



Behçet's UK

*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 2022

Registered Charity Number 326679

Contents

Medical Advisory Panel.....	2
Chair's Report	5
Fundraising	11
Report of the Trustees for the year ended 31 August 2022	14
Staff and Trustees.....	16
Report on Financial Statement 2021/22	17
Statement of Financial Activities 2021/22	18
Statement of Financial Activities 2020/21	19
Balance Sheet	20
Notes to the Accounts	21
Independent Examiner's Report.....	23

Medical Advisory Panel



Robert J Moots
Chair of Advisory Panel

Job title: Professor of Rheumatology/Consultant Rheumatologist

Qualifications/Post Nominals: BSc (Hons), MB BS (Hons), PhD, FRCP

Where qualified: Imperial College, London

Year of initial qualification: 1985

Currently practising at: University Hospital Aintree, University of Liverpool

Special interests: Clinical and basic science, Behçet's disease, systemic vasculitis, rheumatoid arthritis, immunotherapy of rheumatic diseases



Adnan Al-Araji

Job title: Consultant Neurologist

Qualifications/Post Nominals: MB ChB, FRCP, FRCP (Glasg.)

Where qualified: Baghdad, Iraq

Year of initial qualification: 1977

Currently practising at: Royal Stoke University Hospital, Stoke-on-Trent

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

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

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



Clive B Archer

Job title: Cons Dermatologist & Hon Clinical Snr Lecturer

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

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

Year of initial qualification: 1978

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

Special interests: Clinical interests in inflammatory skin diseases, benign and malignant skin tumours, immuno-bullous diseases; research interests in immuno-pharmacology, cell regulatory mechanisms and medical education



Paul Brogan

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

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

Where qualified: Manchester Medical School

Year of initial qualification: 1993

Currently practising at: Great Ormond St Hospital, London

Special interests: Vasculitis, vascular inflammation in the young



Andrew de Burgh-Thomas

Job title: Consultant in Genitourinary Medicine
Qualifications/Post Nominals: BSc, MBBS, MRCP, Dip GUM, Dip HIV
Where qualified: University of London
Year of initial qualification: 1994
Currently practising at: Gloucester Royal Hospital, Cheltenham General Hospital and Bristol Southmead Hospital
Member of: British Association of Sexual Health and HIV, British Medical Association, Royal College of Physicians, FSRH, ESSM
Special interests: HIV and genital dermatology



Farida Fortune CBE

Job title: Director London Behçet's Centre, Barts Health and Queen Mary University of London
Qualifications/Post Nominals: FRCP, FRCS, FDS, RCS, PhD
Where qualified: University College London
Year of initial qualification: Dentistry 1975; Medicine 1980
Currently practicing at: Barts Health, Royal London site
 Queen Mary University of London
Special interests: Immunology and Oral Medicine



Dorian O Haskard

Job title: Professor of Cardiovascular Medicine and Rheumatology, Imperial College
Qualifications/Post Nominals: DM FRCP FMedSci
Where qualified: University of London
Year of initial qualification: 1977
Currently practising at: Now retired from clinical practice
Special interests: Vascular inflammation



Desmond Kidd

Job title: Consultant Neurologist
Qualifications/Post Nominals: MD BCh BAO MD FRCP
Where qualified: Ireland
Year of initial qualification: 1986
Currently practising at: Royal Free Hospital, London
Special interests: Neurological complications of inflammatory diseases, particularly Behçet's syndrome, sarcoidosis and histiocytosis; neuro-ophthalmology



Philip Ian Murray

Job title: Professor of Ophthalmology, University of Birmingham
Qualifications/Post Nominals: MBBS, DO(RCS), PhD, FRCP, FRCS, FRCOphth
Where qualified: St George's Hospital Medical School, University of London
Year of initial qualification: 1978
Currently practising at: Birmingham and Midland Eye Centre, City Hospital, Sandwell and West Birmingham Hospitals NHS Trust
Special interests: All types of uveitis including Behçet's disease. Scleritis. *Clinical Research:* Quality of Life in uveitis, *Laboratory Research:* The eye has evolved many mechanisms to prevent significant inflammation, which can lead to visual impairment. I am investigating why in patients with uveitis, the eye cannot control the inflammation. Jazz!



Catherine Nelson-Piercy

Job title: Professor Obstetric Physician

Qualifications/ Post Nominals: MBBSMA, FRCP, FRCOG

Where qualified: Cambridge University and St Bartholomew's Hospital

Year of initial qualification: 1986

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

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



Graham Wallace

Job title: Senior Lecturer

Qualifications/Post Nominals: BSc Immunology, PhD

Where qualified: University of London

Year of initial qualification: 1985 (PhD)

Currently practising 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

Our Quarterly Newsletters reflect yet another successful year for the Society, of which research looms large. Much of this we have no control over but are quietly making steps to try to influence, the most significant of which will be used to establish a Behçet's Patient Registry. For the first time in the UK, two specific drug trials to treat Behçet's have been funded, to the tune of nearly £1.5 million; one report has been published and the next trial due to start shortly.

We continue to benefit from members carrying out fantastic fundraising. As I said last year whether they are small or relatively larger they represent a great team effort, and every person's contribution is important and significant. We also continue to benefit from the bequest we received in 2020/2021, from a former member in her Will, helpfully underpinning our financial stability.

Alan Lane, our amazing Hon. Treasurer, continues to provide exemplary and careful thought and preparation to our accounts. His detailed report features later but in sum we have accumulated reserves of £155.3k half of which was earmarked to fund usual operating costs for a 4-year period. We will also be able to support further research projects opportunities in due course.

Our successful Annual Conference and AGM was once more conducted online with the support of the Royal Society of Medicine (RSM) but we look forward to a hybrid version in 2022, both face to face and relayed online to the wider membership. This is likely to be the formula in years to come, and we will note feedback with interest.

Board membership has remained stable, for which as Chair I am most grateful, and we continue to work closely with the Behçet's Patients Centres who, on top of their separate role supporting the multidisciplinary centres of excellence, provide substantive input to our Newsletters. Membership has remained stable.

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

Governance

The governance of the Society is now well-embedded, in accordance with Charity Commission guidance. This is thanks to the thorough and conscientious efforts of Gemma Darlow; the aim being to ensure that as and when appointees change a seamless transition occurs so that knowledge, experience and lessons-learned is not wasted, and we reduce potential 'single points of failure'.

We intend to invest in a Constituent Relationship Management System, similar to Customer Relationship Management which is routinely used in commerce and will facilitate best use of time by our part-time administrators, and indeed trustees. Currently, for example, much administrative time is expended when Gemma 'merely' sends out an email to all members. This will promote resilience and succession planning and traceability will also be enhanced. Deborah Cardinal continues to enhance our presence considerably on Social Media, which in turn helps to promote understanding and awareness of Behçet's. Our business processes continue to improve.

As always, I take this opportunity to thank our trustees on your behalf, for their excellent contribution and loyal commitment to the Society – noting again, for the benefit of new members, that this is offered

voluntarily and unremunerated. We continue to have a trustee representing each of the Devolved Nations and 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 2021 Behçet's UK Conference and Annual General Meeting took place online, supported by 1 Wimpole Street 'home of The Royal Society of Medicine'. It was a great success, and a total of 203 people registered to attend, of whom 103 attended live and another 85 watched the recording after the event. Most (77%) of the registered participants were patients/carers and 76% lived in the UK. Feedback survey results indicate that 38% of those attending watched with two or more people. The focus reflected the various research initiatives, which was well received by members in positive feedback.

The 2021 Judith Buckle Award was presented to Jan Mather in recognition of all she has done for Behçet's members; a driving force behind the Behçet's Syndrome Society, now Behçet's UK, and the creation of the centres of excellence; becoming involved in the charity in 2003 when she started making Christmas cards along with her mother to raise funds, a Trustee in 2005, Chair in 2006 and then Director of the separate charity Behçet's Patients Centres in 2013.

Behçet's Friends and Family Day

Having suffered a couple of cancellations of our usual Friends and Family Day, thanks to COVID-19, it was with great relief, particularly after all the hard work Gemma Darlow expends in their arrangement, that this year we did indeed meet up at the Underbank Activity Centre, just outside Sheffield. It was a resounding success, and much enjoyed by everyone that attend (25 people in total). It was slightly disappointing that a few who had registered were unable to attend. Whilst the unpredictable and relapsing nature of Behçet's is noted, a few individuals did not respond to reminding emails well in advance of the event, alluding to the fact that they probably were not going to attend anyway; who could thus have notified cancellation earlier so that the long waiting-list could have been used. The event is funded by the Society's hard-earned money, and we must use it economically.

Newsletter

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

Medical Factsheets and Alert Card

Other important points of reference, to both patients and clinicians, are our Medical Fact Sheets. They are significant source of information particularly for patients who are 'new to Behçet's' and are referenced by all four Nations' NHS websites. A drive to update them is underway as they must look current, even though the very nature of them does not change much – as I said last year there is no 'magic bullet' for Behçet's unfortunately.

A new Alert Card, which Sarah Hardy, Nurse Consultant at the Liverpool centre helped to update has been submitted to Fiona Marley, Head Highly Specialised Commissioning for hopefully formal adoption with an accompanying NHS logo.

Medical Advisory Panel

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

Fundraising and Membership

Once more we have witnessed the generosity of individuals to give of their time and effort to raise essential funds for the Society. Neil Williams continues to develop our Fundraising Strategy and is presently seeking additional members with appropriate skills to assist in this endeavour. The Behçet's to the Beach initiative did indeed raise £10,100, as predicted last year, and an example of other marvellous and varied fund-raising efforts has been prepared by Judi Scott and Gemma Darlow. Trustees thank everyone for their important efforts, without which there would be no society!

Membership has remained steady at just over 1300, but we took the opportunity to review the membership of those whose interest and interaction with the Society appeared to have ceased and subsequently deleted them from our database. Trustees also took time to carefully refine the documentation of our membership rules so they are more accurately defined, particularly in regard to eligibility for the award of grants. This helps the Grants Board when considering grant applications.

Research

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

The initial phase of Dr Priyanka Chandratre's study is nearing conclusion; match-funded by Behçet's UK. As a reminder this is capturing data from the three national Behçet's Syndrome Centres of Excellence, Hospital Episode Statistics, cross-checked with Clinical Practice Research Datalink, and recorded in the Behçet's UK membership (who may or may not have been captured by the other pathways).

As a testimony to Dr Chandratre's research ability, she has secured additional funding to continue the research when she moves abroad to Canada. The Society is most grateful that Dr Chandratre has agreed to do this. The original intention was that the data would be fed into Public Health England's National Rare Disease Registration Service (NDRS). Public Health England was then replaced by the UK Health Security Agency and Office for Health Improvement and Disparities, and thanks to another NHS England reorganisation, NDRS now resides under NHS Digital. The chair has always been suspicious that this may not be the optimal location to hold this data; gaining access for legitimate research studies will doubtless be protracted, real-world (patient-entered) data might not be possible (restricting for example the capture of annual quality of life statistics, vital to gain a realistic view of the progression of the condition).

As I reported last year, disease registration is (claimed to be) central to public health and healthcare, and as part of the 2021 UK Rare Diseases Framework, with the use of national registries being championed. However sufficient resources to make this so are not forthcoming, and lots of bureaucracy is in play. Moreover, this exercise needs to be replicated in Wales (CARIS), Scotland (CARDRISS) and Northern Ireland Rare Diseases & Congenital Abnormalities Registry (NIRADCAR). An obvious concern is 'joining up' the data in the four separate registries.

So, whilst Behçet's patients are now well placed (ahead of most others in the pack) some hurdles need to be negotiated. Trustees are thus reviewing the way forward as you read this annual report. Notwithstanding, it is vital that everyone signs-up when requested.

Other Research

The results of the Bio-Behçet's trial (head-to-head comparison of Roferon (interferon-alpha) and infliximab) overseen by Professor Moots were published this year and he thanked the trial participants and Behçet's UK, which was a key partner in the trial. Professor Moots has also secured significant funding from Novartis for a major trial on the biologic Secukinumab, which is a biologic that is extensively used, and highly effective, in several inflammatory conditions such as psoriasis. It inhibits interleukin 17 and has a better side-effect profile than infliximab. A small retrospective study in Italy showed it to be very

effective in Behçet's, and Novartis has announced £700,000 of funding for a major trial in the UK. This is potentially very good news for Behçet's patients in the UK.

Dr Graham Wallace continues to conduct much research and we have funded work, first, looking at generating a metabolomic data set in comparison with the clinical and genetic data already obtained on patients. Second, funding an International Behçet's Syndrome Gut Microbiome Initiative.

Professor Fortune has conducted analysis into Behçet's Patients and COVID-19 which we have part-funded, and the results were recently presented to the 2022 International Conference for Behçet's Disease, in Athens.

A significant piece of research, recently completed, under the supervision of Professor Paul Brogan from GOSH, and one of the members of our Medical Advisory Panel, has been conducted by Alice Burleigh, a UCL PhD student. As reported in Newsletter No 59 Alice Burleigh has been 'Researching the genetics of Behçet's and diseases in disguise'; sequencing 33 patients who have a diagnosis of Behçet's to investigate whether they in fact have a monogenic disease in disguise.

The computational method that Alice designed to genetically analyse this group allowed her to determine not only the true cause of their disease but also their HLA genotypes, which is an important test in the diagnosis of Behçet's that is usually carried out in a laboratory. Whilst the study has had large benefits for the small cohort she and Professor Brogan's wish is to work towards rolling out the genetic analysis method to hospitals more widely.

This study will therefore push for a move towards genome sequencing as standard for diagnosis of Behçet's. This will help not only in differentiating Behçet's from cases of monogenic disease, but also in building a better picture of the genetic landscape of Behçet's in the UK. The more we understand about this, the faster we can move towards a possibility of being able to assess a person's risk of Behçet's based on genetic tests and translating this into personalised treatments.

Supporting Initiatives

BAD/BSR NICE accredited guideline

This important joint initiative is nearing completion; this is work that clinicians carry out voluntarily, for which the Society is most grateful. The guideline will help improve patient outcomes; consistent standards of care, treatment and conducting subsequent audits/Quality Assurance. The National drugs pathway will be reflected in the guideline. Because many clinicians are members of the British Association of Dermatologist or British Society of Rheumatology significantly more visibility of Behçet's will be achieved by this guideline; as it will be seen on their respective websites, much more so than the current EULAR guideline (with which it will inevitably chime in many areas) but focusing on UK patients.

Communications Strategy

We continue to identify opportunities in this area, and have yet to document a policy but it is on our 'to do list'. I continue to attend a significant number of events online, with various patient advocacy groups and this raises awareness of Behçet's and Behçet's UK. I have been quite busy since the start of 2022, after I was invited to become Alliance Network Chair of the Central and South Genomic Medicine Service Alliances (GMSA) – basically the Patient and Public Voice (PPV) or Patient and Public Involvement (PPI) representative. This is one of seven GMSA alliances in England which have been charged to "co-ordinate the embedding of genomics into routine care locally and across the whole population the NHS serves in England, by bringing together the vital multi-disciplinary clinical leadership and other operational and digital functions that are necessary to make this possible". On every communication the Behçet's UK signature block features, including in a national NHS Peoples and Citizens PPV group, thus much additional

visibility of our condition is being achieved. I am also, inevitably, keeping an eye out for 'opportunities for Behçet's' in the Genomic space!

Social Media

Visibility on Social Media increases. Deborah Cardinal maintains a keen eye to spot opportunities for promoting Behçet's UK. Our Facebook page now has 1,574 followers and we continue to attract more followers each year with content from our page reaching over 45,000 people between September 2021 and August 2022. Our Twitter page has 928 followers, with Deborah regularly tweeting. Instagram now has 1,045 followers with our content reaching over 4,000, and increase of 62%. Thus, our online presence continues to increase our visibility across all age groups. During the International Conference for Behçet's Disease 2022 a suggestion was made to use social media to help promote research papers. This we will now do. I was forced to attend online rather than in person thanks to contracting COVID-19 at an inopportune moment! Statistic of Social Media used by Behçet's advocacy groups was highlighted and Behçet's UK came top. So well done Deborah, thank you for your great efforts.

Support Groups

Our Member Support Groups comprise: England (online), which is increasing in popularity, and Thames Valley both kindly managed by 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 all thanked once again for their important contribution. New initiatives in this area are welcomed, so do get in touch with Gemma or Deborah if you have ideas on this matter. The use of Zoom suits some and not others.

The Health Unlocked 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 now 5,027 all time members of which 254 are currently active and 39,287 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 where appropriate, with their local politicians 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 keeps in close contact, together with Beacon (formerly Findacure) and National Voices. The groups with which we support are: All Party Group on Skin (APPGS); Cross Party Group on Rare, Genetic and Undiagnosed Conditions in The National Assembly for Wales; The Scottish Parliament Cross-party Group on Rare, Genetic and Undiagnosed conditions; and the Prescription Charges Coalition.

An All-Party Group (APG) for Rare Disease has now been established 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; and with Patient Representative Organisations in the UK (e.g. Genetic Alliance UK, Unique), in 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

Similar to that recorded last year, calls to the Helpline remain 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 inevitably remain however a number of patients who are experiencing difficulty with their treatment, and need moral support if nothing else. This function is presently carried out on most days by the Tony Thornburn and Fionnuala McKinley, with Catherine O'Hara and Gemma Darlow in close support who are all thanked for their vital contributions. 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 endeavour. Trustees continue to review this aspect going forward.

Devolved Nations

Our representatives in the Devolved Nations continue to carry out an important role; Catherine O'Hara, our Vice Chair, in Scotland, Rachael Humphreys in Wales and Fionnuala McKinley in Northern Ireland. In particular, trustees are seeking to establish a Behçet's Specialist Nurse post in Scotland to help coordinate care; hopefully as a minimum with joint funding from NHS Scotland. This may take time, but we have started.

Conclusion

In summary, the Society continues to discharge its responsibilities and is strengthening its position in a number of areas within the wider rare disease community. Our financial position is stable and strong, allowing routine annual expenditure to be guaranteed for the next three years. Member fundraising has again been substantial and it is vital this remains so. The development of a formal Fundraising Strategy is an important initiative we are embarking upon.

As I noted last year, 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. We are fortunate to benefit from Gemma Darlow and Deborah Cardinal's excellent service and thanked for their significant contribution to underpin all the necessary administrative aspects of the Society. Your Trustees continue to give of their valuable time, voluntarily.

On the clinical side, principally in England of course, we benefit from three specialist National multi-disciplinary Centres of Excellence led by the Clinical Directors Professor Rob Moots, Professor Farida Fortune CBE and Dr Deva Situnayake. They are well-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. This is managed by a separate charitable company limited by guarantee; named The Behçet's Patients Centres. Our Medical Advisory Panel remain on hand to offer advice, and through initiatives such as with the RSM increased awareness of Behçet's amongst the medical community is being achieved.

The establishment of a Patient Registry, is taking much longer to initiate than I had wished, partly thanks to the initial suggestion to establish it under NHS England's National Disease Registration Service (and its move to reside under NHS Digital). Dr Priyanka Chandratre's data-gathering research initiative is an essential part in this initiative, from which it will be possible to carry out a study into 'The Natural History of Behçet's within the UK'. Hopefully this will be followed, in due course, by entry into Whole Genome Sequencing at scale (though that might be a little time away). I repeat what I said last year, it is vital that members fully support these initiatives and allow their data to be shared for research, in a fully secure environment which will be anonymised to ensure patient confidentiality. In short, research into discovering treatment and cures for rare conditions needs reliable data.

Tony Thornburn OBE, Chair

16 September 2022

Fundraising

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!

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 2021 to August 2022 stand at £17 507. Over the next few pages we have included just a few of our fantastic fundraisers, as well as ways to fundraise for us every day life.

Our Trustee Neil Williams is hoping to form a Fundraising Committee and would welcome any members who are keen to join and examine ways to raise much-needed funds.

Judi Scott (Hon. Secretary)

Gemma Darlow (Administrator)



For Christmas 2021, Jan Mather and her mother, Mary kindly produced their beautiful Christmas cards for Behçet's UK which raised £750.



In May 2022, Behçet's patient and seasoned fundraiser, Laura F, cycled 61 miles in just 4 hours and 43 mins, raising £413 for Behçet's UK when she completed the Ride London – Essex.



In July 2022, Behçet's UK Trustee and patient Neil, along with friends, cycled 170 miles over 3 days along the 'Way of the Roses' Coast 2 Coast route and raised over £2450.



For International Behçet's Awareness Day, on 20 May 2022, Tom C took on and conquered the Three Peaks Challenge.

Tom climbed Ben Nevis, Scafell Pike and Snowdon. That's 23 miles of mountains, a total ascent of over 10,000ft, and all in just 24 hours and aided over £3200 for Behçet's UK.



In September 2021 Behçet's to the Beach came to an end when our challengers crossed their virtual finish lines. The team raised an astounding £10,100!



In June 2022 Gemma B showed support for her niece, who has Behçet's, by braving a tandem skydive in aid of Behçet's UK and raised £1160.

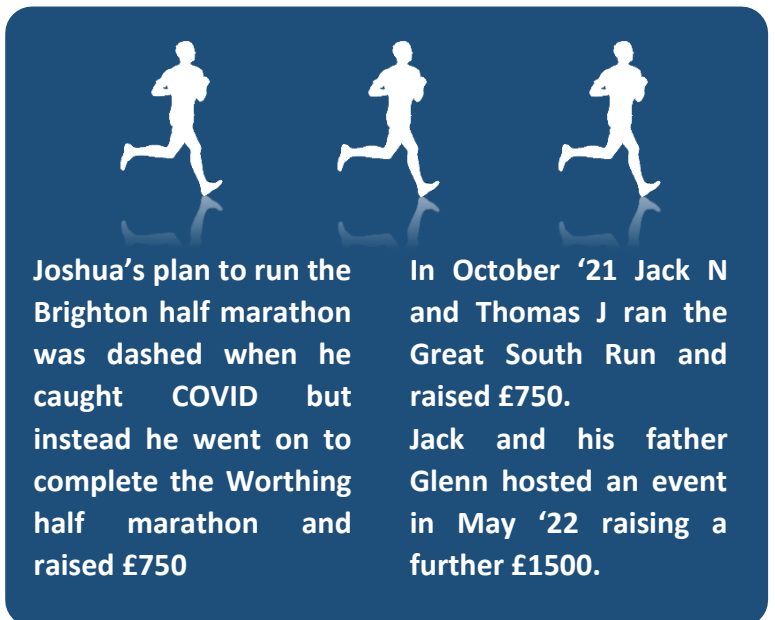
Ruth F held her annual ladies ball, the first since before COVID, in aid of Behçet's UK and raised £1393.50



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



Six year old Lily combined her love of crafting and baking with Mum and ran a stall in April 2022 to raise funds for Behçet's UK in honour of her Uncle who has Behçet's. Lily raised £385.20 for all her hard work.



Joshua's plan to run the Brighton half marathon was dashed when he caught COVID but instead he went on to complete the Worthing half marathon and raised £750

In October '21 Jack N and Thomas J ran the Great South Run and raised £750. Jack and his father Glenn hosted an event in May '22 raising a further £1500.

34 members and supporters kindly set up a Facebook Fundraiser this year. The majority were birthday fundraisers - where friends and family make a donation in aid of Behçet's UK in lieu of birthday gifts. Thanks to their generosity, and that of their friends and family we received £1563 via Facebook Fundraisers.



Nikkie's 11 year old daughter, Belle, has Behçet's and had been suffering from hair loss, so Nikkie decided they should go on a hair loss journey together. By braving the shave Nikkie raised £812.64.



Behçet's patient Emma C held a Behçet's awareness event and fundraisers including dress-down days and a raffle at her place of work raised a £420 for Behçet's UK.



Laura F and her husband took part in the Brutal 5K race at Eelmoor in Jan 2022 in memory of her aunt, Mary Rose, who had Behçet's. They raised £805.

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 2022

The trustees present their report along with the financial statements of the charity for the year ended 31 August 2022. The financial statements have been prepared in accordance with the accounting policies set out in this report and comply with the charity's trust deed and applicable law.

Constitution and objects

Behçet's UK is constituted under a trust deed dated 11 October 2008 and is a registered charity number 326679.

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

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

Organisation

The trustees who have served during the year and since the year-end are set out on page 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.

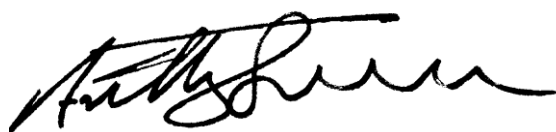
However, should a particularly large donation be received, Trustees would normally treat the larger part as an earmarked reserve, to be used over the next three financial years to underwrite any possible shortfall in income or need for exceptional expenditure.

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

16 September 2022

Staff and Trustees

Trustees

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

Staff

Gemma Darlow (Administrator)
Deborah Cardinal (Assistant Administrator)

Newsletter editor

Clare Griffiths

Medical Advisory Panel

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

Banks

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

Scottish Widows Bank
PO Box 883
LEEDS
LS1 9TY

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

Independent Examiner of Accounts

UHY Ross Brooke
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 2021/22

After two very unusual years, for this Society as for the world at large, more normal conditions began to return during the financial year that has recently ended. On the one hand, our normal programmes and meetings had been restricted, but on the other hand, we had received a large bequest from a former member that had greatly increased our available resources. As a result, we had begun the last financial year with exceptionally large reserves but, as the year progressed, we were able to start drawing on them in order to maintain and to supplement our usual activities.

At the end of the year we still had much larger reserves than Trustees would normally wish to keep. These will now support our planned activities for the next few years and allow for further support for research projects in due course.

There is of course still a great need for research into the causes of Behçet's and into effective treatment for it. There is also an increasing need to support members in the current challenging financial climate with basic household equipment and mobility aids, so it is most encouraging to see that the splendid fundraising efforts of our members and supporters have not been diminished during the pandemic.

The General Fund received income this year of £55.6k, including £28.4k in subscriptions and donations, £17.5k from fundraising activities and sales and other income totalling £4.3k. Expenditure was £62.7k and there was a net deficit on the General Fund of £7.1k, leaving accumulated reserves of £155.3k.

The Research Fund had a total income of £1.1k and Trustees approved one research grants of £0.7k, leaving £7.9k in reserves.

Membership has remained steady, the large majority of members being patients or carers for Behçet's sufferers. In September 2022, we had 1234 full members, compared with 1206 on that date last year. In addition, there were 31 junior members and 71 associate members (mainly medical professionals). Our subscription rate has remained unchanged for over 10 years and we are still able to offer free membership to those who are under 25 or are in receipt of UK means-tested benefits.

The total number of names on our database was 1444, compared with 1391 the previous year, of whom 1184 were patients and 74% were female. The number in receipt of UK state benefits, including pensions, was 985, compared with 973 the previous year, a continuing of the steady increase seen in previous years.

Much of our membership administration is carried out by the Society's two part-time members of staff, to whom I give my grateful thanks, and those of the Trustees, for all their hard work.

Alan Lane, Hon. Treasurer

16 September 2022

Statement of Financial Activities

2021/22

Statement of Financial Activities for the year ended 31 August 2022

	General Fund	Restricted Fund	Total 2022	Total 2021	
	£	£	£	£	
Income and endowments					
Donations	18 573	1 030	19 603	13 131	Note 5
Bequests and legacies	263	0	263	52 438	
Subscriptions	9 885	0	9 885	9 645	
Gift Aid tax reclaimed	4 724	28	4 752	4 505	
Grants received	0	0	0	0	Note 6
Fundraising activities	17 507	0	17 507	14 563	
Sales of goods	771	0	771	753	
Other	3 837	0	3 837	3 704	Note 7
Total income and endowments	55 560	1 058	56 618	98 739	
Expenditure on charitable activities					
Trading costs	1 105	0	1 105	127	
Event costs	2 551	0	2 551	77	
Fundraising costs	1 251	0	1 251	546	
Staff training	25	0	25	175	
Grants and bursaries	4 260	0	4 260	2 189	
Research grants	0	700	700	9 784	
Subscriptions to other organizations	436	0	436	756	
Helpline costs	81	0	81	73	
Salaries and wages	26 380	0	26 380	25 581	Note 8
Social security and pensions	564	0	564	538	Note 8
Travel and subsistence	1 424	0	1 424	70	
Insurance	878	0	878	683	
Telephone charges	404	0	404	367	
Printing, postage, stationery etc.	540	0	540	576	
Equipment purchases	35	0	35	0	
Newsletter	9 165	0	9 165	8 908	
Web site and publicity	5 600	0	5 600	515	
ICT software	1 288	0	1 288	1 047	
Annual Conference and AGM	3 734	0	3 734	2 360	
Governance costs	1 782	0	1 782	2 266	
Other	1 240	0	1 240	1 245	
Total expenditure	62 743	700	63 443	57 883	
Net expenditure before gains on investments	-7 183	358	-6 825	40 856	
Net gains on investments	45	117	162	24	
NET EXPENDITURE	-7 138	475	-6 663	40 880	
Transfers between funds	0	0	0	0	
Net movements in Funds after transfers	-7 138	475	-6 663	40 880	
RECONCILIATION OF FUNDS					
Fund balance brought forward at 1 Sep 2021	162 388	7 380	169 768	128 888	
Fund balance carried forward at 31 Aug 2022	155 250	7 855	163 105	169 768	

Statement of Financial Activities 2020/21

Statement of Financial Activities for the year ended 31 August 2021

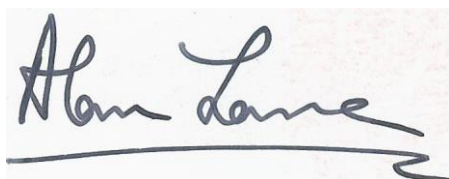
	General Fund	Restricted Fund	Total 2021	Total 2020	
	£	£	£	£	
Income and endowments					
Donations	11 661	1 470	13 131	53 077	Note 5
Bequests and legacies	52 438	0	52 438	100 000	
Subscriptions	9 645	0	9 645	9 634	
Gift Aid tax reclaimed	4 198	307	4 505	3 408	
Grants received	0	0	0	2 125	Note 6
Fundraising activities	14 563	0	14 563	11 426	Note 5
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
Total income and endowments	96 962	1 777	98 739	184 766	
Expenditure on charitable activities					
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	
Total expenditure	48 099	9 784	57 883	98 834	
Net income before gains on investments	48 863	-8 007	40 856	85 932	
Net gains on investments	15	9	24	142	
NET INCOME	48 878	-7 998	40 880	86 074	
Transfers between funds	0	0	0	0	
Net movements in Funds after transfers	48 878	-7 998	40 880	86 074	
RECONCILIATION OF FUNDS					
Fund balance brought forward at 1 Sep 2020	113 510	15 378	128 888	42 814	
Fund balance carried forward at 31 Aug 2021	162 388	7 380	169 768	128 888	

Balance Sheet

Balance Sheet as at 31 Aug 2022	General Fund	Research Fund	Total 2022	Total 2021	
	£	£	£	£	
Current Assets					
Stock in hand	870	0	870	917	<i>Note 9</i>
Debtors	907	0	907	5	<i>Note 10</i>
Prepayments	647	0	647	520	<i>Note 11</i>
Accrued income	0	42	42	520	<i>Note 11</i>
Recoverable Gift Aid	369	363	732	752	
Deposit Accounts	151 097	7 450	158 547	168 428	
Current Accounts	4 904	0	4 904	57 455	
Petty Cash	350	0	350	350	<i>Note 12</i>
Total current assets	159 144	7 855	166 999	228 427	
Current Liabilities					
Creditors	269	0	269	356	<i>Note 13</i>
Deferred income	360	0	360	420	<i>Note 14</i>
Accrued expenses	3 265	0	3 265	57 883	<i>Note 15</i>
Total current liabilities	3 894	0	3 894	58 659	
Total net assets	155 250	7 855	163 105	169 768	
TOTAL FUNDS	155 250	7 855	163 105	169 768	

The financial statements were approved by the trustees on 15 September 2022

Signed



Alan Lane

Hon. Treasurer

Date: 16 September 2022

Notes to the Accounts

Notes forming part of the financial statements for the year ended 31 Aug 2022

1. Basis of accounting

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

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

2. Income

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

3. Expenditure

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

4. Funds

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

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

Analysis of net assets between funds

	Unrestricted Funds	Restricted Funds	Total
	£	£	£
Net current assets	155 250	7 855	163 105
Total	155 250	7 855	163 105

5. Donations and Fundraising Activities

An adjustment has been made to the figures for earlier years to include receipts from Just Giving in the totals shown for fundraising activities, rather than for donations, as this more accurately reflects the nature of these receipts.

The Society also received a number of small donations to the Research Fund during the year. One grant of £700 was agreed during the year to support a research project. Just under £8k is currently available in this fund to support further projects.

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	2022	2021
	£	£
Wages and salaries	26 380	25 581
National Insurance contributions	0	0 (after deduction of rebate)
Employer's pension contributions	<u>564</u>	<u>538</u>
	26 944	26 119

The average number of staff employed during the year was 2 persons (2021: 2 persons). There are no employees earning above £60 000 (2021: 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 £1227 (2021: £0).

9. Stock

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

10. Debtors

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

11. Prepayments

Deposit for Annual Conference in October 2022 and part of insurance premium paid in 2021/22 that relates to 2022/23.

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 2022 salaries.

14. Deferred Income

Advance subscriptions for 2021/22 received before 1 September 2022.

15. Accrued expenses

Staff expenses relating to 2021/22 and provision for fees for independent examination of accounts, as well as funds committed to a planned workshop to be held in 2022/23.

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 2022 which are set out on pages 18 to 22.

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
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Suite I
Windrush Court
Abingdon
OX14 1SY

13 October 2022