



*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 2025

Registered Charity Number 326679

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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, immunobullous diseases; research interests in immunopharmacology, 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 practising 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 at Imperial College London/Hammersmith Hospital

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: Now retired from clinical practice 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: PhD, FRCP, FRCS, FRCOphth

Where qualified: St George's Hospital Medical School, University of London

Year of initial qualification: 1978

Currently practising at: Now retired from clinical practice at Birmingham and Midland Eye Centre but continues with research and teaching.

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 properly for its members. It remains highly visible in several areas within the wider rare disease community and external commentators are oft heard lauding our work, as a small charity punching well above its weight. Our financial position this year was again assisted with a significant bequest, with the caveat to be spent on research. But the need continues to identify an enduring and more predictable revenue stream to cover annual salaries and charitable activities. Members as ever continue to carry out fantastic fundraising, but this does not cover core costs and a net deficit of income over expenditure remains apparent. Our Quarterly Newsletters continue to bear testimony to all the important work that many people are involved with toward supporting each other in our Behçet's community. We are a compassionate, supportive and great institution that, together with Behçet's Patient Support and 'our' 'Behçet's clinicians', support our patients directly.

Governance

Governance of the Society remains mature and comprehensive in accordance with Charity Commission guidance. We are not complacent and continue to systematically review our policies and procedures. The introduction of a Constituent Relationship Management (CRM) system will enhance efficiency considerably allowing our part-time administrative staff to operate more effectively, and within an auditable and secure system. Gemma Darlow is thanked once again for her thorough and conscientious efforts. Board membership has remained stable. Alan Lane, Hon. Treasurer has once again shown exemplary governance of our accounts and helping steer the transition of some responsibilities to the CRM. As always, I take this opportunity to thank our trustees on behalf of members, for their significant contribution and loyal commitment to the Society - offered voluntarily and un-remunerated. We continue to hold a minimum of two joint meetings annually with the Behçet's Patients Centres (BPC) Board of Directors to ensure we are moving forward in harmony and aligned with long-term goals.

Annual Conference

The 2024 Behçet's UK Conference and Annual General Meeting was held at the Liverpool Holiday Inn City Centre, again adopting the successful hybrid style of in-person and online via Zoom Webinar. A total of 98 attended, of whom 38% attended in-person and 62% online. Prof Rob Moots and his team from Liverpool kindly sponsored the occasion. The 2024 Judith Buckle Award was presented to Kai Li in recognition of his significant contribution as a Trustee in 1999 and later Honorary treasurer in 2004 providing a solid foundation and a safe pair of hands for the charities' accounts. It is clear from speaking to those who know Kai and from reading old Newsletters that he did far more than add up a few numbers! The Chair presented the Members Award to John Mather who, for 10-years, was the Operations Manager of the BPC, directly supporting the three Centres of Excellence and investing much time in building the team of Behçet's Support Coordinators. He transformed reporting and how technology is used within the BPC charity and built a strong, trusted relationship with the Commissioners of the Highly Specialised Services who fund the three Centres of Excellence. On top of that John also spent much time and effort fundraising. On all fronts John has been a fantastic ambassador for our patient community and wider membership.

Behçet's Friends and Family Day

Our eighth year of hosting our Behçet's Friends and Family Day, witnessed yet another great occasion, this time hosted at Grafham Water Centre, located between Peterborough and Bedford. This year it was most pleasing to witness a full attendance with only a couple of people needing to pull-out at the last minute. As the event is funded by the Society's hard-earned money, it is important that this trend continues. Gemma Darlow is thanked for the considerable amount of detailed work that is expended to ensure an enjoyable and safe day is had by all.

Newsletter

Our Newsletters remain fundamental to supporting our members. Clare Griffith, Editor, adeptly crafts their compilation and is once more thanked for the high quality of standard produced. Her summaries of conference are particularly comprehensive. All contributors are thanked for their positive articles, which Judi Scott kindly collates. A core product of the Society, including significant input from the BPC, we continue to promote the use of our electronic version which saves the Society money, but the printed version will remain where demand exists.

Medical Factsheets

Our authoritative Medical Fact Sheets are reviewed and amended every couple of years and are important points of reference to both patients and clinicians. A significant source of information particularly for patients who are 'new to Behçet's' they are referenced by all four Nations' NHS websites.

Medical Advisory Panel

Succession planning remains a goal and the panel is an important facility when specific patient query arises. It is with regret that we learned of the death of Dr Colin Barnes (1936-2025) recently who was a leading global figure in promoting research and better care for patients with Behçet's between 1988 and 1997 in addition to his own clinical duties. He was a past Chair of the panel.

Fundraising and Membership

We have again witnessed the generosity of individuals to continue to give of their time and effort to raise essential funds for the Society - £5k in Fundraising activities and donations and other income of £6.7k. We have still to progress our Fundraising Strategy, and this will be a priority for 2025/26. Members with appropriate skill sets are encouraged to assist in this endeavour. We must establish underpinning predictable income generation as *de rigueur*, as notwithstanding the considerable endeavours of individuals to raise money for the Society, we currently do not cover our costs. Following a membership review as part of our CRM implementation, our membership stood at 1318 standard members and 37 junior members as of 31 August 2025.

Research and Supporting Initiatives

Underpinning Pillars

Encouraging research into Behçet's is vital, and it remains my wish to improve the logic of it all, to a strategic plan and collegiately addressed by clinicians and researchers world-wide. The first pillar of this in the UK is to establish a Patient Registry. This has now been agreed and work begun in earnest to prepare the Business Case for submission to the Highly Specialised Services. This is being led by Dr Deva Situnayaka, with Megan Rutter from the Sandwell and West Birmingham Hospitals Trust and Jon Higham from the Birmingham Community Healthcare NHS Foundation Trust, together with the Liverpool and London Centres of Excellence (CoE). It will be based on the West Midlands Secure Data Environment (SDE); SDE data facilities being established across the NHS as a matter of priority in accordance with the 10 Year Health Plan for England. It will start by capturing the data for patients on the CoE books, but a complementary, linked registry is likely to be required to cater for other Behçet's patients in England and especially those in the Devolved Nations. As a minimum, a Patient Reported Outcome Measures System (PROMS) is envisaged so we routinely capture data on patient experience within our health services; and in time compare their treatment, by way of audit, against the joint British Association of Dermatologists and British Society for Rheumatology living guideline for managing people with Behçet's 2024.

The second pillar is conducting a Naturally History Study tracking Behçet's patients in the UK. This will be facilitated by the aforementioned, to establish our particular phenotype (observable characteristics) of the condition within the UK. Thirdly, a Priority Setting Partnership with the James Lind Alliance (to set the 10 most important research questions that are mutually agreed by clinicians, researchers and most importantly including the patient perspective). Regarded as the 'Gold Standard' it attracts 'budding' researchers with an eye on career progression and thus into the bargain will increase awareness of Behçet's within the wider research community.

Finally, we need to get into the genomic medicine arena; where the field of genomic medicine operates, encompassing education, clinical practice, research, and the infrastructure to integrate genomic information into healthcare. The NHS Genomic Medicine Service (GMS), with which the chair is involved, is importantly now undergoing a re-procurement exercise to deliver genomic testing and personalized care across the NHS for the next 10-years (8+2 in the jargon!). A key goal of the GMS is establishing the ability to sequence and analyse entire human genomes at scale and incorporating genomic insights into routine clinical care, such as for diagnosing rare diseases or guiding cancer therapies, and really get into the preventative medicine space. As noted last year, my attendance at the International Conference for Behçet's Disease, ICBD 2024 reinforced my view as to how important this issue is; particularly my discussion in the margins with Dan Kastner, M.D., Ph.D. NIH Distinguished Investigator from the USA, who has maintained a vigorous clinical research program that studies patients with both known and undiagnosed disorders of inflammation.

Gradually, our clinician and scientific colleagues are gaining insights into or DNA – of which the genome only makes up 2%. It is a highly complex area and requires a systemic, collegiate approach to make meaningful progress. The HLA region, particularly, hides much and the focus needs to go much wider than the oft quoted HLAB*51 'association'. Located on the short arm of chromosome 6, it is the most polymorphic (exists or behaves in multiple distinct forms) region of the human genome and encodes proteins responsible for presenting antigens to the immune system. This crucial immune region contains over 200 genes, including Class I and Class II HLA genes (like HLA-A, HLA-B, HLA-C, HLA-DR, HLA-DQ, and HLA-DP) which are highly variable and play a vital role in distinguishing self from non-self by binding and presenting peptides to T-cells. Due to its high variability and strong association with various diseases especially autoimmune diseases understanding the HLA region is critical for medicine.

BAD/BSR living guideline

This important joint initiative promulgated in September 2024, has witnessed its successful initial year of implementation and the first annual review recently completed, for promulgation shortly. This important initiative adds visibility to members of the British Association of Dermatologists (BAD) and British Society for Rheumatology (BSR), ensuring more awareness of Behçet's within the UK. We are most grateful to all those who kindly gave of their own time, unpaid, to 'pull this together' and particularly to Firouz Mohd Mustapa and Alina Constantin - on behalf of the British Association of Dermatologists' Clinical Standards Unit who manage the ongoing administration of the living guideline. Richard West and Laura Forest are thanked once again for their essential input into this area, representing the patient view. We now aim to develop a process of engaging with the wider-membership to help co-produce further this ongoing publication. In time it should be used as 'the standard' to audit against as a check on how patients are actually being treated across respective Health Services. This is something, for example, LUPUS UK successfully carried against their BSR guideline some years ago, and a valuable tool to help achieve equity of treatment.

Other Research

As noted last year, Professor Moots secured significant funding from Novartis for a major trial on the biologic Secukinumab; 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. Behçet's UK contributed £35k to assist with the recruiting of patients, time for which needed to be extended and thus adding to costs.

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Professor Graham Wallace continues to conduct much important research into Microbiome and other areas, some of which we help fund when requested. Professor Fortune continues to support her PhD students with important research papers as does Professor Moots.

Communications Strategy

I continue to represent the Society on Genetic Alliance UK's England Rare Disease Action Plan Patient Advisory Group, with National Voices Heads of Policy Group, the Neurological Alliance, the Prescriptions Charges Coalition, Public Policy Projects and with Beacon (formerly Findacure), alongside several other fora.

On the genomics front, 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.

Social Media

Deborah Cardinal once again maintains a keen eye to spot opportunities for promoting Behçet's UK as followers continue to increase. Facebook now has 2,224 followers of which 75% are from the UK. Instagram has 1,678 followers of which 52% are from the UK. HealthUnlocked now has 5,553 'All Time Members' with consistent active engagement of 712 posts and replies over the year. On TikTok we have 314 followers, while we have only shared the Living with Behçet's animation that one video has secured 19.5k views. We are registered on Linked In with 182 followers although we do not currently post on this site and this option continues to be reviewed. In sum, our online presence continues to increase our visibility across all age groups.

Support Groups

Member Support Groups remain active, and Sarah McAllister has successfully encouraged increased attendance on the England group. Rachael Humphreys' Wales group meets monthly online on Saturdays and held a F2F summer brunch. Fionnuala Mc Kinley's Northern Ireland group meets online and in-person, including in the Republic of Ireland. Yvonne Morris has been in touch with existing members and tends to keep in touch on a 1-2-1 basis. Catherine O'Hara continues to offer support to members in Scotland. As mentioned last year new initiatives from members in this area are welcomed. We are looking to start a 'Spouses Group' which Fionnuala Mc Kinley has suggested we establish. Please get in touch with Gemma or Deborah if you have other ideas to promote member engagement.

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) share their experiences of healthcare, free from stigma or judgement, talk to people living with Behçet's, and gain support from each other and patient advocacy organisations. There are more than 1.5M members, 315 public communities, 250 condition areas and 300 patient organisations 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

We continue to encourage members to get involved with their local politicians, as and when appropriate although best done in a coordinated manner particularly when requested by Behçet's UK. Genetic Alliance UK and National Voices lead in this area with whom the Society keeps in routine contact.

For the record, and repeated from last year, 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,

Links continue with the Republic of Ireland (IPPOSI, MRCG and GRDO) and Europe (EURORDIS).

Calls to the Helpline remain a vital aspect the Society provides. This function continues to be carried out by the chair and Fionnuala McKinley, who is thanked for her important support. Gemma Darlow and Deborah Cardinal are in close support who are often mistakenly telephoned for this function on our administrative number! The use of CRM will greatly improve the passage of information and audit trail in a highly secure environment; conversations that remain confidential and are not shared with anyone unless without the individual's specific consent. We need to develop this function, noting that longevity in role is essential as costs with administrative checks are invoked in providing the necessary preparation for individuals involved in this endeavour.

Our representatives in the Devolved Nations remain Catherine O'Hara, our Vice Chair, in Scotland, Rachael Humphreys in Wales and Fionnuala Mc Kinley in Northern Ireland. Our efforts to establish a Behçet's Specialist Nurse post in Scotland, to help coordinate care in a diverse area, is progressing albeit it slower than hoped. We have been supported by Dr Martina Rodie BSc MBChB MRCPCH PhD who co-chairs the Rare Disease Implementation Board (RDIB) in Scotland, and a successful 'Management of Behçet's Syndrome' Webinar was held on 7 March 2025, with over 80 people registered and a good mix of Health Care Professionals and patients/carers.

The focus for 2026 will be on the Patient Registry initiative which, not before time, is now making real progress. It has the support from Sarah Watson, NHS England, who oversees the Centre of Excellence, as the Highly Specialised Services Senior Commissioning Manager. As I have said previously “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”.

+ Our Future Health

A strong collaboration across the life sciences sector and health system

-for-profit organisation combining support from industry, charities and government to build a world-leading health research programme

Funders

- UK Research and Innovation
- GSK
- AstraZeneca
- Illumina
- Novartis
- Roche
- Amgen
- Pfizer
- MSD
- Biogen
- Johnson & Johnson
- Novartis

Affiliate charities

- Alzheimer's Society
- Cancer Research UK
- Dementia Research Service
- Diabetes UK
- Heart Foundation
- Macmillan Cancer Support
- MRC
- NCI
- Nuffield Foundation
- Wellcome
- and others

become an Affiliate Member – at no cost to the Society (apart from your Chair's time....!)

I will again remind that, on the clinical side, we continue to benefit from the three specialist National multi-disciplinary Centres of Excellence led by three highly renowned Clinical Director's; Professor Rob Moots, Professor Farida Fortune CBE and Dr Deva Situnayake. The centres having increased patient numbers, with effectively no additional resources comparative to 2013/14 when they were formed. This has resulted in less timely response times and so forth but with initiatives such as Patient Initiated Follow-up (a National Health Service initiative) more efficiency is being achieved, given finite resources, to help Behçet's patients as optimally as possible. All staff operating within the centres have many other roles within the NHS, which must be acknowledged and accepted.

The Behçet's Patients Support staff, namely Jean Christians, Rebecca Hyder and Jackie Pooler, managed by Denise Lavers, the newly appointed Operational Lead, directly support them. John Mather is thanked for his considerable efforts to guide this vital aspect since the formation of the Centres; together with Jan Mather and her Board of Directors supporting.

Conclusion

In summary, the Society continues to discharge its responsibilities, strengthening its position in many areas within the wider rare disease community, and is oft quoted as an exemplar given it's relatively small size comparatively to most other charities. The promulgation of the BAD/BSR living guideline, as I stated last year, will over time reap wide benefits – and we now need to facilitate a method of feedback from members in advance of the annual review process. Instigating the Constituent Management System is already making a difference to our administrator's efficient use of valuable but limited time. Strategically, it will safeguard succession planning, so that vital, hard-earned information capture does not disappear when post-holders inevitably move on. It will improve our knowledge, understanding, connections and feedback with our membership.

We are most grateful to all of you who help resource what we do to assist each other; whether financially or by way of other support. As stated last year, our financial position remains relatively strong by comparison to the past but only thanks to significant bequests. So we must 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 are not currently covering our costs. We continue to benefit from an astute Treasurer in this regard who is guiding fellow trustees in exemplary fashion, and ensuring we spend your money wisely.

Once more I thank everyone who continues to make Behçet's UK the compassionate and great institution that it is, together with the clinicians who support our patients. Gemma Darlow and Deborah Cardinal's significant efforts underpin all the necessary administrative aspects that the Society needs, backed-up by your Trustees who continue to give of their valuable time, voluntarily. I remain most grateful for their continued loyal support.

Tony Thornburn OBE

Chair of Trustees

19 September 2025

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 never cease to amaze us with the events they plan and the challenges they take on. For the year from September 2024 to August 2025 income from fundraising activities and their associated donations came to £17k. Over the next couple of pages we have included just a few of our fantastic fundraisers from the past financial year.

We always welcome supporters who are keen to get involved in fundraising. Visit our website <https://behcetsuk.org/get-involved> to find out ways you can help and how we can support your fundraiser. Alternatively contact our admin team by email at info@behcetsuk.org or call 0345 130 7328 and they will be happy to help.

Neil Williams

Trustee & Fundraising Committee Chair

14 September 2025

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





Magnificent Marathoners

We have always been lucky to have supporters keen to take on a running challenge but this year seemed to be the year of the

Emily conquered the RunFest Marathon raising over £400

Jemma's Manchester half marathon raised over £800 to honour her aunt

Harry ran the London Marathon in honour of his brother and raised over £1000

David took on a staggering 4 marathons in 4 days in honour of his sister and raised in excess of £3,000

Bea who has Behçet's ran the Yorkshire Marathon to achieve a life goal as well as raise over £800



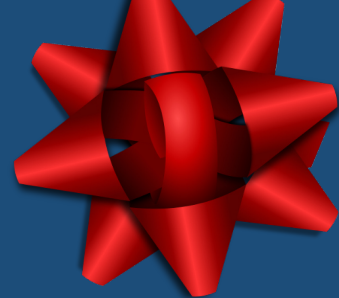
Kerry held a bake sale for International Behçet's Awareness Day in May with her colleagues and raised £54



Ruth held her annual ladies ball which she has been running for over 10 years. 100 ladies attended the evening in March 2025 which raised £2000

Facebook, Instagram & general fundraisers

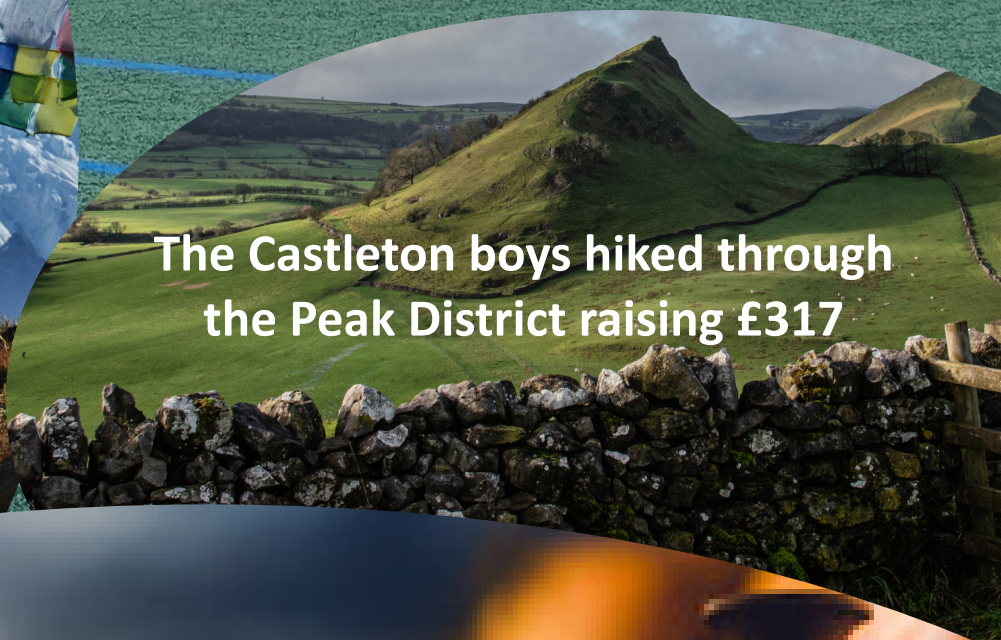
16 members and supporters kindly set up a Facebook Fundraiser this year, most of which were to celebrate their birthday which allowed friends and family to make a donation in lieu of birthday gifts and raised £1171.68



Emily's trek to Everest Base Camp for her 30th birthday raised £300



FC Hyndurn held a memorial football fundraiser for Gary Moore with a match and evening event raising over £850



The Castleton boys hiked through the Peak District raising £317

Stephen & Clare helped make Halloween even more spooktacular for their village by putting on the most gruesome display for the local trick or treaters. They raised over £1000 in memory of their friend Chris who had always loved their annual Halloween displays.



Report of the Trustees for the year ended 31 August 2025

The trustees present their report along with the financial statements of the charity for the year ended 31 August 2025. 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; and
- providing financial assistance to relieve poverty among Behçet's Patients.

Organisation

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 of Trustees

19 September 2025

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
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
Suite I, Windrush Court
ABINGDON
OX14 1SY

Administration Office

Behçet's UK
124 City Road
LONDON
EC1V 2NX

Office Tel: 0345 130 7328
Helpline Tel: 0345 130 7329
Email: info@behcetsuk.org
Web: behcetsuk.org

Registered Charity No: 326679

Report on Financial Statement 2024/25

In last year's report, I remarked that 2023/24 had been a 'more normal year', after the two previous years in which the Society had benefited from several bequests and had been able to set aside sums of £50k each, one towards the creation of a post for a specialist nurse in Scotland and the other for the establishment of a Patient Registry to aid research into Behçet's. These had been noted in the accounts as 'Project Funds' so that it was clear that they were not available for other purposes.

In the event, progress has been made with regard to the Patient Registry without a call on our funds, so that part of the Project Fund has been taken back into our General Fund. Some steps have been taken towards the Scottish project, but only small costs have been incurred to date.

This year The Society has received its largest ever single donation (almost £178k), being the balance of the estate of a wonderful former member, Mrs Margaret Bane, who had made several donations to our Research Fund in her lifetime and to which fund Trustees have allocated her bequest.

It is great news that we have entered 2025/26 with our largest ever reserves, which we hope to be able to use to help with one or more major research projects. However, I have to note that we are crucially dependent upon bequests and fundraising events, as our only predictable income, from subscriptions and donations, is significantly less than our commitments on salaries and charitable activities.

The General Fund received income this year of £37.4k, including £9.6k in subscriptions, £18.7k in donations and fundraising activities, £1k from a legacy and other income totalling £6.7k. Expenditure was £101.3k and there was a net deficit on the General Fund of £11.5k, after the return of £50k from the Projects Fund, leaving accumulated reserves of £62.8k.

Expenditure was larger than usual, as costs were incurred in setting up a web-based 'Constituent Relationship Management' (CRM) system, that will enable us to keep records of contacts with members and others more efficiently in future, with some saving of staff time.

The Research Fund had a total income of £178.0k, compared with £0.4k last year, when there were just a few small donations. One grant of £35k was made to the University of Liverpool to support its trial of Secukinamab. Its reserves now stand at £160.7k. It will be an important task for Trustees to determine how best to utilise this balance in the year ahead.

The Projects Fund now holds a balance of £49k, earmarked for the Scottish project mentioned above.

Subscriptions. It was agreed by members at our AGM in October to increase the annual subscription for standard membership to £30, the first increase since 2011. Members under 25 and those in receipt of means-tested UK state benefits continue to be eligible for free membership. Many members already make more generous donations or undertake fundraising for the Society, which will continue to be encouraged, as well as Gift Aiding subscriptions, where possible, and consideration of making bequests in wills to help the service we give to members and to assist us in supporting research into this rare disease.

We continue to be indebted to our two part-time members of staff, who do the bulk of our administration, and I should like to thank them for all their hard work during the past year.

Alan Lane

Hon. Treasurer

22 September 2025

Statement of Financial Activities

2024/25

Statement of Financial Activities for the year ended 31 August 2025

	General Fund	Research Fund	Projects Fund	Total 2025	Total 2024	
	£	£	£	£	£	
Income and endowments						
Donations and fundraising	18 744	160	0	18 904	25 609	Note 5
Bequests and legacies	1 000	177 824	0	178 824	0	
Subscriptions	9 617	0	0	9 617	9 141	
Gift Aid tax reclaimed	3 085	8	0	3 093	3 140	
Grants received	0	0	0	0	4 062	Note 6
Sales of goods	1 252	0	0	1 252	775	
Other	3 684	0	0	3 684	4 663	Note 7
Total income and endowments	37 382	177 992	0	215 374	47 390	
Expenditure on charitable activities						
Trading costs	300	0	0	300	129	
Event costs	3 432	0	0	3 432	1 925	
Fundraising costs	415	0	0	415	779	
Staff training	63	0	63	0	0	
Grants and bursaries	1 303	0	1 000	2 303	1 145	
Research grants	0	35 000	0	35 000	0	
Subscriptions to other organizations	863	0	0	863	683	
Helpline costs	127	0	0	127	117	
Grants to other charities	25 000	0	0	25 000	0	Note 8
Salaries and wages	35 187	0	0	35 187	31 623	Note 9
Social security and pensions	707	0	0	707	650	Note 9
Travel and subsistence	3 289	0	0	3 289	3 863	
Insurance	1 480	0	0	1 480	988	
Telephone charges	700	0	0	7 00	585	
Printing, postage, stationery etc.	659	0	0	659	1 246	
Equipment purchases	192	0	0	192	181	
Newsletter	10 697	0	0	10 697	10 375	
Web site and publicity	670	1 020	0	1 690	600	
ICT hardware	912	0	0	912	53	
ICT software and management	4 713	0	0	4 713	2 651	
Annual Conference and AGM	7 894	0	0	7 894	9 265	
Governance costs	1 286	0	0	1 286	1 646	
Other	1451	0	0	1451	807	
Total expenditure	101 340	36 020	1 000	138 360	69 311	
Net expenditure before gains on investments	-63 958	141 972	-1 000	77 014	-21 921	
Net gains on investments	2 449	1 515	0	3 964	3 806	
NET INCOME	-61 509	143 487	-1 000	80 978	-18 115	
Transfers between funds	50 000	0	-50 000	0	0	
Net movements in Funds after transfers	-11 509	143 487	-51 000	80 978	-118 115	
RECONCILIATION OF FUNDS						
Fund balance brought forward at 1 Sep 2024	74 309	17 217	100 000	191 526	209 641	
Fund balance carried forward at 31 Aug 2025	62 800	160 704	49 000	272 504	191 526	

Statement of Financial Activities

2023/24

Statement of Financial Activities for the year ended 31 August 2024

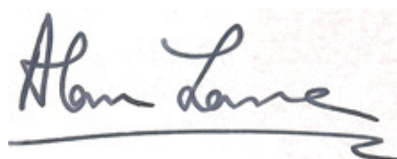
	General Fund	Research Fund	Projects Fund	Total 2024	Total 2023	
	£	£	£	£	£	
Income and endowments						
Donations and fundraising	25 219	390	0	25 609	32 962	Note 5
Bequests and legacies	0	0	0	0	57 081	
Subscriptions	9 141	0	0	9 141	10 051	
Gift Aid tax reclaimed	3 120	20	0	3 140	5 027	
Grants received	4 062	0	0	4 062	0	Note 6
Sales of goods	775	0	0	775	784	
Other	4 663	0	0	4 663	5 085	Note 7
Total income and endowments	46 980	410	0	47 390	110 990	
Expenditure on charitable activities						
Trading costs	129	0	0	129	0	
Event costs	1 925	0	0	1 925	2 652	
Fundraising costs	779	0	0	779	703	
Staff training	0	0	0	0	0	
Grants and bursaries	1 145	0	0	1 145	3 412	
Research grants	0	0	0	0	0	
Subscriptions to other organizations	683	0	0	683	705	
Helpline costs	117	0	0	117	98	
Salaries and wages	31 623	0	0	31 623	29 055	Note 9
Social security and pensions	650	0	0	650	605	Note 9
Travel and subsistence	3 863	0	0	3 863	818	
Insurance	988	0	0	988	913	
Telephone charges	585	0	0	585	515	
Printing, postage, stationery etc.	1 246	0	0	1 246	1 254	
Equipment purchases	181	0	0	181	292	
Newsletter	10 375	0	0	10 375	9 672	
Web site and publicity	600	0	0	600	412	
ICT hardware	53	0	0	53	971	
ICT software and management	2 651	0	0	2 651	1 102	
Annual Conference and AGM	9 265	0	0	9 265	9 078	
Governance costs	1 646	0	0	1 646	2 713	
Other	807	0	0	807	1 267	
Total expenditure	69 311	0	0	69 311	66 237	
Net expenditure before gains on investments	-22 331	410	0	-21 921	44 753	
Net gains on investments	2 227	1 579	0	3 806	1 783	
NET INCOME	-20 104	1 989	0	-18 115	45 836	
Transfers between funds	-50 000	-50 000	100 000	0	0	
Net movements in Funds after transfers	-70 104	-48 011	100 000	-118 115	45 836	
RECONCILIATION OF FUNDS						
Fund balance brought forward at 1 Sep 2023	144 413	65 228	0	209 641	163 105	
Fund balance carried forward at 31 Aug 2024	74 309	17 217	100 000	191 526	209 641	

Balance Sheet (31 August 2025)

Balance Sheet as at 31 Aug 2025	General Fund	Research Fund	Projects Fund	Total 2025	Total 2024	
	£	£		£	£	
Current Assets						
Stock in hand	1 532	0	0	1 532	1 532	Note 10
Debtors	12	0	0	12	116	Note 11
Prepayments	283	0	0	283	649	Note 12
Accrued income	1 920	0	0	1 920	900	Note 12
Recoverable Gift Aid	362	419	0	781	851	
Deposit Accounts	-29 764	192 155	100 000	262 391	185 257	
Current Accounts	89 335	-31 870	-51 000	6 465	3 398	
Petty Cash	350	0	0	350	350	Note 13
Total current assets	64 030	160 704	49 000	273 734	193 053	
Current Liabilities						
Creditors	510	0	0	510	348	Note 14
Deferred income	0	0	0	0	430	Note 15
Accrued expenses	720	0	0	720	749	Note 16
Total current liabilities	1 230	0	0	1 230	1 527	
Total net assets	62 800	160 704	49 000	272 504	191 526	
TOTAL FUNDS	62 800	160 704	49 000	272 504	191 526	

The financial statements were approved by the trustees on 17 September 2025

Signed



Alan Lane

Hon. Treasurer

22 September 2025

Notes to the Accounts

Notes forming part of the financial statements for the year ended 31 Aug 2025

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.

The Projects Fund was opened in 2024 and is intended to hold funds that have been earmarked by Trustees for major projects, but where no contractual obligations have yet been undertaken.

Analysis of net assets between funds

	Unrestricted Funds	Restricted Funds	Project Funds	Total
	£	£	£	£
Net current assets	62 800	160 704	49 000	272 504
Total	62 800	160 704	49 000	272 504

5. Donations

A number of members made small donations to the Research Fund, totalling £0.2k, in addition to their subscriptions this year.

6. Grants received

No grants were received this year from outside bodies.

7. Other income

These items mainly relate to Gift Aid and 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. Grants to other charities

The Trustees made one grant this year of £25k to support the work of our sister charity Behçet's Patients Centres, which employs a part-time support co-ordinator at each of the three Behçet's Centres of Excellence at NHS hospitals in London, Birmingham and Liverpool, as well as a part-time Operations Lead.

9. Salary costs Year ending 31 August	2025	2024
	£	£
Wages and salaries	35 187	31 623
National Insurance contributions	0	0 (after deduction of rebate)
Employer's pension contributions	<u>707</u>	<u>650</u>
	35 894	32 273

The average number of staff employed during the year was 2 persons (2024, 2 persons). There are no employees earning above £60 000 (2024 none).

None of the trustees, nor any persons connected with them, has received any remuneration during the year. One trustee received expenses for travel and subsistence costs this year totalling £1806 (2024: £2777).

10. Stock

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

11. Debtors

Donations received via PayPal that had yet to be transferred to the Society's bank account on 31 August.

12. Prepayments

Parts of subscriptions paid in 2024/25 that relate to 2025/26 and payment in advance for Conference costs.

13. Petty Cash

Expense floats held by Administrator and Assistant Administrator.

14. Creditors

General Fund: Sum owed to HMRC in respect of August 2025 salaries.

15. Deferred Income

Advance subscriptions for 2024/25 received before 1 September 2024 (none received in 2024/25 for 2025/26).

16. Accrued expenses

Provision for fees for independent examination of accounts (plus staff expenses relating to 2023/24 paid in 2024/25)

Independent Examiner's Report

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 2025 which are set out on pages 17 to 21.

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
UHY Ross Brooke
Suite I
Windrush Court
Abingdon
OX14 1SY

Date: 15/10/2025