



*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 2024

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

Once more I am proud to announce that the Society continues to discharge its responsibilities and strengthening its position in several areas within the wider rare disease community. Our financial position has been helped by three significant legacies, allowing routine annual expenditure to be guaranteed for future years, and research and support initiatives to be progressed. Members continue to carry out fantastic fundraising. That all said, we continue to witness 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 has happened over the year. They continue to be a testimony to all the supportive endeavours that many people contribute toward to supporting our Behçet's community. We are a compassionate, supportive and great institution that together with 'our' 'Behçet's clinicians' support our patients directly. It remains a privilege to represent you as its Chair.

Governance

The governance of the Society remains mature and comprehensive in accordance with Charity Commission guidance. We are not complacent however, and continue to review our policies and procedures. Gemma Darlow is once again thanked for her thorough and conscientious efforts in this regard. Much underpinning work continues in the background and the soon-to-be introduced Constituent Relationship Management System, similar to Customer Relationship Management systems which are routinely used in commerce, will improve efficiency considerably. Board membership has remained stable, for which as Chair I am most appreciative. Alan Lane, Hon. Treasurer 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 significant contribution and loyal commitment to the Society – noting again, for the benefit of new members, that this is offered voluntarily and un-remunerated. We have trustee representation 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 2023 Behçet's UK Conference and Annual General Meeting was held at the Mercure Telford Central, again adopting the successful hybrid style; both in-person and online via Zoom Webinar. A total of 171 registered, of whom 71 were in person and 100 online. Dr Deva Situnayake and his team from Birmingham kindly sponsored the occasion. The 2023 Judith Buckle Award was presented to Barrie and Georgina Seaman who joined the Society in 1985 in recognition for all they have done for Behçet's members; as trustees, Honorary Secretary and Honorary Treasurer. The Chair presented the Members Award to Clare Gibson who has been a member since 2014 and noted her inspirational approach to overcoming Behçet's, her chairing of a Support Group and her amazing success in the Invictus Games 2023, held in Dusseldorf; securing three Gold and two Silver medals. Clare also appeared on television at the Royal British Legion Festival of Remembrance.

Behçet's Friends and Family Day

Our seventh year of hosting our Behçet's Friends and Family Day, witnessed another great occasion, this time hosted at Llandegfedd Lake near Pontypool and enjoyed by everyone who participated. The event is funded by the Society's hard-earned money, so it was pleasing to see this year full representation by those who had book a place.

Newsletter

Our Newsletters continue to offer much information and support to members. Our Editor, Clare Griffith, who masterminds their compilation is thanked for the high quality of standard produced. All contributors are thanked for their positive articles, which Judi Scott collates. This is a core product of the Society, 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

Our Medical Fact Sheets are reviewed and amended routinely, which are 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 continue to be frustrated that no progress has been achieved to have an accompanying NHS logo printed on our revised Alert Card.

Medical Advisory Panel

This is an area which still needs work to revitalise with succession planning in mind.

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 - £25k in Fundraising activities and donations this past year. Neil Williams is working-up our Fundraising Strategy and seeks additional members with appropriate skills to assist him. We have to establish underpinning predictable income generation as de rigueur, as notwithstanding the aforesaid generous donations, and the considerable endeavours of individuals to raise money for the Society, we currently do not cover our costs. Our membership stands at 1314 standard members, compared with 1297 last year, 35 junior members and 67 associate members (mainly medical professionals).

Research

I have routinely stated that whilst research is important, much of it (if not all presently) the Society have no control over. When funds permit, we need to conduct a Priority Setting Partnership with the James Lind Alliance, to set the 10 most important research questions that are mutually agreed, by a robust and well-established process, that clinicians, researchers and most importantly 'the patient perspective' agree. It is regarded as the 'Gold Standard' and thus attracts researchers with an eye on their progressing careers – which subliminally would increase interest in Behçet's into the bargain.

I comment under the heading 'looking forward' the issue of a Behçet's Patient Registry so will not repeat here. A 'Natural History study of Behçet's within the UK' should follow. We then need to get into Whole Genome Sequencing at scale. Professor Graham Wallace continues to conduct much research, some of which we help fund. Professor Fortune continues to support her PhD students with research papers as does Professor Moots.

Other Research - Secukinumab

Professor Moots 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. Behçet's UK has pledged £35k to assist with the recruiting of patients, time for which needed to be extended and thus added to costs.

Supporting Initiatives

British Association of Dermatologists and British Society for Rheumatology living guideline for managing people with Behçet's 2024

This important joint initiative was promulgated in September 2024, and as noted last year is an important initiative. First, the visibility it will offer to members of the British Association of Dermatologists (BAD) and British Society for Rheumatology (BSR) will ensure much more awareness of the condition. Second, it has been produced for our own community within the UK. Whilst there remains a current EULAR guideline it was noted in the most recent International Society for Behçet's Disease Conference in Marrakech (ICBD 2024) that the

phenotype (observable traits) varies from country to country. Therefore, it is important to have a guideline tailored to our own nation and written by those who treat patients in the UK.

We are most grateful to all those who kindly gave of their own time, unpaid, to ‘pull this together’ over a period of 5-years: they are Ruth Murphy, Robert Moots, Paul Brogan, Aykut Çelik, Mark Clement-Jones, Ian Coulson, Adam Croft, Suzanne Crozier, Laura Forrest, Jonathan Harrold, Steve Higgins, Ali Jawad, Seema Kalra, Sidra Khan, Hilary McKee, Clare Pain, Harry Petrushkin, Ana Poveda-Gallego, Jane Setterfield, Poonam Sharma, Richard West, Christina Wlodek, Maria Hashme, Lina Manounah, Firouz Mohd Mustapa, and Alina Constantin - on behalf of the British Association of Dermatologists’ Clinical Standards Unit and the British Society for Rheumatology.

I wish to pay particular thanks to Richard West and Laura Forest who represented the all-important ‘patient view’ and for their time and effort reviewing the guideline, and indeed writing-up some aspects. Also, Professor Ruth Murphy who was a driving force behind this initiative. As a ‘living guideline’ this is a ‘first’ in both BAD and BSR, and basically means that rather than becoming defunct in 5-year’s time, and having to be re-written, will be reviewed and update every couple of years; ensuring it is enduring and kept up-to-date with the latest scientific knowledge and treatment proposals. The promulgation of this living guideline will, over time reap wide benefits – and at some stage we will ask that an audit is conducted by the NHS against it, to gauge whether Behçet's patients are indeed being served properly.

Communications Strategy

I continue to 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 and 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 – as I noted last year I remain alert to identifying opportunities where the Behçet's community may benefit from future initiatives. Attendance at the International Conference for Behçet's Disease, ICBD 2024 reinforced my view as to how important this issue is. 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.

Social Media

Deborah Cardinal is commended again on maintaining a keen eye to spot opportunities for promoting Behçet's UK as followers continue to increase. Facebook now has 2,047 followers of which 74% are from the UK. Instagram has 1,472 followers of which 52% are from the UK and has seen a 100% increase in content interactions. HealthUnlocked now has 5,336 ‘All Time Members’ with a high post engagement rate. On TikTok we have 122 followers, while we have only shared the Living with Behçet’s animation that one video has secured 4,648 views. We are registered on Linked In with 168 followers although we do not currently post on this site and this option will be reviewed. In sum, our online presence continues to increase our visibility across all age groups.

Support Groups

As I noted last year Member Support Groups remain active and popular with Clare Gibson’s England group and Rachael Humphreys’ Wales group regularly meeting online and Fionnuala Mc Kinley’s Northern Ireland group meeting online and in-person. Yvonne Morris and Catherine O’Hara continue to offer support to members in their areas. New initiatives from members in this area are welcomed, so please 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) 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 as I noted last year, this is best done in a coordinated manner particularly when requested by Behçet's UK. Genetic Alliance UK leads in this area with whom the Society keeps in routine 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. My attendance at the 2024 EURODIS Open Academy School on Scientific Innovation & Translation Research was helpful in this regard in establishing new contacts – a number of whom I met mentioned Richard West, who did a grand job in this regard.

Helpline

Calls to the Helpline remain an important area that the Society provides. This function continues to be carried out on most days by the Tony Thornburn and Fionnuala Mc Kinley, with Catherine O'Hara and Gemma Darlow in close support who are all thanked for their vital contributions. 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 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 with the support particularly of Dr Martina Rodie BSc MBChB MRCPCH PhD who co-chairs the Rare Disease Implementation Board (RDIB) in Scotland. Our Patron, Baroness Margaret Ritchie, stands ready to assist in Northern Ireland – as with many things, timing is of the essence, and recent elections have inevitably delayed matters.

Looking Forward

The recent International Conference for Behçet's Disease 2024, which I attended, confirmed the judgement I made way back in December 2018, circulated to the three Clinical Directors of the Centres of Excellence, that we need to establish a UK Behçet's Patient Registry which needs to be managed by, effectively a 'neutral bystander' - e.g. Behçet's UK - for the benefit of all and cater for succession planning when our experienced clinicians inevitably retire. It should not, for example, be housed under one NHS University Hospital Trust, ensuring that no conflicts of interest ever emerge. That said, as I did last year, "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". Without this fundamental principle the register will not achieve the desired outcome required.

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 Behçet's Patients Support staff, namely Jean Christians, Rebecca Hyder and Jackie Pooler, managed by John Mather (and now Denise Lavers) the Operations Manager directly support them. John is thanked for his considerable efforts to guide this vital aspect since the formation of the Centres.

Conclusion

I make no apology for repeating much of what I said in last year's report. Facts don't change, though circumstances (context) do of course. The Society continues to discharge its responsibilities and is strengthening its position in many areas within the wider rare disease community. The promulgation of the BAD/BSR living guideline will over time reap wide benefits – and at some stage we will ask that an audit is conducted against it, to gauge whether Behçet's patients are being properly served.

Our financial position is relatively strong, by comparison to the past, but only thanks to three significant bequests, allowing routine annual expenditure to be guaranteed for future years, and research and support initiatives to be initially progressed. But, as our Treasurer notes, 'normal' income that can be expected by the Society is now significantly less than our essential expenditure. This reinforces the point I made last year 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. We benefit from an astute Treasurer who is guiding fellow trustees in exemplary fashion.

I end, as I did last year, 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 of Trustees

22 September 2024

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 2023 to August 2024 income from fundraising and donations stood at £25k and over the next couple of pages we have included just a few of our fantastic fundraisers from the past financial year.

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


Neil Williams

Trustee & Fundraising Committee Chair


20 September 2024

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





Ruth held her annual Ladies Ball in aid of Behçet's UK in March and again beat last years total raising £2421!



Malcolm and Ann have continued their Bake for Behçet's success last year by hosting more events as well as still collecting and selling postage stamps. This year they have raised over £300 for Behçet's UK.



Our Remarkable Runners!

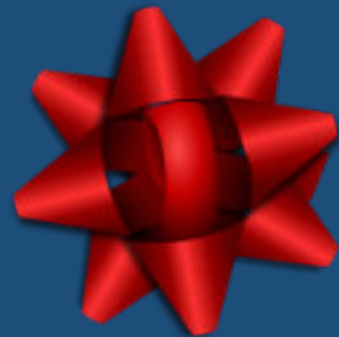
Laura C didn't let her Behçet's beat her and tackled a half marathon in Dublin and raised £972 including Gift Aid.

After years of believing he was a non-runner with dodgy knees Mark went on to run two half-marathons and raised £1788 including Gift Aid.

Facebook and Instagram Fundraisers

13 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 £1432.

Instagram Feed Fundraisers raised a further £127 and general donations via the Facebook button raised £50.



The Evolution Choir performed to raise funds for Behçet's UK with and raised £331 including Gift Aid.



William, Brenda & Jenni, with the Barrossa Somme Association, organised a charity football match and raffle of football memorabilia and raised £1000.



Laura braved a skydive and with the help of her colleagues at three local branches of Natwest they have raised over £2800 (including Gift Aid) so far and are still fundraising!

Report of the Trustees for the year ended 31 August 2024

The trustees present their report along with the financial statements of the charity for the year ended 31 August 2024. 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

18 September 2024

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

2023/24

In last year's report, I was able to share the news that the Trustees had earmarked sums of £50k for each of two exciting developments, the creation of a post for a specialist nurse in Scotland and the establishment of a Patient Registry to aid research into Behçet's. My fellow Trustees have done a great deal of work towards making these possible, but as yet we have not reached the stage of having firm plans and entering into contractual agreements. In setting out our accounts for the financial year just ended, these sums are shown as 'Project Funds' so that it is clear that they are not available for other purposes.

The Society was in a position to do this as a result of receiving three generous bequests from former members during preceding financial years. However, no further benefactions of this kind were received in 2023/24 and so the following accounts describe a more normal year.

The General Fund received income this year of £47.0k, including £31.4k in subscriptions and donations, £3.8k from fundraising activities and sales, one grant of £4.1k and other income totalling £7.7k. Expenditure was £69.3k and there was a net deficit on the General Fund of £20.1k, in addition to the transfer of £50k to the Projects Fund, leaving accumulated reserves of £74.3k.

The Research Fund had a total income of £0.4k, from a number of small donations and, after the transfer of £50k to the Projects Fund, its reserves now stand at £17.2k.

The Projects Fund holds the total of £100k that has been earmarked for the projects stated above.

Subscriptions. In view of the fact that the 'normal' income that can be expected by the Society is now significantly less than our essential expenditure, which includes our newsletters, Annual Conference, charitable grants and staff costs, Trustees have had to make the decision to recommend 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 will 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 for the future benefit of the.

Membership continues to show a steady increase, the large majority of members being patients or carers for Behçet's sufferers. In September 2024, we had 1314 standard members, compared with 1297 on that date last year. In addition, there were 35 junior members and 67 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 1437, compared with 1423 the previous year, of whom 1183 were patients and 75% were female. The number in receipt of UK means-tested state benefits, was 1015, compared with 995 the previous year, a further small increase as in previous years.

I should, once again, 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

9 September 2024

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	22 237	390	0	22 627	27 806	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
Fundraising activities	2 982	0	0	2 982	5 156	
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 8
Social security and pensions	650	0	0	650	605	Note 8
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	46 536	
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	46 536	
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	

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	27 776	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	5 186	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	

Balance Sheet

Balance Sheet as at 31 Aug 2024	General Fund	Research Fund	Projects Fund	Total 2024	Total 2023	
	£	£		£	£	
Current Assets						
Stock in hand	1 532	0	0	1 532	1 719	Note 9
Debtors	116	0	0	116	133	Note 10
Prepayments	649	0	0	649	577	Note 11
Accrued income	900	0	0	900	406	Note 11
Recoverable Gift Aid	441	410	0	851	2 003	
Deposit Accounts	69 616	15 641	100 000	185 257	204 962	
Current Accounts	2 232	1 166	0	3 398	1 636	
Petty Cash	350	0	0	350	350	Note 12
Total current assets	75 836	17 217	100 000	193 053	211 786	
Current Liabilities						
Creditors	348	0	0	348	362	Note 13
Deferred income	430	0	0	430	400	Note 14
Accrued expenses	749	0	0	749	1 383	Note 15
Total current liabilities	1 527	0	0	1 527	2 145	
Total net assets	74 309	17 217	100 000	191 526	209 641	
TOTAL FUNDS	74 309	17 217	100 000	191 526	209 641	

The financial statements were approved by the trustees on 18 September 2024

Signed



Alan Lane

Hon. Treasurer

22 September 2024

Notes to the Accounts

Notes forming part of the financial statements for the year ended 31 Aug 2024

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	74 309	17 217	100 000	191 526
Total	74 309	17 217	100 000	191 526

5. Donations

A number of members made small donations to the Research Fund, totalling £0.4k, in addition to their subscriptions this year. No new research grants were awarded by the Trustees.

6. Grants received

Trustees were pleased to receive one grant of £4062 this year from the British Association of Dermatologists.

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. Salary costs Year ending 31 August

	2024	2023
	£	£
Wages and salaries	31 623	29 055
National Insurance contributions	0	0 (after deduction of rebate)
Employer's pension contributions	<u>650</u>	<u>605</u>
	32 273	29 660

The average number of staff employed during the year was 2 persons (2023, 2 persons). There are no employees earning above £60 000 (2023 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 £2777 (2022: £605).

9. Stock

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

10. Debtors

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

11. Prepayments

Part of insurance premium paid in 2032/24 that relates to 2024/25 and payment in advance for other subscriptions.

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 2024 salaries.

14. Deferred Income

Advance subscriptions for 2024/25 received before 1 September 2024.

15. Accrued expenses

Staff expenses relating to 2023/24 and provision for fees for independent examination of accounts

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 2024 which are set out on pages 16 to 20.

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: 14/10/2024