors open at 1pm with live music from 1.45pm

American Supper

Raffle & Games

Tickets  
**£12**

Details/tickets call Paul 07772 508063

Email: [westonmusic@hotmail.com](mailto:westonmusic@hotmail.com)

[www.westonmusic.com](http://www.westonmusic.com)



**Behçet's Syndrome Society**

Wythall Community Association

Silver Street, Wythall, Birmingham B47 6LZ

programmes subject to change without prior notice

## Report of the Trustees for the year ended 31 August 2018

The trustees present their report along with the financial statements of the charity for the year ended 31 August 2018. 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 15. 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.

### Reserves

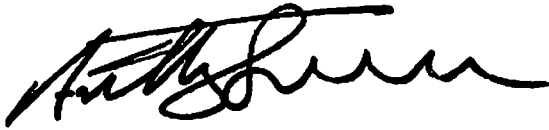
The trustees aim to maintain reserves at a level that lies approximately between the total income that the Society would expect in a six month period and that in a full financial year: currently the reserves are slightly higher than that so the Board will be looking into additional projects and services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

A handwritten signature in black ink, appearing to read 'Tony Thornburn', written in a cursive style.

**Tony Thornburn OBE  
Chair**

**1 October 2018**

## Staff and Trustees

### Trustees

Tony Thornburn OBE (Chair)  
Richard West (Vice-Chair)  
Judi Scott (Hon Secretary)  
Alan Lane (Hon Treasurer)  
Mark Friston  
Rachael Humphreys  
Hazel McLachlan  
Amanda Moseley

### Staff

Gemma Darlow (Administrator)  
Deborah Cardinal (Assistant  
Administrator)  
Julie Collier (Helpline Co-ordinator)

### Website / Newsletter editor

Clare Griffiths

### 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

Ross Brooke Ltd  
Suite I, Windrush Court  
ABINGDON  
OX14 1SY

### 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**

# Report on Financial Statement 2017/18

## Gearing up for expansion

Last year, I expressed some concern to the Trustees that, whilst the Society's reserves were the highest in its history, they were higher than one year's normal income, which is the upper limit envisaged in our policy.

Subsequently there has been a lot of discussion about ways in which we can improve our services to members and can sponsor further research activities. This naturally led to a reduction in our balances during 2017/18, during which Trustees have done a great deal to build links with medical organizations as well increasing our part-time paid staff to support a larger range of activities.

The Society has run a Family Day this year without charge to members attending and has continued to fund a research project at the University of Liverpool into the incidence of Behçet's in children.

The annual membership subscription has not been raised for over six years and remains at £20, with exemption for those in receipt of UK state benefits, who form an increasing proportion of our members, with the result that our total income from subscriptions has been gradually decreasing.

We continue to rely for income almost entirely on the subscriptions and generous donations of our members, some of whom have worked hard during the year to raise funds through a wide variety of events. We are particularly grateful to a member who donated the magnificent sum of £10 000 to the Research Fund this year.

**The General Fund** received income of £41.9k, including £10.1k of subscriptions, £17.4k of donations and activities and sales of £5.0k. The expenditure from this fund was £60.8k. Consequently there was a net deficit on the General Fund of £18.9k, giving accumulated reserves of £57.4k. However this should not be seen as a matter of concern, as the Trustees do not wish to hold a balance exceeding the income to be expected in one year, as the purpose of the Society is to use its income for the benefit of members.

**The Restricted Fund** had a total income of £10.6k from donations. The balance of £4k of a previously agreed grant to the University of

Liverpool is shown in the accounts under 'Accrued Expenses' as it represents a commitment against the fund. The accumulated reserve on this fund now stands at £24.4k, putting the Society in a good position to fund another research project in 2018/19.

## Membership

The Society's membership has continued to grow slowly. On 1 September 2018, we had 1014 full members, compared with 931 on the corresponding date last year. In addition there were 12 junior members and 71 associate members (most of whom are medical professionals).

The total number of names on our database was 1186 on that date, compared with 1095 the previous year, of whom 947 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 728, compared with 689 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 the Trustees are optimistic that the Society will continue to go from strength to strength.

**Alan Lane, Hon. Treasurer**  
**October 2018**



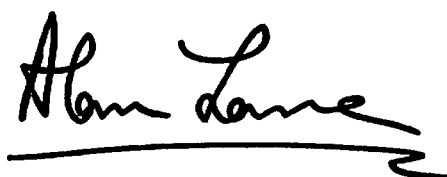
## Statement of Financial Activities and Balance Sheet for the year ended 31 August 2018

	General Fund	Restricted Fund	Total 2018	Total 2017	
	£	£	£	£	
<b>Income and endowments</b>					
Donations	17 367	10 515	27 882	26 124	
Bequests and legacies	4 454		4 454	0	
Subscriptions	10 148		10 148	9 135	
Gift Aid tax reclaimed	2 201	60	2 261	2 425	
Grants received	0		0	11 756	Note 6
Fundraising activities	2 825		2 825	10 875	
Sales of goods	1 104		1 104	1 019	
Charitable activities income	1 061		1 061	337	
Other	2 777		2 777	3 152	Note 7
<b>Total income and endowments</b>	<b>41 937</b>	<b>10 575</b>	<b>52 512</b>	<b>64 823</b>	
<b>Expenditure on charitable activities</b>					
Trading costs	316		316	844	
Event costs	5 442		5 442	11 103	
Fundraising staff costs	5 097		5 097	7 361	Note 8
Fundraising other costs	426		426	216	
Staff recruitment	193		193	0	
Grants and bursaries	6 437		6 437	3 073	
Research grants	0		0	14 000	
Subscriptions to other organizations	434		434	315	
Helpline costs	1 671		1 671	1 239	
Charitable support staff costs	1 699		1 699	2 851	Note 8
Other staff costs	6 387		6 387	0	Note 8
Employment rebate	-649		-649	-830	Note 8
Travel and subsistence	5 310		5 310	3 607	
Insurance	485		485	481	
Administrative staff costs	1 699		1 699	2 454	Note 8
Telephone charges	500		500	319	
Printing, postage, stationery etc.	1 447		1 447	2 614	
Equipment purchases	922		922	50	
Newsletter	8 358		8 358	8 081	
Web site and publicity	1 616		1 616	1 190	
Public relations staff costs	1 798		1 798	2 454	Note 8
AGM expenditure	7 492		7 492	4 351	
Governance costs	2 757		2 757	2 819	
Other	1 000		1 008	107	
<b>Total expenditure</b>	<b>60 837</b>	<b>0</b>	<b>60 837</b>	<b>68 699</b>	
<b>Net income before gains on investments</b>	<b>-18 900</b>	<b>10 575</b>	<b>-8 325</b>	<b>-3 876</b>	
Net gains on investments	30	13	43	114	
<b>NET INCOME</b>	<b>-18 870</b>	<b>10 588</b>	<b>-8 282</b>	<b>-3 762</b>	
Transfers between funds	0	0	0	0	
<b>Net movements in Funds after transfers</b>	<b>-18 870</b>	<b>10 588</b>	<b>-8 282</b>	<b>-3 762</b>	
<b>RECONCILIATION OF FUNDS</b>					
Fund balance brought forward at 1 Sep 2017	76 314	13 772	90 086	93 848	
Fund balance carried forward at 31 Aug 2018	57 444	24 360	81 804	90 086	

<b>Balance Sheet as at 31 Aug 2018</b>	<b>General Fund</b>	<b>Research Fund</b>	<b>Total 2018</b>	<b>Total 2017</b>	
	£	£	£	£	
<b>Current Assets</b>					
Stock in hand	147		147	463	<i>Note 9</i>
Debtors	101		101	75	<i>Note 10</i>
Prepayments	4 680		4 680	241	<i>Note 11</i>
Accrued income	0		0	112	
Recoverable Gift Aid	114	470	584	575	
Deposit Accounts	51 268	27 891	79 159	97 115	
Current Accounts	2 186		2 186	6 617	
Petty Cash	350		350	250	<i>Note 12</i>
<b>Total current assets</b>	<b>58 847</b>	<b>28 360</b>	<b>87 207</b>	<b>105 448</b>	
<b>Current Liabilities</b>					
Creditors	0	4 000	4 000	14 139	<i>Note 13</i>
Deferred income	480		480	660	<i>Note 14</i>
Accrued expenses	923		923	563	<i>Note 15</i>
<b>Total current liabilities</b>	<b>1 403</b>	<b>4 000</b>	<b>5 403</b>	<b>15 362</b>	
<b>Total net assets</b>	<b>57 444</b>	<b>24 360</b>	<b>81 804</b>	<b>90 086</b>	
<b>TOTAL FUNDS</b>	<b>57 444</b>	<b>24 360</b>	<b>81 804</b>	<b>90 086</b>	

The financial statements were approved by the trustees on 1 October 2018

Signed



Alan Lane  
Hon. Treasurer

Date: 1 October 2018

## Notes forming part of the financial statements for the year ended 31 Aug 2018

### 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 FRS102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Behcet's Syndrome Society meets the definition of a public benefit entity under FRS 102. The financial statements have been prepared on a going concern basis. The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern.

### 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. Expenditure

Expenditure is recognised in the year to which it relates. 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	57 444	24 360	81 804
Total	<u>57 444</u>	<u>24 360</u>	<u>81 804</u>

### 5. Research Fund

The Society has received a number of donations during the year to augment the Research Fund. It had agreed a grant of £14k to the University of Liverpool in 2016/17 to support a research project, of which £10k has so far been paid to the University and £4k remains to be drawn down.

### 6. Grants received

The Society has not received any external grants this year.

### 7. Other income

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

### 8. Salary costs

	Year ending 31 August	2018	2017
		£	£
Wages and salaries		16 032	14 148
National Insurance contributions		0	0 (after deduction of rebate)
Employer's pension contributions		<u>207</u>	<u>141</u>
		16 239	14 289

The average number of staff employed during the year was 1 person (2017 1 person). There are no employees earning above £60 000 (2017 none). Some of the staff salary and on-costs have been apportioned between the activities undertaken for the Society.

None of the trustees, nor any persons connected with them, has received any remuneration during the year. Seven trustees received expenses for travel and subsistence costs amounting to £2079 (2017: £727) during the year.

### 9. Stock

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

### 10. Debtors

Sums owed to the Society by HMRC (PAYE refund) and CAF Bank (donation in transit at 31 August 2018).

### 11. Prepayments

Payments in advance for the Annual Conference in October 2018 and part of the insurance premium paid in 2017/18 that relates to 2018/19.

### 12. Petty Cash

Expenses float held by Administrator.

### 13. Creditors

Provision for final instalment of agreed grant to University of Liverpool £4000

### 14. Deferred Income

Advance subscriptions for 2018/19 received before 1 September 2018.

### 15. Accrued expenses

Staff expenses relating to August 2018 and provision for fees for independent examination of accounts.

**INDEPENDENT EXAMINER'S REPORT  
TO THE TRUSTEES OF  
THE BEHÇET'S SYNDROME SOCIETY**

I report to the charity trustees on my examination of the accounts of the charity for the year ended 31 August 2018 which are set out on pages 15 to 17.

**Responsibilities and basis of report**

As the charity's trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the charity's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**Independent examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the charity as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

  
Caroline Webster FCA  
Ross Brooke Ltd

Suite 1  
Windrush Court  
Abingdon  
OX14 1SY

..... 4<sup>th</sup> October ..... 2018