

# Annual Report 2021



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

Registered Charity No: 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, immuno-bullous diseases; research interests in immuno-pharmacology, cell regulatory mechanisms and medical education





## Paul Brogan

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

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

**Where qualified:** Manchester Medical School

**Year of initial qualification:** 1993

**Currently practising at:** Great Ormond St Hospital, London

**Special interests:** Vasculitis, vascular inflammation in the young



## Andrew de Burgh-Thomas

**Job title:** Consultant in Genitourinary Medicine

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

**Where qualified:** University of London

**Year of initial qualification:** 1994

**Currently practising at:** Gloucester Royal Hospital, Cheltenham General Hospital and Bristol Southmead Hospital

**Member of:** British Association of Sexual Health and HIV, British Medical Association, Royal College of Physicians, FSRH, ESSM

**Special interests:** HIV and genital dermatology



## Farida Fortune CBE

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

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

**Where qualified:** University College London

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

**Currently practicing at:** Barts Health, Royal London site Queen Mary University of London

**Special interests:** Immunology and Oral Medicine



## Dorian O Haskard

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

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

**Where qualified:** University of London

**Year of initial qualification:** 1977

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

**Special interests:** Vascular inflammation





## Desmond Kidd

**Job title:** Consultant Neurologist

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

**Where qualified:** Ireland

**Year of initial qualification:** 1986

**Currently practising at:** Royal Free Hospital, London

**Special interests:** Neurological complications of inflammatory diseases, particularly Behçet's syndrome, sarcoidosis and histiocytosis; neuro-ophthalmology



## Philip Ian Murray

**Job title:** Professor of Ophthalmology, University of Birmingham

**Qualifications/Post Nominals:** MBBS, DO(RCS), PhD, FRCP, FRCS, FRCOphth

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

**Year of initial qualification:** 1978

**Currently practising at:** Birmingham and Midland Eye Centre, City Hospital, Sandwell and West Birmingham Hospitals NHS Trust

**Special interests:** All types of uveitis including Behçet's disease. Scleritis.

*Clinical Research:* Quality of Life in uveitis, *Laboratory Research:* The eye has evolved many mechanisms to prevent significant inflammation, which can lead to visual impairment. I am investigating why in patients with uveitis, the eye cannot control the inflammation. Jazz!



## Catherine Nelson-Piercy

**Job title:** Professor Obstetric Physician

**Qualifications/ Post Nominals:** MBBSMA, FRCP, FRCOG

**Where qualified:** Cambridge University and St Bartholomew's Hospital

**Year of initial qualification:** 1986

**Currently practising at:** Guy's and St Thomas' Hospitals Foundation Trust and Queen Charlotte's Hospital, Imperial College Healthcare Trust

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



## 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



## Graham Wallace

**Job title:** Senior Lecturer

**Qualifications/Post Nominals:** BSc Immunology, PhD

**Where qualified:** University of London

**Year of initial qualification:** 1985 (PhD)

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

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



## Medical Advisory Board - Past Members



### Colin Barnes (Past Chairman)

Dr Colin G Barnes (BSc, MBBS, FRCP) qualified at the University of London in 1961. Now retired Colin was formerly Clinical Director for Rheumatology at The Royal London Hospital. He is Honorary Life President of the International Society for Behçet's Disease (ISBD), past President of the European League Against Rheumatism and past Chairman of the Executive of the Arthritis and Rheumatism Council (now Arthritis Research Campaign). A member of the British Society for Rheumatology and has a special interest in clinical rheumatology and, of course, in Behçet's.



### Sue Lightman

Sue Lightman (FRCP FRCOphth PhD FMedSci) qualified at University of London in 1975. She is now retired from her role as Professor of Clinical Ophthalmology/Consultant Ophthalmologist at Moorfield Eye Hospital. Sue has a special interest in Uveitis in adults and children, infective eye disease, ocular inflammation of all types associated with systemic disease



### Reuben C S Ayres

Dr Reuben Ayres (BM, DM, FRCP) qualified at Southampton in 1982. He is now retired from full time clinical practice, other than endoscopy. He was formerly Consultant Gastroenterologist, who specialised in colorectal cancer, inflammatory bowel disease and Behçet's, practicing at The Royal Devon and Exeter NHS Trust, 1 The Quadrant Exeter and the Nuffield Health Exeter Hospital. As a Provincial Grand Charity Steward of the Devonshire Freemasons he has been instrumental in raising funds to assist a wide range of charities and other good causes both locally and nationally. In his spare time he is a member of Lunar Plexus, a musical duo crafting original music available on Spotify, iTunes and other major musical platforms.



# Chair's Report

## Overview

I took the opportunity to review our quarterly newsletters again since last-year's report and it records another highly successful year for the Society, with progress being made to expand the Society's range of activities in many areas. Coronavirus COVID-19 (SARS-CoV-2) has continued to be an impediment to some areas of activity.

Members of the Society have remained stoic and although restrictions on fundraising opportunities have been apparent there have been considerable individual achievements. Whether they are small or relatively larger they represent a great team effort, and every person's contribution is important and significant. The resolution of a late member's estate reported in more detail in our Financial Report has assured we are financially secure to cover routine expenditure, principally the salary of our two part-time staff, who continue to carry out fantastic work, and increase the funds available to members eligible for grants.

Two highlights this past year have been our Annual Conference and AGM conducted online, for the first time and a Medicine and Me: Living with Behçet's webinar, both with the support of, or sponsored by, the Royal Society of Medicine. The latter in particular has increased the visibility of Behçet's amongst the medical community; together with a myriad of Zoom/Microsoft Teams events that I have attended again this past year on your behalves. Whilst research initiatives have been impeded again, latterly in the year they have picked up.

Board membership has remained stable, which is always a good sign in an organisation, but with the addition this year of Neil Williams, bringing added needed skills in the business arena and who will focus on fundraising. We continue to work closely with the Behçet's Patients Centres. Membership witnesses a steady increase.

In sum, much underpinning work is being carried out in the background which I am confident will bring great rewards to all.

## Governance

Gemma Darlow and Deborah Cardinal, our part-time Administration team, continue to underpin the governance aspects of the Society as mandated by the Charity Commission, Fundraising Regulator and so forth. This continues to ensure members are more efficiently and effectively supported. As last year, assistance to support the Helpline and within Support Groups has waned once more, and trustees continue to review this aspect going forward. Our business processes and procedures system remain in place to check we are doing tasks when required, but I need to make more effective use of the process. To a degree this is a consequence of many initiatives on the go but our Board meetings review outstanding actions more effectively now. My aim is to continue to ensure we minimise nugatory work by trustees, ensure we reduce 'single points of failure' and facilitate smooth succession as and when individuals move on in the future. I take this opportunity to thank our trustees for their excellent contribution and loyal commitment to the Society – noting for the benefit of new members that this is offered voluntarily and unremunerated. We continue to have a trustee representing each of the Devolved Nations and hold a joint meeting with the Behçet's Patients Centres Board to ensure we are moving forward in harmony and aligned with long-term goals.

## Annual Conference

The Conference and Annual General Meeting online, supported by The Royal Society of Medicine and secured through the technical services of the team at 1 Wimpole Street was a resounding success and received much positive feedback; and it is to be repeated in October 2021 due to the continuing concerns of COVID-19. The initial focus was on the importance of data and particularly Patient Registry. This was a topic I first raised with the three Clinical Directors of the Centres of



Excellence in Liverpool, Birmingham and London in December 2018. It has taken longer than I would have wished to get to where we are, partly thanks to COVID-19, but has been greatly facilitated by the initial study in 2018/19 conducted by Dr Priyanka Chandratre; A retrospective cross-sectional analysis of medical records between 2012 and 2018 conducted at the Behçet's specialist centre in Birmingham.

The Judith Buckle Award was posthumously awarded to inseparable twins Katy and Emma Davis, in recognition of all they had done in their lives to help others, before their very sad and untimely death after contracting COVID-19 in April 2020. The award was kindly presented by the Mayor of Yeovil and accepted by sister Zoe Elizabeth Davis, together with Katy and Emma's parents Julie and Alan Davis.

## **The Behçet's Forum Meeting – RSM Medicine and Me**

As reported last year, the Behçet's Forum initiative remains in abeyance, and in any case COVID-19 put a stop to Face-to-Face events. As foretold the Royal Society of Medicine (RSM) Medicine and Me series may very well provide a useful alternative. RSM Medicine and Me: Living with Behçet's met online on 20 April 2021 and was a resounding success. 231 registered of whom 71 were patients or carers, 44 student/trainee, and 116 health professionals. Both latter figures are extremely encouraging. These programmes bring together those who have experience with a condition with those who have clinical and/or research expertise in the condition and encourage wider awareness amongst trainees/students. A live 2022 event is to be scheduled.

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

Once more our planned Friends and Family Day was postponed, due to concerns over COVID-19. We will continue to schedule these popular events and encourage more members to participate in them, which are always highly successful and enjoyable.

## **Newsletter**

Our Editor, Clare Griffith continues to design our marvellous Newsletters and contributors are thanked again for their positive articles, which Judi Scott helps draw together. This remains a core product that the Society produces and includes significant input from the Behçet's Patients Centres, who update on their activity within the Centres of Excellence, and provide other helpful articles. We continue to promote the use of our electronic version, which helps save money, but we will continue the printed version where demand exists.

## **Medical Factsheets and Alert Card**

These remain an important point of reference to both patients and clinicians. They are particularly important for patients who are 'new to Behçet's' and linked with all four Nations' NHS sites. We need to more routinely keep them updated, as much as for no other reason than they look current, even though the very nature of them does not change much – there is no 'magic bullet' for Behçet's unfortunately.

The Alert Card has been updated with the assistance Sarah Hardy, Nurse Consultant at the Liverpool Centre and this will be submitted to Fiona Marley, Head Highly Specialised Commissioning for hopefully formal adoption with an accompanying NHS logo.

## **Medical Advisory Panel**

There is still some work to do with revitalising some aspects of the Medical Advisory Panel and particularly to address succession planning, as and when required.

## **Fundraising and Membership**

Each year generous individuals give much of their time and effort to boost our much-needed funds. The Behçet's to the Beach initiative, which Gemma Darlow set up, following a similar group effort



last year, Bike for Behçet's/Run for Rare looks to have raised a similar £10,000 figure. This really is a fantastic effort by everyone involved. Whatever the amounts collected (great or relatively small) is a testimony to our strong group identity, and everyone is thanked most sincerely by the Trustees. Membership continues to increase, comprising principally of patients or carers, with a grand total of nearly 1400.

## Research

### *Research Award Prizes*

The Board-endorsed paper (our three Research Award Prizes; Behçet's UK Prize, Adamantiades Prize and The Patrons' Prize) remains on the books, and we will push to progress this initiative in 2022.

### *Behçet's Patient Registry (UK)*

Although delayed by COVID-19, Dr Priyanka Chandratre's study has begun, updating data from her initial study at Birmingham and teasing out modalities to collect and validate data at the Liverpool and London centres. This data will then be fed into Public Health England's National Rare Disease Registration Service (NDRS), under NHS Digital, identifying patients with Behçet's diagnosed by the Centres of Excellence, captured from Hospital Episode Statistics, cross-checked with Clinical Practice Research Datalink, and recorded in the Behçet's UK membership (who may or may not have been captured by the other pathways). Disease registration is central to public health and healthcare, and as part of the recent 2021 UK Rare Diseases Framework, the use of national registries is being championed. Behçet's patients are now well placed, ahead of most others in the pack, provided we keep momentum going. It is therefore vital that everyone signs up when requested. This exercise needs to be replicated in Wales (CARIS), Scotland (CARDRISS) and in Northern Ireland with the Rare Diseases & Congenital Abnormalities Registry (NIRADCAR). An obvious concern is 'joining up' the data in the four separate registries, and the inclusion of Real-World Data (that entered by patients).

### *Other Research*

Two research grants previously allocated to Dr Graham Wallace are also now progressing. The first is looking at generating a metabolomic data set in comparison with the clinical and genetic data already obtained on patients. Second, involving an International Behçet's Syndrome Gut Microbiome Initiative.

## Supporting Initiatives

### *BSR/BAD NICE accredited guideline*

This joint initiative progresses and will be an important step to improve patient outcomes; consistent standards of care, treatment and conducting subsequent audits/Quality Assurance. The National pathway for treatment of Behçet's based on the available international evidence, drafted by Dr Deva Situnayake with the support of the Liverpool and Birmingham centres, will be reflected in the guideline.

## Communications Strategy

We continue to identify opportunities in this area. During the second year of the pandemic the Chair has attended a significant number of events online, and seeks every opportunity to promote Behçet's, often via commenting on the Q&A function (e.g. in two-years attending just shy of 100 COVID-19 RSM webinar sessions. Public Policy Projects (PPP) is one such area, which is a subscription based public policy institute, based in London, UK – though no subscription is currently involved. The Executive Chair is Rt Hon Stephen Dorrell, with Co-Chairs Baroness Blackwood and Stephen Hammond MP. PPP is a unique policy institute that offers practical analysis and development within the UK, producing reports, white papers and due-diligence for local, national and regional



governments, the NHS, private and public/third sector organisations. The Chair has joined select round table discussion, most recently on potential future health technology opportunities, increasing the visibility of Behçet's and contributing to the rare disease cause. Involvement with NICE, who are developing policy in their Single Technology Evaluation (STA) and Highly Specialised Technology Evaluation (HTA), is another more recent example.

## Social Media

Visibility on Social Media continues to increase with Deborah Cardinal maintaining a keen eye to spot opportunities and this remains a vital area to maintain. The Behçet's UK Facebook page followers have increased by 65% to 1264, and our private Facebook groups, open to Behçet's UK members, continue to attract more members. Our Twitter page has increased by 22% to 804 and Instagram has increased by 76% with 810 followers. Thus, our online presence continues to increase our visibility across all age groups.

## Support Groups

Our Member Support Groups, now comprise: England (online) and Thames Valley, Clare Gibson; Liverpool, Yvonne Morris; Scotland, Catherine O'Hara; South Wales, Rachael Humphreys; Northern Ireland, Fionnuala McKinley; and Parents of Children with Behçet's, Amanda Moseley. They are thanked for their important contribution. We look to identify new initiatives in this area. Interestingly, online with Zoom produces mixed results, but as individuals become more accustomed to this way of working it does offer significant opportunities as our member cohort is spread widely throughout the country.

## Heath Unlocked

This platform, which is pointed-to on our website continues to provide a helpful discussion area for those with Behçet's by which to exchange patient and carer views and experiences. There are 4,933 all time members of which 360 are currently active and 38,579 items of all-time content. It is important that this is monitored, and where necessary mediated, which is carried out by the administration staff and the Chair. The Chair also monitors 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, as and when appropriate, and in a coordinated manner particularly when requested. Whilst face-to-face activity remains reduced there continues to be activity principally organised by Genetic Alliance UK, with whom the Society remains intimately involved, together with National Voices. The groups with which we support are: All Party Group on Skin (APPGS); Cross Party Group on Rare, Genetic and Undiagnosed Conditions (CPG RGUC) in The National Assembly for Wales; The Scottish Parliament Cross-party Group on Rare, Genetic and Undiagnosed conditions; Prescription Charges Coalition. Moves are afoot to establish a Northern Ireland Assembly group, 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; and with Patient Representative Organisations in the UK (Genetic Alliance UK; Unique) Republic of Ireland (IPPOSI, MRCG and GRDO) and Europe (EURORDIS), as well as with a wide range of condition-specific groups and organisations. The Chair and Fionnuala McKinley keep in routine touch with them.

## Helpline

Calls to the Helpline remains relatively low, by comparison to the past, which is a good sign in that support to patients (and members) is undoubtedly being found elsewhere – hopefully through responsive interaction with clinicians. There do though remain a number of patients who are experience difficulty with their treatment. This function is presently carried out on most days by the Chair and Fionnuala McKinley, 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 and administrative checks are involved in providing the necessary preparation for individuals involved in this task.

## **Devolved Nations**

Our representatives in the Devolved Nations continue to carry out an important role; Catherine O'Hara in Scotland, Rachael Humphreys in Wales and Fionnuala McKinley in Northern Ireland.

## **Conclusion**

Despite the continuing COVID-19 situation the Society has continued to discharge its responsibilities and is strengthening its position in a number of areas within the wider rare disease community. Thanks to a generous legacy, our financial position is now stable and strong, allowing routine annual expenditure to be guaranteed for the next three years. Member fundraising has again been substantial.

I take the opportunity to thank everyone who continue 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 are thanked for their significant efforts to underpin all the necessary administrative aspects of the Society. Your Trustees continue to give of their valuable time, voluntarily.

On the clinical side we are fortunate to benefit from three specialist National Centres of Excellence led by the Clinical Directors Professor Rob Moots, Professor Farida Fortune CBE and Dr Deva Situnayake, who are supported by the Behçet's Patients Support staff, Jean Christians, Rebecca Hyder and Jackie Pooler, managed by John Mather the Operations Manager and supported by their Board of Directors, and led by Jan Mather. Our Medical Advisory Panel remain on hand to offer assistance, and through initiatives such as with the RSM increased awareness of Behçet's amongst the medical community is being achieved.

The Society is entering another significant point in its history with the establishment of a Patient Registry. A study into the Natural History of Behçet's within the UK will follow and in due course entry into Whole Genome Sequencing at scale. It is vital that members fully support these initiatives and allow their data to be shared, in a fully secure environment which will be anonymised to ensure confidentiality. I strongly recommend to members support me in this endeavour.

**Tony Thornburn OBE, Chair**

**11 October 2021**



# Fundraising Activities

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

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

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

The ongoing effects of COVID 19 have continued to make a significant impact upon fundraising opportunities for all charities and BUK is no exception.

However, as always, we have some amazing members who haven't let this deter them from finding ways to support the charity. Just Giving donations, along with Gift Aid, for the year from September 2020 to August 2021 stand at £16,233.50.

We welcome the expertise of Neil Williams, a new Trustee, who is looking to find more ways to raise much needed funds for the future. Neil has raised over £1,800 for BUK already.

The Board of Trustees would like to say a huge thank you to everyone who has raised funds for Behçet's UK. Your efforts and generosity are much appreciated. What would we be without you?

**Judi Scott (Hon. Secretary)**

**Gemma Darlow (Administrator)**



The Bike for Behçet's – Run for the Rare team completed their challenge in time for our Conference and AGM in October 2020 and raised over £10,000!

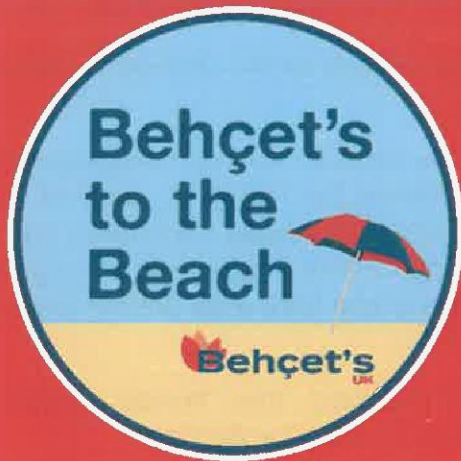
Huge thanks to the the whole team: Trustee Rachael Humphreys, Laura and Zoe Forrest, Clare Gibson; Lauren Bradfield; Stacey Rodger; Isabelle Grant and the Skinner-Grant family; Lorraine Harper; Malcom Coall, Colin Crick; Greg Thompson; Amanda Chapman; Mike Rawlins; Adinda Hirst; Jean Christians and John Mather.



Adam completed the 64 London to Brighton cycle ride last September and raised £585.

His mother Mandy and her employer added another £333 to this resulting in almost £1,000 raised.





In spring 2021 we launched 'Behçets to the Beach'. The idea was to run, walk, row, cycle, swim, scoot or skate a virtual route from Behçet's UK registered address in London to one (or all) of the best beaches in the UK.

Teams and individuals signed up and the ongoing total stands at over £8000.

A huge thank you to all our challengers who have clocked up the miles and added £££s to the total.

Arianne ran an online fundraiser in May for International Behçet's Awareness Day – smashing her original fundraising target by 1520% and raised £760.



In June, Steph organised sponsored beach clean in Devon, not only to clean up the environment but also to raise funds and awareness for Behçet's UK.

The beach cleaning team raised £435 which blew their original target of £125 out of the water!



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

Details of where to send your used stamps are in the newsletter.



Jan Mather and her mother produced their beautiful Christmas cards which raised over £870 from the sales.



Many of our generous members and supporters have celebrated their birthdays by creating a Facebook fundraiser in aid of Behçet's UK with donations from their family and friends raising over £4500!



Behçet's UK also raises much needed funds from the sale of merchandise including greeting cards, online shopping, and bequests in wills.



# Report of the Trustees for the year ended 31 August 2021

The trustees present their report along with the financial statements of the charity for the year ended 31 August 2021. 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 No 326679.

The object of the charity is to relieve and mitigate the distress of persons suffering from Behçet's Disease by: -

- promoting the study of the cause and treatment of the disease and allied conditions.
- gathering and publishing information useful to sufferers and the general public
- co-operating with the medical, allied professions and other societies with similar aims.
- providing financial assistance to relieve poverty among Behçet's Patients.

## *Organisation*

The trustees who have served during the year and since the year-end are set out on page 16. Trustees are elected at any time during the year and the trustees are presented to the members at the Annual General Meeting.

The trustees act as a management committee and meet quarterly to administer the business of the society. All trustees are unpaid volunteers working on behalf of the Society in their own time.

## *Trustees' responsibilities in relation to the financial statements*

Law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the charity's financial activities during the year and of its financial position at the end of the year. In preparing those financial statements, the trustees are required to: -

- select suitable accounting policies and then apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards and statements of recommended practice have been followed subject to any departures disclosed and explained in the financial statements; and
- prepare the financial statements on a 'going concern' basis unless it is inappropriate to presume that the charity will continue in business

The trustees are responsible for keeping accounting records which disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

## *Reserves*

The trustees aim to maintain reserves at a level that lies approximately between the total income that the Society would expect in a six-month period and that in a full financial year.

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



### *Risks and public benefits*

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

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

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

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

**Tony Thornburn OBE**

**Chair**

**11 October 2021**

# 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 (appointed 15 March 2021)

## Staff

Gemma Darlow (Administrator)  
Deborah Cardinal (Assistant  
Administrator)

## Website / Newsletter editor

Clare Griffiths

## Medical Advisory Panel

Prof Rob Moots  
Dr Adnan Al-Araji  
Dr Clive Archer  
Prof Paul Brogan  
Dr Andrew de Burgh-Thomas  
Prof Farida Fortune  
Prof Dorian Haskard  
Dr Desmond Kidd  
Prof Phil Murray  
Dr Catherine Nelson-Piercy  
Prof Jane Setterfield  
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  
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Office Tel: 0345 130 7328  
Helpline Tel: 0345 130 7329  
Email: [info@behcetsuk.org](mailto:info@behcetsuk.org)  
Web: [behcetsuk.org](http://behcetsuk.org)

**Registered Charity No: 326679**



# Report on Financial Statement 2020/21

The financial year just ended has been the second one to have been significantly affected by two unusual factors: on the one hand, we have had to cope with the restrictions of the COVID-19 'lockdown' and, on the other hand, the Society received, in each of those years, part of an unprecedented large bequest from a former member.

Despite the pandemic and the limits upon physical activities, some significant fund-raising was still able to take place, for which we are very grateful, and is described earlier in this Annual Report. However, much of the Society's work was able to continue: in particular our quarterly newsletter, distributed by post or email to members and others, and our Annual General Meeting in October, though it was a 'virtual' event this time. There were some reductions in expenditure, as a result of the use of the internet to replace face-to-face meetings.

When our late member's estate was fully settled, the total gifted to the Society came to some £152k, which represented over two years' normal income. Consequently the accounts for this year and last appear to show significant operating surpluses, which are somewhat misleading in that, without the bequest, our expenditure would have exceeded our income and that is likely to be the case in 2021/22. The Trustees have wisely decided to use the 'windfall' to underwrite and expand our normal activities over four years and, in particular, to increase the funds available to members eligible for grants, such as for household equipment and mobility aids that they could not otherwise afford.

The pandemic has also led to delays in the use of funds previously agreed for research projects. Our balance sheet for 31 August 2021 shows a total of £58k in 'accrued expenses'. The bulk of this relates to research grants totalling £9.5k to the University of Liverpool, £36k to Sandwell and West Birmingham Hospitals NHS Trust and £10k for a study on immunopathology at the Royal London Dental Hospital. It is anticipated that these projects will all be able to go ahead soon.

**The General Fund** received income this year of £97.0k, including £9.6k in subscriptions, £25.1k in donations, and activities and sales totalling £1.9k. Expenditure was £48.1k and there was a net surplus on the General Fund of £48.9k, leaving accumulated reserves of £162.4k.

**The Restricted Fund** had a total income of £1.7k and Trustees approved research grants totalling £9.8k, leaving £7.4k in reserves.

## Membership

Membership continues to show a steady increase, the large majority of members being patients or carers for Behçet's sufferers. In September 2021, we had 1206 full members, compared with 1186 on that date last year. In addition, there were 29 junior members and 81 associate members (mainly medical professionals). There was again no increase in our subscription rate this year.

The total number of names on our database was 1391, compared with 1347 the previous year, of whom 1135 were patients and 74% were female. The number in receipt of UK state benefits, including pensions, was 973, compared with 916 the previous year: these are entitled to free membership, but many make donations when they can, for which we are very grateful.

Finally, may I express my sincere thanks, on behalf of the Trustees and of our members, to our two excellent members of staff, who do much of the routine work of membership administration.

**Alan Lane, Hon. Treasurer**

**11 October 2021**

# Statement of Financial Activities 2020/21

## Statement of Financial Activities for the year ended 31 August 2021

|  | General Fund   | Restricted Fund | Total 2021     | Total 2020     |        |
|--|----------------|-----------------|----------------|----------------|--------|
|  | £              | £               | £              | £              |        |
| <b>Income and endowments</b>                       |                |                 |                |                |        |
| Donations  | 25 096         | 1 470           | 26 566         | 62 816         | Note 5 |
| Bequests and legacies                              | 52 438         | 0               | 52 438         | 100 000        |        |
| Subscriptions                                      | 9 645          | 0               | 9 645          | 9 634          |        |
| Gift Aid tax reclaimed                             | 4 198          | 307             | 4 505          | 3 408          |        |
| Grants received                                    | 0              | 0               | 0              | 2 125          | Note 6 |
| Fundraising activities                             | 1 128          | 0               | 1 128          | 1 687          |        |
| Sales of goods                                     | 753            | 0               | 753            | 1 125          |        |
| Charitable activities income                       | 0              | 0               | 0              | 178            |        |
| Other  | 3 704          | 0               | 3 704          | 3 793          | Note 7 |
| <b>Total income and endowments</b>                 | <b>96 962</b>  | <b>1 777</b>    | <b>98 739</b>  | <b>184 766</b> |        |
| <b>Expenditure on charitable activities</b>        |                |                 |                |                |        |
| Trading costs                                      | 127            | 0               | 127            | 191            |        |
| Event costs  | 77             | 0               | 77             | 2 375          |        |
| Fundraising costs                                  | 546            | 0               | 546            | 284            |        |
| Staff training                                     | 175            | 0               | 175            | 0              |        |
| Grants and bursaries                               | 2 189          | 0               | 2 189          | 3 604          |        |
| Research grants                                    | 0              | 9 784           | 9 784          | 35 960         |        |
| Subscriptions to other organizations               | 756            | 0               | 756            | 270            |        |
| Helpline costs                                     | 73             | 0               | 73             | 152            |        |
| Salaries and wages                                 | 25 581         | 0               | 25 581         | 25 777         | Note 8 |
| Social security and pensions                       | 538            | 0               | 538            | 535            | Note 8 |
| Travel and subsistence                             | 70             | 0               | 70             | 5 198          |        |
| Insurance  | 683            | 0               | 683            | 545            |        |
| Telephone charges                                  | 367            | 0               | 367            | 433            |        |
| Printing, postage, stationery etc.                 | 576            | 0               | 576            | 2 015          |        |
| Equipment purchases                                | 0              | 0               | 0              | 0              |        |
| Newsletter   | 8 908          | 0               | 8 908          | 8 899          |        |
| Web site and publicity                             | 515            | 0               | 515            | 720            |        |
| ICT software                                       | 1 047          | 0               | 1 047          | 869            |        |
| Annual Conference and AGM                          | 2 360          | 0               | 2 360          | 4 921          |        |
| Governance costs                                   | 2 266          | 0               | 2 266          | 5 247          |        |
| Other  | 1 245          | 0               | 1 245          | 839            |        |
| <b>Total expenditure</b>                           | <b>48 099</b>  | <b>9 784</b>    | <b>57 883</b>  | <b>98 834</b>  |        |
| <b>Net income before gains on investments</b>      | <b>48 863</b>  | <b>-8 007</b>   | <b>40 856</b>  | <b>85 932</b>  |        |
| Net gains on investments                           | 15             | 9               | 24             | 142            |        |
| <b>NET INCOME</b>                                  | <b>48 878</b>  | <b>-7 998</b>   | <b>40 880</b>  | <b>86 074</b>  |        |
| Transfers between funds                            | 0              | 0               | 0              | 0              |        |
| <b>Net movements in Funds after transfers</b>      | <b>48 878</b>  | <b>-7 998</b>   | <b>40 880</b>  | <b>86 074</b>  |        |
| <b>RECONCILIATION OF FUNDS</b>                     |                |                 |                |                |        |
| Fund balance brought forward at 1 Sep 2020         | 113 510        | 15 378          | 128 888        | 42 814         |        |
| <b>Fund balance carried forward at 31 Aug 2021</b> | <b>162 388</b> | <b>7 380</b>    | <b>169 768</b> | <b>128 888</b> |        |



# Statement of Financial Activities 2019/20

## Statement of Financial Activities for the year ended 31 August 2020

|  | General Fund   | Restricted Fund | Total 2020     | Total 2019     |        |
|--|----------------|-----------------|----------------|----------------|--------|
|  | £              | £               | £              | £              |        |
| <b>Income and endowments</b>                       |                |                 |                |                |        |
| Donations  | 26 121         | 36 695          | 62 816         | 21 894         | Note 5 |
| Bequests and legacies                              | 100 000        | 0               | 100 000        | 0              |        |
| Subscriptions                                      | 9 634          | 0               | 9 634          | 8 881          |        |
| Gift Aid tax reclaimed                             | 3 381          | 27              | 3 408          | 2 794          |        |
| Grants received                                    | 2 125          | 0               | 2 125          | 520            | Note 6 |
| Fundraising activities                             | 1 687          | 0               | 1 687          | 4 944          |        |
| Sales of goods                                     | 1 125          | 0               | 1 125          | 658            |        |
| Charitable activities income                       | 178            | 0               | 178            | 531            |        |
| Other  | 3 793          | 0               | 3 793          | 3 586          | Note 7 |
| <b>Total income and endowments</b>                 | <b>148 044</b> | <b>36 722</b>   | <b>184 766</b> | <b>43 808</b>  |        |
| <b>Expenditure on charitable activities</b>        |                |                 |                |                |        |
| Trading costs                                      | 191            | 0               | 191            | 201            |        |
| Event costs  | 2 375          | 0               | 2 375          | 4 859          |        |
| Fundraising costs                                  | 284            | 0               | 284            | 216            |        |
| Staff training                                     | 0              | 0               | 0              | 354            |        |
| Grants and bursaries                               | 3 604          | 0               | 3 604          | 5 645          |        |
| Research grants                                    | 0              | 35 960          | 35 960         | 9 535          |        |
| Subscriptions to other organizations               | 270            | 0               | 270            | 661            |        |
| Helpline costs                                     | 152            | 0               | 152            | 567            |        |
| Salaries and wages                                 | 25 777         | 0               | 25 777         | 23 859         | Note 8 |
| Social security and pensions                       | 535            | 0               | 535            | 405            | Note 8 |
| Travel and subsistence                             | 5 198          | 0               | 5 198          | 8 069          |        |
| Insurance  | 545            | 0               | 545            | 489            |        |
| Telephone charges                                  | 433            | 0               | 433            | 637            |        |
| Printing, postage, stationery etc.                 | 2 015          | 0               | 2 015          | 2 627          |        |
| Equipment purchases                                | 0              | 0               | 0              | 519            |        |
| Newsletter   | 8 899          | 0               | 8 899          | 8 404          |        |
| Web site and publicity                             | 720            | 0               | 720            | 2 450          |        |
| ICT software                                       | 869            | 0               | 869            | 0              |        |
| Annual Conference and AGM                          | 4 921          | 0               | 4 921          | 5 833          |        |
| Governance costs                                   | 5 247          | 0               | 5 247          | 6 950          |        |
| Other  | 839            | 0               | 839            | 622            |        |
| <b>Total expenditure</b>                           | <b>62 874</b>  | <b>35 960</b>   | <b>98 834</b>  | <b>82 902</b>  |        |
| <b>Net income before gains on investments</b>      | <b>85 170</b>  | <b>762</b>      | <b>85 932</b>  | <b>-39 094</b> |        |
| Net gains on investments                           | 116            | 26              | 142            | 104            |        |
| <b>NET INCOME</b>                                  | <b>85 286</b>  | <b>788</b>      | <b>86 074</b>  | <b>-38 990</b> |        |
| Transfers between funds                            | 749            | -749            | 0              | 0              |        |
| <b>Net movements in Funds after transfers</b>      | <b>86 035</b>  | <b>39</b>       | <b>86 074</b>  | <b>-38 990</b> |        |
| <b>RECONCILIATION OF FUNDS</b>                     |                |                 |                |                |        |
| Fund balance brought forward at 1 Sep 2019         | 27 475         | 15 339          | 42 814         | 81 804         |        |
| <b>Fund balance carried forward at 31 Aug 2020</b> | <b>113 510</b> | <b>15 378</b>   | <b>128 888</b> | <b>42 814</b>  |        |

# Balance Sheet

| Balance Sheet as at 31 Aug 2021  | General Fund   | Research Fund | Total 2021     | Total 2020     |         |
|----------------------------------|----------------|---------------|----------------|----------------|---------|
|                                  | £              | £             | £              | £              |         |
| <b>Current Assets</b>            |                |               |                |                |         |
| Stock in hand                    | 917            | 0             | 917            | 979            | Note 9  |
| Debtors                          | 5              | 0             | 5              | 41             | Note 10 |
| Prepayments                      | 520            | 0             | 520            | 341            | Note 11 |
| Recoverable Gift Aid             | 418            | 334           | 752            | 794            |         |
| Deposit Accounts                 | 108 334        | 60 094        | 168 428        | 167 404        |         |
| Current Accounts                 | 55 009         | 2 446         | 57 455         | 8 061          |         |
| Petty Cash                       | 350            | 0             | 350            | 350            | Note 12 |
| <b>Total current assets</b>      | <b>165 553</b> | <b>62 874</b> | <b>228 427</b> | <b>177 970</b> |         |
| <b>Current Liabilities</b>       |                |               |                |                |         |
| Creditors                        | 356            | 0             | 356            | 269            | Note 13 |
| Deferred income                  | 420            | 0             | 420            | 430            | Note 14 |
| Accrued expenses                 | 2 389          | 55 494        | 57 883         | 48 383         | Note 15 |
| <b>Total current liabilities</b> | <b>3 165</b>   | <b>55 494</b> | <b>58 659</b>  | <b>49 082</b>  |         |
| <b>Total net assets</b>          | <b>162 388</b> | <b>7 380</b>  | <b>169 768</b> | <b>128 888</b> |         |
| <b>TOTAL FUNDS</b>               | <b>162 388</b> | <b>7 380</b>  | <b>169 768</b> | <b>128 888</b> |         |

The financial statements were approved by the trustees on 11 October 2021

Signed



Alan Lane  
Hon. Treasurer  
Date: 11 October 2021



# Notes to the Accounts

## Notes forming part of the financial statements for the year ended 31 Aug 2021

### 1. Basis of accounting

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with FRS102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

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

### 2. Income

All income is included in the financial statements without netting off expenditure. Donations and fundraising income are treated as General Fund unless they are specifically designated by the donor for the Research Fund.

### 3. Expenditure

Expenditure is recognised in the year to which it relates. Irrecoverable VAT is included in the relevant heading.

### 4. Funds

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

The Research Fund was opened in 1995 and is specifically intended to provide for financial grants to be given to research projects in the UK concerned with the study of Behçet's Disease.

#### Analysis of net assets between funds

|                    | Unrestricted<br>Funds | Restricted<br>Funds | Total          |
|--------------------|-----------------------|---------------------|----------------|
|                    | £                     | £                   | £              |
| Net current assets | 162 388               | 7 380               | 169 768        |
| Total              | <u>162 388</u>        | <u>7 380</u>        | <u>169 768</u> |

### 5. Research Fund

The Society received a number of small donations during the year. Grants totalling £9.8k were agreed during the year to support a research project, which have yet to be drawn down.

### 6. Grants received

No grants were received during the year.

### 7. Other income

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

### 8. Salary costs

|                                  | Year ending 31 August 2021 | 2020                          |
|----------------------------------|----------------------------|-------------------------------|
|                                  | £                          | £                             |
| Wages and salaries               | 25 581                     | 25 777                        |
| National Insurance contributions | 0                          | 0 (after deduction of rebate) |
| Employer's pension contributions | <u>538</u>                 | <u>535</u>                    |
|                                  | 26 119                     | 26 312                        |

The average number of staff employed during the year was 2 persons (2020 2 persons). There are no employees earning above £60 000 (2020 none).

None of the trustees, nor any persons connected with them, has received any remuneration during the year. No trustees received expenses for travel and subsistence costs this year (2020: £4508).

### 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 that had yet to be transferred to the Society's bank account on 31 August.

### 11. Prepayments

Payments in advance for post forwarding and part of the insurance premium paid in 2020/21 that relates to 2021/22.

### 12. Petty Cash

Expenses float 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 2021 salaries.

Research Fund: Grants awarded to University of Birmingham but not yet drawn down.

### 14. Deferred Income

Advance subscriptions for 2020/21 received before 1 September 2020.

### 15. Accrued expenses

Staff and trustees' expenses relating to August 2021 and provision for fees for independent examination of accounts, as well as funds committed to research projects to be undertaken in 2021/22.

# 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 2021 which are set out on pages 18 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').

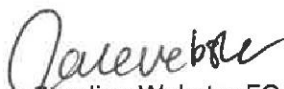
I report in respect of my examination of the charity's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

### 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 1  
Windrush Court  
Abingdon  
OX14 1SY

18<sup>th</sup>  
October 2021