



*Caring for all affected by this rare, complex and lifelong condition;  
promoting research into the cause, effects, treatment and management of Behçet's*

# Annual Report 2023

Registered Charity Number 326679

# Contents

Medical Advisory Panel.....	2
Chair's Report .....	5
Fundraising Report .....	11
Report of the Trustees for the year ended 31 August 2023 .....	15
Staff and Trustees .....	17
Report on Financial Statement 2022/23 .....	18
Statement of Financial Activities 2022/23 .....	19
Statement of Financial Activities 2021/22 .....	20
Balance Sheet .....	21
Notes to the Accounts .....	22
Independent Examiner's Report.....	24

# Medical Advisory Panel



**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, rheumatoid arthritis, immunotherapy of rheumatic diseases



**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:** Royal Stoke University Hospital, Stoke-on-Trent

**Special interests:** Neuro-Behçet's disease, multiple sclerosis and other

**Member of:** British Medical Association, Association of British Neurologists, Royal College of Physicians of London; past-Convenor, Neuro Behçet Study Group/ International Society of Behçet's Disease

**Special interests:** Neuro-Behçet's disease, multiple sclerosis and other inflammatory diseases of the central nervous system, Clinical Director: Royal Stoke Multiple Sclerosis Centre of Excellence.



**Clive B Archer**

**Job title:** Cons Dermatologist & Hon Clinical Snr Lecturer

**Qualifications/ Post Nominals:** BSc (Hons), MB BS, MRCP (UK), MD (Lond), PhD, MRCS (Engl), FRCP (Lond), FRCP (Edin), FRCP (Glasg), PG Cert, PG Diploma & MSc in Medical Education, LLM

**Where qualified:** Guy's Hospital Medical School, University of London

**Year of initial qualification:** 1978

**Currently practising at:** St John's Institute of Dermatology at Guy's and St Thomas' NHS Foundation Trust and honorary senior clinical lecturer at King's College London (KCL).

**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



**Paul Brogan**

**Job title:** Professor of Vasculitis, Infection, Immunity & Inflammation Dept UCL GOS Institute of Child Health, Faculty of Pop Health Sciences

**Qualifications/Post Nominals:** BSc, MBBS, MRCP, Dip GUM, Dip HIV, MJCSM

**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





**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, FSRH, ESSM

**Special interests:** HIV and genital dermatology



**Farida Fortune CBE**

**Job title:** Director London Behçet's Centre, Barts Health and Queen Mary University of London

**Qualifications/Post Nominals:** FRCP, FRCS, FDS, RCS, PhD

**Where qualified:** University College London

**Year of initial qualification:** Dentistry 1975; Medicine 1980

**Currently practicing at:** Barts Health, Royal London site

Queen Mary University of London

**Special interests:** Immunology and Oral Medicine



**Dorian O Haskard**

**Job title:** Professor of Cardiovascular Medicine and Rheumatology, Imperial College

**Qualifications/Post Nominals:** DM FRCP FMedSci

**Where qualified:** University of London

**Year of initial qualification:** 1977

**Currently practising at:** Now retired from clinical practice

**Special interests:** Vascular inflammation



**Desmond Kidd**

**Job title:** Consultant Neurologist

**Qualifications/Post Nominals:** MD BCh BAO 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



**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:** All types of uveitis including Behçet's disease. Scleritis. *Clinical Research:* Quality of Life in uveitis, *Laboratory Research:* 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!



## 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, Imperial College Healthcare Trust

**Special interests:** Medical problems in pregnancy, particularly connective tissue diseases, thromboembolism, cardiac and renal disease



## Graham Wallace

**Job title:** Associate Professor Senior Lecturer,

Qualifications/Post Nominals: BSc Immunology, PhD

**Where qualified:** University of London

Year of initial qualification: 1985 (PhD)

**Currently practicing at:** Institute of Inflammation and Ageing, University of Birmingham

**Special interests:** Ocular immunology, Behçet's disease, immunogenetics, innate immunity



## Jane Setterfield

**Job title:** Professor of Oral and Dermatological Medicine KCL/Honorary Consultant Dermatologist

**Where qualified:** University College Hospital, London

**Year of initial qualification:** Dentistry 1980, Medicine 1987

**Currently practising at:** Guy's and St Thomas' NHS Foundation Trust  
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 disorders

**Research:** Translational studies in the field of immunobullous diseases and lichen planus

# Chair's Report

## Overview

The Society continues to discharge its responsibilities and is strengthening its position in several areas within the wider rare disease community. Our financial position is stable and strong, thanks to two significant legacies, allowing routine annual expenditure to be guaranteed for future years, and research and support initiatives to be progressed. We continue to benefit from members carrying out fantastic fundraising. There was though a net deficit of income over expenditure, more of which later.

I always flag our Quarterly Newsletters, which act as a detailed historic record of what is happening over the year. This our 40<sup>th</sup> Anniversary and Gemma Darlow has done a fantastic job in capturing significant and interesting past articles. It demonstrates how far we have come from modest beginnings and reflects the compassionate, supportive and great institution that it is, together with 'our' 'Behçet's clinicians' who support our patients directly. Indeed, I often pick-up comments on how professional our charity comes across to 'outsiders'.

## Governance

The governance of the Society is mature and comprehensive in accordance with Charity Commission guidance, though we are not complacent and there is still work to do to improve. Gemma Darlow is thanked for her thorough and conscientious efforts in this regard. Much underpinning work continues in the background.

We have not yet invested in a Constituent Relationship Management System, similar to Customer Relationship Management which is routinely used in commerce. This will increase efficiency and cost-effective use of our administrator's time (and ironically that is what is delaying matters presently to produce the business case), alongside improving resilience, support succession planning and traceability. It will help to ameliorate potential 'single points of failure'.

Board membership has remained stable, for which as Chair I am most grateful. Alan Lane, Hon. Treasurer, continues to 'run a tight ship' and provides exemplary and careful thought and preparation to our accounts.

I take this opportunity, as always, to thank our trustees on your behalf, for their excellent contribution and loyal commitment to the Society – noting again, for the benefit of new members, that this is offered voluntarily and unremunerated. We continue to have a trustee representing in each of the Devolved Nations and aim to hold a minimum of two joint meetings annually with the Behçet's Patients Centres Board of Directors to ensure we are moving forward in harmony and aligned with long-term goals.

## Annual Conference

The 2022 Behçet's UK Conference and Annual General Meeting was for the first time a hybrid event, both in-person located at the Holiday Inn in Stevenage and online via Zoom. It proved a successful model. A total of 193 registered, of whom 54 attended in-person and another 56 online. It was slightly disappointing that 80-odd did not show in either guise and we will seek to try to identify why this is if this situation recurs in 2023. Professor Fortune and her team from London were the sponsors and are thanked for their time and expertise; a detailed summary of which was adeptly put together by our fantastic Editor Clare Griffith in Issue No. 62 Winter 2022/23.

The 2022 Judith Buckle Award was presented to Richard West in recognition of all he has done for Behçet's members; Richard was diagnosed with Behçet's in the 1990s and, like many others, spoke to Georgina Seaman at what was then the Behçet's Syndrome Society and realised that he was not alone. Wanting to do the same for other patients, he became a Trustee in 2001 and went on to be Secretary and Vice Chair of the Society. He has made a major contribution to improving care for people with Behçet's, raising the profile of the condition across Europe as a patient representative at EURORDIS and acting as a patient representative on the EULAR Guidelines.

The Chair announced a new initiative to recognise the contribution of individuals who have been instrumental in supporting anyone in the Behçet's UK community, improving their quality of life, independence, and dignity. The first Behçet's UK Members' Award was awarded posthumously to Annette Robinson, who ran support groups in London and East Anglia as well as a private Facebook site where more than 400 people could share personal information. The award was accepted by Annette's husband Brian.

## **Behçet's Friends and Family Day**

This was the sixth year of hosting our Behçet's Friends and Family Day, which this year was to Dinton Activity Centre on Saturday 24 June. The centre is located in Dinton Pastures Country Park in Berkshire. It was a great success with 22 attending but sadly, we had a few late cancellations which we were unable to fill resulting in some unused places. The event is funded by the Society's hard-earned money, and we must use it economically.

## **Newsletter**

These continue to provide much valuable information to all. Our Editor, Clare Griffith, who designs them is once more thanked for the enduring quality of standard produced. Contributors are again thanked for their positive articles, which Judi Scott collates. This is a core product that the Society produces, including significant input from the Behçet's Patients Centres. We continue to promote the use of our electronic version, which helps save money, but the printed version will remain where demand exists.

## **Medical Factsheets and Alert Card**

The majority of our Medical Fact Sheets have been reviewed and amended where necessary; important points of reference, to both patients and clinicians. They remain a significant source of information particularly for patients who are 'new to Behçet's' and are referenced by all four Nations' NHS websites.

I am disappointed to inform that no progress has been achieved with our proposed new Alert Card, which Sarah Hardy, Nurse Consultant at the Liverpool centre helped to update. It was submitted to the Head of the Highly Specialised Commissioning for hopefully formal adoption with an accompanying NHS logo.

## **Medical Advisory Panel**

I noted last year that this is an area which still needs work to revitalise with succession planning in mind. Succession planning has been highlighted as a weakness this year when we have lost two experienced clinicians on retirement, and no one apparent to replace them.

## **Fundraising and Membership**

Once more we have witnessed the generosity of individuals to continue to give generously of their time and effort to raise essential funds for the Society - £19.8k in Fundraising activities and £19.6k in donations this past year. Neil Williams continues to work-up our Fundraising Strategy, wishing to seek additional members with appropriate skills to assist him.

We must not lose sight of the need to establish underpinning predictable income generation as de rigueur, as without those generous donations, and notwithstanding the considerable endeavours of individuals to raise money for the Society, we would not currently cover our costs.

Membership has increased steadily even though we have 'culled' those who appeared to have disengaged - which we are required to due regarding data protection - and now stands at 1297.

## Research

Research is important, however much of this (if not all presently) we have no control over but are quietly making steps to try to influence, the most significant of which will be used to establish 'our' UK Behçet's Patient Registry.

As I noted last year, and do not apologise for repeating, I posit that the establishment of a comprehensive Behçet's Patient Registry in the UK, and managed by the Society, is optimal way of supporting you all into the future. A 'Natural History study of Behçet's within the UK' should follow, as should a Priority Setting Partnership for research questions be established to inform a strategic 'research road map'. This should be followed by entry into Whole Genome Sequencing at scale.

Dr Graham Wallace continues to conduct much research some of which we have helped fund. Professor Fortune brought with her 8 research posters to the 2022 Behçet's UK Conference, research papers that had previously been submitted to the 2022 International Conference for Behçet's Disease held in Athens.

### *Other Research - Secukinumab*

Professor Moots has secured significant funding from Novartis for a major trial on the biologic Secukinumab, which is a biologic that is extensively used, and highly effective, in several inflammatory conditions such as psoriasis. It inhibits interleukin 17 and has a better side-effect profile than infliximab. A small retrospective study in Italy showed it to be very effective in Behçet's, and Novartis has announced £700,000 of funding for a major trial in the UK. This is potentially very good news for Behçet's patients in the UK. However, recruiting participants from some centres to take part in the trial is currently proving problematic. Additional money has been secured, needed because of delays already.

### *Retrospective Epidemiological Study/Behçet's Patient Registry (UK)*

The initial phase of Dr Priyanka Chandratre's study is complete; match-funded by Behçet's UK. As a reminder this is capturing data from the three national Behçet's Syndrome Centres of Excellence, Hospital Episode Statistics, cross-checked with Clinical Practice Research Datalink, and recorded in the Behçet's UK membership (who may or may not have been captured by the other pathways). However, the initiative highlighted some weakness in our current data gathering processes, but this merely reflects a fundamental, well-known, problem within the NHS. Research into discovering treatment and cures for rare conditions needs reliable data.

## Supporting Initiatives

### *BAD/BSR NICE accredited guideline*

I reported last year that this important joint initiative was nearing completion. Unfortunately, promulgation has been delayed thanks to the lack of appropriate expertise in the neurology arena; consequent upon the recent retirement of two of our most experienced 'Behçet's Neurologists'. This flags-up an important issue regarding potential 'single points of failure' within the 'Behçet's Workforce' and the need for comprehensive succession planning within the NHS Highly Specialised Services. Moreover, I find it surprising, if not highly inappropriate frankly, that this important aspect of clinical care is carried out voluntarily by clinicians. The Society is most grateful for their continued support. Guidelines help to improve patient outcomes; encouraging consistent standards of care, treatment and with the



ability to conduct subsequent Quality Assurance audits from an established clinical 'baseline'. As I did last year, I highlight that the National drugs pathway will be reflected in the guideline (offering wider exposure amongst the clinical fraternity, and since many clinicians are members of the British Association of Dermatologists or British Society of Rheumatology significantly more visibility of Behçet's will be achieved by this guideline; as it will be readily visible on their respective websites, much more so than the current EULAR guideline (with which it will inevitably chime in many areas though with the subtle difference of focusing on UK patients).

## **Communications Strategy**

We continue to identify opportunities in this area, have yet to document a policy but it remains on our 'to do list'. I discharge quite a personal commitment to represent the Society on Genetic Alliance UK's England Rare Disease Action Plan Patient Advisory Group, together with Beacon (formerly Findacure) Patient Group Engagement Committee, National Voices Heads of Policy Group, the Neurological Alliance and the Prescriptions Charges Coalition.

As Alliance Network Chair of the Central and South Genomic Medicine Service Alliance (GMSA) – basically the Patient and Public Voice (PPV) or Patient and Public Involvement (PPI) representative – I remain alert to identifying opportunities where the Behçet's community may benefit from future initiatives; moreover on every communication the Behçet's UK signature block features, including on the national NHS Peoples and Citizens PPV group, thus much additional visibility of our condition is being achieved.

Jan Mather has been appointed as a PPV member on the National Rare Disease Advisory Group, and this will undoubtedly offer further opportunities for additional visibility of Behçet's, and indeed an exemplar of how things can be achieved within the Highly Specialised Services space – albeit constrained by NHS resources.

## **Social Media**

Deborah Cardinal is to be commended on maintaining a keen eye to spot opportunities for promoting Behçet's UK. Our Facebook page has increased by 372, now totalling 1,846 followers, of which 74% reside in the UK. X (formerly Twitter) has 984 followers (928 in 2022), with Deborah regularly tweeting. Instagram now has 1,269 followers with our content reaching 12,332 (a massive increase over 4,000 last year) of which 52% is a UK audience. HealthUnlocked, which has 5,103 'All Time Members', witnessed a reduction in active membership, though conversely there has been a 78% increase in new content.

In sum, our online presence continues to increase our visibility across all age groups. We still need to address a point I made last year, highlighted during the International Conference for Behçet's Disease 2022, to use social media to help promote research papers.

## **Support Groups**

Member Support Groups remain active and popular with Clare Gibson's England group and Rachael Humphreys' Wales group regularly meeting online and Fionnuala McKinley's Northern Ireland group meeting online and in-person. Yvonne Morris and Catherine O'Hara continue to offer support to members in their areas. Any new initiatives in this area are welcomed, so do get in touch with Gemma or Deborah if you have ideas.

HealthUnlocked, which is linked from our Behçet's UK website, is a space where those with Behçet's (or those caring for individuals with Behçet's, or indeed parents of children with Behçet's) can share their experiences of healthcare, free from stigma or judgment, talk to people living with Behçet's, and gain support from each other and patient advocacy organizations. There are more than 1.5M members, 315 public communities, 250 condition areas and 300 patient organizations represented within

HealthUnlocked. I continue to monitor one or two other sites, for example the discussion forum for LUPUS UK, the National Migraine Centre and Vasculitis UK.

## Political Lobbying

As and where appropriate, we continue to encourage members to get involved with their local politicians though best in a coordinated manner particularly when requested by Behçet's UK. Genetic Alliance UK, leads in this area with whom the Society keeps in close contact.

The groups which we support are: The [England] Cross Party Group on Rare, Genetic and Undiagnosed Conditions; All Party Group on Skin; the All Party Group on Rare Conditions in The National Assembly for Wales; The Scottish Parliament Cross-party Group on Rare, Genetic and Undiagnosed conditions; and the Prescription Charges Coalition; the All-Party Group for Rare Disease at the NI Assembly, with the assistance of the Northern Ireland Rare Disease Partnership (NIRDP).

NIRDP also work closely with: the Northern Ireland Department of Health; the Health and Social Care Board; Public Health Agency and the Patient Client Council. Behçet's UK remains affiliated with Patient Representative Organisations in the UK (e.g. Genetic Alliance UK, Unique). I maintain links with the Republic of Ireland (IPPOSI, MRCG and GRDO) and Europe (EURORDIS), as well as with a wide range of condition-specific groups and organisations.

## Helpline

Calls to the Helpline remain an important area that the Society provides. This function is presently carried out on most days by the Tony Thornburn and Fionnuala McKinley, with Catherine O'Hara and Gemma Darlow in close support who are all thanked for their vital contributions. As I noted last year, we continue to seek more volunteers for this role, bearing in mind that longevity in post is important as costs with administrative checks are invoked in providing the necessary preparation for individuals involved in this endeavour. Trustees continue to review this aspect going forward.

## Devolved Nations

Our representatives in the Devolved Nations continue to carry out an important role; Catherine O'Hara, our Vice Chair, in Scotland, Rachael Humphreys in Wales and Fionnuala McKinley in Northern Ireland. Trustees are seeking to establish a Behçet's Specialist Nurse post in Scotland to help coordinate care and recent omens are looking positive through initial discussions with Dr Martina Rodie, who heads up the Office for Rare Diseases in Glasgow.

## Looking Forward

Personal circumstances have precluded me for progressing the establishment of a Behçet's UK Patient Registry this past year. Dr Priyanka Chandratre's data-gathering research initiative highlighted some weakness in our current data gathering processes, but this merely reflects a fundamental, well-known, problem within the NHS. Research into discovering treatment and cures for rare conditions needs reliable data.

On the clinical side, we continue to benefit from the three specialist National multi-disciplinary Centres of Excellence led by Clinical Director's Professor Rob Moots, Professor Farida Fortune CBE and Dr Deva Situnayake. The Behçet's Patients Support staff, namely Jean Christians, Rebecca Hyder and Jackie Pooler, managed by John Mather the Operations Manager directly support them.

## Conclusion

The Society continues to discharge its responsibilities and is strengthening its position in a number of areas within the wider rare disease community. Our financial position is stable and strong, thanks to two significant legacies, allowing routine annual expenditure to be guaranteed for future years, and research

and support initiatives to be progressed. However, we must not lose sight of the need to establish underpinning predictable income generation as de rigueur, as without those generous donations, and notwithstanding the considerable endeavours of individuals to raise money for the Society we would not currently cover our costs.

There is a major opportunity, with the funds we now have to set secure foundations for research into Behçet's in the UK, based on establishing a Patient Registry. It is vital that members fully support this initiative and allow their data to be shared in a fully secure environment with safeguards in place to anonymise, when required, to ensure patient confidentiality.

I end by thanking everyone who continues to make this Society the compassionate and great institution that it is, together with the clinicians who support our patients. Gemma Darlow and Deborah Cardinal significant efforts underpin all the necessary administrative aspects that the Society needs. Your Trustees continue to give of their valuable time, voluntarily, and I am most grateful for their continued loyal support.

**Tony Thornburn OBE, Chair**

27 September 2023

# Fundraising Report

Behçet's UK receives no external funding and therefore relies heavily on the revenue received from fundraising.

The income from fundraising enables Behçet's UK to provide funds for new and ongoing research into the condition, grants to members who are in need, finance the Society's presence at both national and international conferences, helps facilitate Behçet's UK's Annual Conference and AGM and provides part of the resources for the quarterly newsletter. It also enables the employment of our Administrator and Assistant Administrator whose efficiency and hard work ensure the smooth running of the Society.

Behçet's UK depends upon the fantastic endeavours of members, their friends, families and supporters who continue to commit to exciting and often crazy forms of fundraising!

As 2023 is our 40<sup>th</sup> Anniversary we launched some fundraising initiatives which encouraged our members and supporters to get involved and as always, they didn't disappoint! With fundraising events, along with Gift Aid, for the year from September 2022 to August 2023 standing at £19,788. Over the next few pages we have included just a few of our fantastic fundraisers, as well as ways to fundraise for us in everyday life.

I am always looking for keen volunteers to form a Fundraising Committee and would welcome any members who are keen to join and examine ways to raise much-needed funds.

**Neil Williams**  
Trustee & Fundraising

**Gemma Darlow**  
Administrator



**Behçet's UK**  
also raises much  
needed funds from  
the sale of  
merchandise, payroll  
giving, online  
shopping, online sales  
and bequests in wills.

Give as you Live  
Online

easyfundraising  
feel good shopping

Recycle 4 Charity

The Giving  
Machine

ebay

DontSend  
MeACard

pga





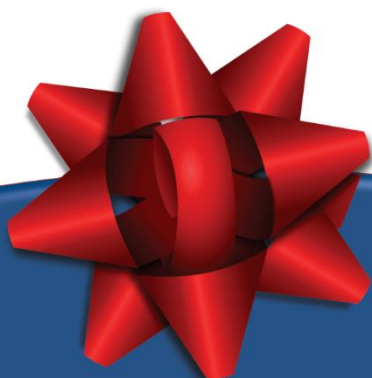
## Half Marathon Done!

Taking part in the Great North Run together last September was something Cat and Chris will never forget with an incredible atmosphere.

They completed the half marathon in 2 hrs 39 and £808 for Behçet's UK.

Rumour has it Chris is now considering a full marathon!

Ruth held her annual Ladies Ball in May and beat last years total raising £1834!



## Facebook and Instagram Fundraisers

25 members and supporters kindly set up a Facebook Fundraiser to celebrate their birthday this year, allowing friends and family to make a donation in lieu of birthday gifts and raised over £2800.

Instagram Feed Fundraisers raised a further £647 and general donations via the Facebook button raised £72.



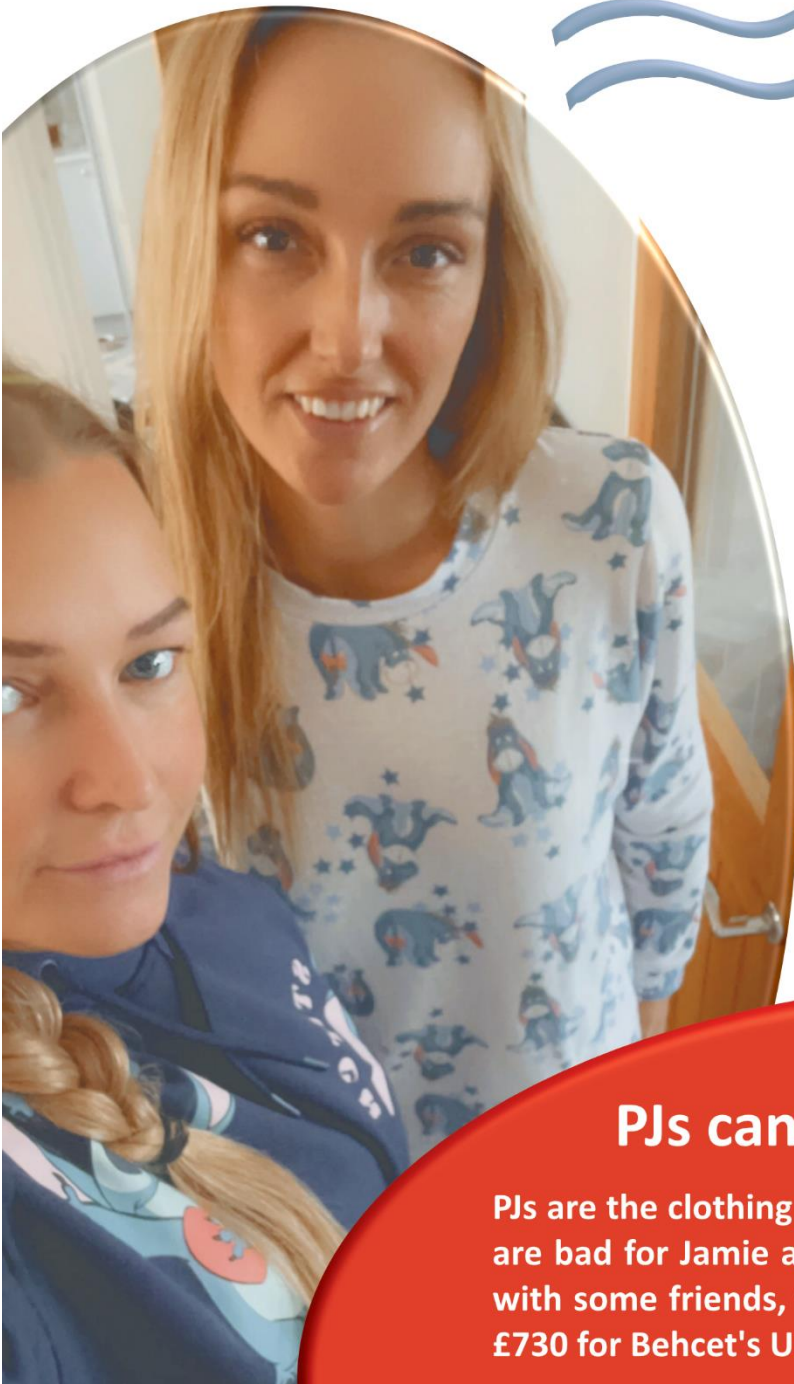
## Sky High Fundraisers

Amy's mum has Behçet's so she took on a skydive in October 2022 to raise funds for Behçet's UK and raised £850.

Samantha wanted to show her son, who has Behçet's, that she could be as brave as him. So, in February she leapt out of a plane and also raised £1100!



Malcolm continues to collect and sell postage stamps to raise funds for Behçet's UK



Singer and songwriter Anthony donates the sales of his music to Behçet's UK in honour of his daughter who has Behçet's and has raised £110 for Behçet's UK this year.

## PJs can make a bad day better!

PJs are the clothing of choice and comfort when Behçet's symptoms are bad for Jamie and two of her daughters. So in February, along with some friends, they spent a whole week in their PJs and raised £730 for Behçet's UK.





## Life begins at 40

Trying new things doesn't  
**HAVE** to be scary!

Eve donned her running shoes for the Great Manchester Run in May, in honour of her dad who has Behçet's, and raised £360.

Behçet's UK Trustee, Rachael, has also been putting her running shoes through their paces by taking part in various running events and races throughout the spring and summer of 2023 raising £225.

Mike's sister has Behçet's so he took on a two week challenge he named "The Broken Spoke" taking to two wheels and cycled 1000 miles from John O'Groats to Lands End. Mike encountered many challenges along the way but raised £3769.

By the end of the financial year we still had more supporters lining up to take on their "Life begins..." challenges.

# 4



**Behçet's**  
UK

## 40 in 40

Run, walk or push 40 miles or 40 kilometres in 40 days!

The fundraiser ran May and June and we had six keen supporters, many of whom have Behçet's themselves, take part and between them they aised a staggering £4321.

Many thanks to Nikki, Debbie, Emma, Mateja, Melissa and Laura for taking part and raising an amazing total!

# Report of the Trustees

## for the year ended 31 August 2023

The trustees present their report along with the financial statements of the charity for the year ended 31 August 2023. 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*

Behçet's UK is constituted under a trust deed dated 11 October 2008 and is a registered charity number 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 17. 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.



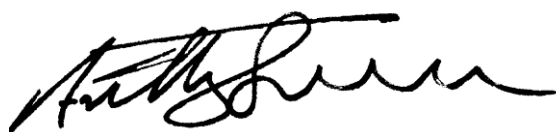
However, should a particularly large donation be received, Trustees would normally treat the larger part as an earmarked reserve, to be used over the next three financial years to underwrite any possible shortfall in income or need for exceptional expenditure.

#### *Risks and public benefits*

The trustees consider that the Society is in a strong financial position currently and do not consider that the Society faces any significant risks in the longer future, but they will continue to monitor income and expenditure regularly.

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**

27 September 2023

# Staff and Trustees

## Trustees

Tony Thornburn OBE (Chair)  
Catherine O'Hara (Vice Chair)  
Judi Scott (Hon. Secretary)  
Alan Lane (Hon. Treasurer)  
Mark Friston  
Rachael Humphreys  
Fionnuala McKinley  
Amanda Moseley  
Neil Williams

## Staff

Gemma Darlow (Administrator)  
Deborah Cardinal (Assistant Administrator)

## Newsletter editor

Clare Griffiths

## Medical Advisory Panel

Prof Rob Moots  
Dr Adnan Al-Araji  
Dr Clive Archer  
Prof Paul Brogan  
Dr Andrew de Burgh-Thomas  
Prof Farida Fortune  
Prof Dorian Haskard  
Dr Desmond Kidd  
Prof Phil Murray  
Dr Catherine Nelson-Piercy  
Dr Graham Wallace

## Banks

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

Scottish Widows Bank  
PO Box 883  
LEEDS  
LS1 9TY

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

## Independent Examiner of Accounts

UHY Ross Brooke  
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## Administration Office

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**Registered Charity No: 326679**

# Report on Financial Statement 2022/23

As a charity, this Society exists to provide support for its members and to promote research into a medical condition that can be both chronic and severe. It is therefore a little concerning for your Hon. Treasurer to have to report that the Society's already relatively large reserves increased further during the financial year that ended on 31 August 2023.

On the other hand, it is remarkable that any organization in this day and age can maintain, and even expand, its operations without any need to increase its membership fees. It is actually over twelve years since our subscription was last increased.

This apparent contradiction is entirely due to the generosity of a very small number of former members who have kindly left significant sums to the Society in their wills, without which our normal income from subscriptions and donations would not have kept up with the general increases in expenditure on our Annual Conference, newsletters, charitable grants, salaries and other operational costs. It would be wonderful if similar benefactions could be received in the future!

However, it is not the wish of our Trustees to keep large sums of money in the bank and they have agreed to earmark sums of £50k each towards the creation of a Patient Registry to facilitate research into Behçet's and towards the provision of a specialist nurse to support patients in Scotland (as our sister charity, Behçet's Patients Centres, only has a contract to provide non-medical support in England).

Trustees are also keen to increase the number of charitable grants the Society can make to members in the UK who would benefit from the provision of essential household goods and medical equipment and who meet the criteria for support.

**The General Fund** received income this year of £54.2k, including £37.4k in subscriptions and donations, £5.2k from fundraising activities and sales and other income totalling £5.9k. Expenditure was £66.2k and there was a net deficit on the General Fund of £10.8k, leaving accumulated reserves of £144.4k.

**The Research Fund** had a total income of £56.8k, largely from a single bequest, and the reserves now stand at £65.2k.

**Membership** continues to show a steady increase, the large majority of members being patients or carers for Behçet's sufferers. In September 2023, we had 1297 full members, compared with 1234 on that date last year. In addition, there were 32 junior members and 73 associate members (mainly medical professionals). We are still able to offer free membership to those who are under 25 or who are in receipt of UK means-tested benefits.

The total number of names on our database was 1423, compared with 1444 the previous year, of whom 1181 were patients and 75% were female. The number in receipt of UK state benefits, including pensions, was 995, compared with 985 the previous year, a further small increase as in previous years.

As always, I should like to thank the Society's two part-time members of staff, who do the bulk of our administration, for all their hard work during the past year.

**Alan Lane, Hon. Treasurer**

25 September 2023

# Statement of Financial Activities 2022/23

## Statement of Financial Activities for the year ended 31 August 2023

	General Fund	Restricted Fund	Total 2023	Total 2022	
	£	£	£	£	
Income and endowments					
Donations	27 306	470	27 806	19 603	Note 5
Bequests and legacies	805	56 276	57 081	263	
Subscriptions	10 051	0	10 051	9 885	
Gift Aid tax reclaimed	4 999	28	5 027	4 752	
Grants received	0	0	0	0	Note 6
Fundraising activities	5 156	30	5 156	17 507	
Sales of goods	784	0	784	771	
Other	5 085	0	5 085	3 837	Note 7
Total income and endowments	54 186	56 804	110 990	56 618	
Expenditure on charitable activities					
Trading costs	0	0	0	1 105	
Event costs	2 652	0	2 652	2 551	
Fundraising costs	703	0	703	1 251	
Staff training	0	0	0	25	
Grants and bursaries	3 412	0	3 412	4 260	
Research grants	0	0	0	700	
Subscriptions to other organizations	705	0	705	436	
Helpline costs	98	0	98	81	
Salaries and wages	29 055	0	29 055	26 380	Note 8
Social security and pensions	605	0	605	564	Note 8
Travel and subsistence	818	0	818	1 424	
Insurance	913	0	913	878	
Telephone charges	515	0	515	404	
Printing, postage, stationery etc.	1 254	0	1 254	540	
Equipment purchases	292	0	292	35	
Newsletter	9 672	0	9 672	9 165	
Web site and publicity	412	0	412	5 600	
ICT hardware	971	0	971	0	
ICT software and management	1 102	0	1 102	1 288	
Annual Conference and AGM	9 078	0	9 078	3 734	
Governance costs	2 713	0	2 713	1 782	
Other	1 267	0	1 267	1 240	
Total expenditure	66 237	0	66 237	63 443	
Net expenditure before gains on investments	-12 051	56 804	44 753	-6 825	
Net gains on investments	1 214	569	1 783	162	
NET INCOME	--10 837	57 373	46 536	-6 663	
Transfers between funds	0	0	0	0	
Net movements in Funds after transfers	-10 837	57 373	46 536	-6 663	
RECONCILIATION OF FUNDS					
Fund balance brought forward at 1 Sep 2022	155 250	7 855	163 105	169 768	
Fund balance carried forward at 31 Aug 2023	144 413	65 228	209 641	163 105	



# Statement of Financial Activities 2021/22

## Statement of Financial Activities for the year ended 31 August 2022

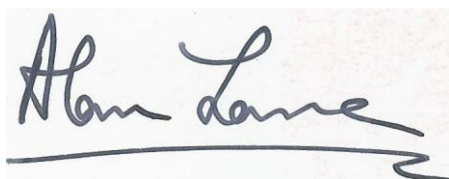
	General Fund	Restricted Fund	Total 2022	Total 2021	
	£	£	£	£	
Income and endowments					
Donations	18 573	1 030	19 603	26 566	Note 5
Bequests and legacies	263	0	263	52 438	
Subscriptions	9 885	0	9 885	9 645	
Gift Aid tax reclaimed	4 724	28	4 752	4 505	
Grants received	0	0	0	0	Note 6
Fundraising activities	17 507	0	17 507	1 128	
Sales of goods	771	0	771	753	
Other	3 837	0	3 837	3 704	Note 7
Total income and endowments	55 560	1 058	56 618	98 739	
Expenditure on charitable activities					
Trading costs	1 105	0	1 105	127	
Event costs	2 551	0	2 551	77	
Fundraising costs	1 251	0	1 251	546	
Staff training	25	0	25	175	
Grants and bursaries	4 260	0	4 260	2 189	
Research grants	0	700	700	9 784	
Subscriptions to other organizations	436	0	436	756	
Helpline costs	81	0	81	73	
Salaries and wages	26 380	0	26 380	25 581	Note 8
Social security and pensions	564	0	564	538	Note 8
Travel and subsistence	1 424	0	1 424	70	
Insurance	878	0	878	683	
Telephone charges	404	0	404	367	
Printing, postage, stationery etc.	540	0	540	576	
Equipment purchases	35	0	35	0	
Newsletter	9 165	0	9 165	8 908	
Web site and publicity	5 600	0	5 600	515	
ICT software	1 288	0	1 288	1 047	
Annual Conference and AGM	3 734	0	3 734	2 360	
Governance costs	1 782	0	1 782	2 266	
Other	1 240	0	1 240	1 245	
Total expenditure	62 743	700	63 443	57 883	
Net expenditure before gains on investments	-7 183	358	-6 825	40 856	
Net gains on investments	45	117	162	24	
NET EXPENDITURE	-7 138	475	-6 663	40 880	
Transfers between funds	0	0	0	0	
Net movements in Funds after transfers	-7 138	475	-6 663	40 880	
RECONCILIATION OF FUNDS					
Fund balance brought forward at 1 Sep 2021	162 388	7 380	169 768	128 888	
Fund balance carried forward at 31 Aug 2022	155 250	7 855	163 105	169 768	

# Balance Sheet

Balance Sheet as at 31 Aug 2023	General Fund	Research Fund	Total 2023	Total 2022	
	£	£	£	£	
<b>Current Assets</b>					
Stock in hand	1 719	0	1 719	870	<i>Note 9</i>
Debtors	133	0	133	907	<i>Note 10</i>
Prepayments	577	0	577	647	<i>Note 11</i>
Accrued income	406	0	406	42	<i>Note 11</i>
Recoverable Gift Aid	1 612	391	2 003	732	
Deposit Accounts	140 901	64 061	204 962	158 547	
Current Accounts	860	776	1 636	4 904	
Petty Cash	350	0	350	350	<i>Note 12</i>
<b>Total current assets</b>	<b>146 558</b>	<b>65 228</b>	<b>211 786</b>	<b>166 999</b>	
<b>Current Liabilities</b>					
Creditors	362	0	362	269	<i>Note 13</i>
Deferred income	400	0	400	360	<i>Note 14</i>
Accrued expenses	1 383	0	1 383	3 265	<i>Note 15</i>
<b>Total current liabilities</b>	<b>2 145</b>	<b>0</b>	<b>2 145</b>	<b>3 894</b>	
<b>Total net assets</b>	<b>144 413</b>	<b>65 228</b>	<b>209 641</b>	<b>163 105</b>	
<b>TOTAL FUNDS</b>	<b>144 413</b>	<b>65 228</b>	<b>209 641</b>	<b>163 105</b>	

The financial statements were approved by the trustees on 20 September 2023

Signed



Alan Lane

Hon. Treasurer

Date: 27 September 2023

# Notes to the Accounts

Notes forming part of the financial statements for the year ended 31 Aug 2023

## 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).

Behçet's UK 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	144 413	65 228	209 641
Total	144 413	65 228	209 641

## 5. Research Fund

The Society received a significant bequest from a former member, together with a number of small donations during the year. No further grants to support research projects were made, but Trustees have earmarked £50k towards the possible creation of a Patient Registry to support research.

## 6. Grants received

No grants were received during the year.

## 7. Other income

These items mainly relate to administrative support given to 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	2023	2022
		£	£
	Wages and salaries	29 055	26 380
	National Insurance contributions	0	0 (after deduction of rebate)
	Employer's pension contributions	<u>605</u>	<u>564</u>
		29 660	26 944

The average number of staff employed during the year was 2 persons (2022 2 persons). There are no employees earning above £60 000 (2022 none).

None of the trustees, nor any persons connected with them, has received any remuneration during the year. Two trustees received expenses for travel and subsistence costs this year totalling £605 (2022: £1227).

**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 rechargeable to Behçet's Patients Centres and donations received via PayPal that had yet to be transferred to the Society's bank account on 31 August.

**11. Prepayments**

Part of insurance premium paid in 2022/23 that relates to 2023/24 and payment in advance for postal forwarding service.

**12. Petty Cash**

Expense floats held by Administrator and Assistant Administrator.

**13. Creditors**

General Fund: Sums owed to HMRC and to the Society's pension provider in respect of August 2023 salaries.

**14. Deferred Income**

Advance subscriptions for 2023/24 received before 1 September 2023.

**15. Accrued expenses**

Staff expenses relating to 2022/23 and provision for fees for independent examination of accounts, as well as sums due for newsletter editing and website maintenance



# Independent Examiner's Report

## TO THE TRUSTEES OF BEHÇET'S UK

I report to the charity trustees on my examination of the accounts of the charity for the year ended 31 August 2023 which are set out on pages 19 to 23.

### *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.



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19 October 2023