

Annual Report 2020



*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

Reviewing our quarterly newsletters since my last report bears testament to another highly successful year for the Society, with progress being made to expand the Society's range of activities in many areas. Despite the challenges that have been felt by everyone in 2020, consequent upon Coronavirus COVID-19 (SARS-CoV-2), the Society (its members) have come together and quietly but stoically confronted the extraordinary situation in exemplary fashion. Behçet's patients routinely have to take care to avoid secondary infection and this approach, together with increasing knowledge by our renowned clinicians at the multi-disciplinary Centres of Excellence has helped keep us safe. It has been a psychologically difficult time, of course, but I venture to suggest that as Behçet's is a challenging condition in its own right, patients have already learnt that a helpful strategy to confront it, despite the debilitating and unpredictable nature of the condition, is to remain positive. The same approach is relevant to help face down the pandemic.

An accompanying fiscal challenge has been significant, which I report on later, but I congratulate trustees, and particularly our Treasurer Alan Lane, in judging matters optimally, ever conscious that in the background a long-disputed legacy would eventually be forthcoming. Generous individuals have continued to give much of their time and effort to boost our funds, and this has been readily apparent since 'lockdown' measures were eased. It does though, as I flagged last year, point to the need to achieve a more enduring and predictable income generation outcome into the future. Some research initiatives have been on hold, but these will pick up and trustees have formally endorsed the need to encourage the establishment of a Patient Registry, a study into the natural History of Behçet's in the UK and concomitant research that will result. To move this agenda forward will, again, need resources and influence. We continue to seek a President to act as a further enabler. I remain confident that, akin to the 'rolling snowball' analogy, which I mentioned last year, once the right person is secured at the top the remainder will follow.

In similar regard, it was with great pleasure that I was able to formally announce, in the Spring 2020 Newsletter, that Lady Margaret Ritchie, Baroness Ritchie of Downpatrick, had kindly agreed to become a Patron of Behçet's UK. Lady Ritchie has been instrumental in assisting our Northern Ireland patient cohort, as reported upon last year, and further progress has been made with her direct support early this year, for which we are most grateful.

Stability within the Board remains and the success of employing an Administrator and Assistant Administrator has become increasingly apparent in shifting all the work, particularly Governance tasks, that is necessary to manage a Society, and thence allowing members to be more efficiently and effectively supported. That said, assistance to support on the Helpline and within Support Groups has waned a little this year, and this is an area to be considered going forward.

The Annual General Meeting and Conference in Harrogate was a great success where once more we witnessed many members joining who had not attended a conference previously. In 2020 we will be breaking new ground by holding the event online, facilitated by the Royal Society of Medicine.

Governance

Substantial progress has been made, led by our Administrator, to overhaul and update all our governance documentation. This is no trivial task and underpins all we do. A more recent focus has been to thoroughly document our Safeguarding guidelines, which is not only applicable to our trustees but any member who volunteers to assist and has dealings with members (Helpline, Support Groups etc.). A system has been established to improve our business processes and procedures, originally suggested by the Vice-Chair, and when fully established will minimise nugatory work by trustees, and ensure we reduce 'single points of failure' and facilitate smooth succession as and when individuals move on in the future. We are making progress with a Fund-Raising Strategy, and

trustees have agreed to look into possibly employing, part-time, a suitably qualified and experienced individual to move matters forward in this area.

Recently, our Vice-Chair, Richard West needed to give notice that, for the time being, he needed to step away from his responsibilities with Behçet's UK. In my note of thanks to Richard, on behalf of members, I reflected how highly regarded he is, both within and without the Society. His contribution has been considerable, to the benefit of members, over many years. Richard has been a particularly important 'point of reference' for me whilst I have been Chair, for which I am most grateful. I noted that, in many ways, his achievements were best reflected in the EURORDIS European Black Pearl Award (in the Spring of 2019), which was a rightful accolade for all that Richard has done for others for more than 20-years. We wish him a well-earned break and will undoubtedly see him from time to time in future!

I complete this section of the report by thanking trustees once more for their valuable time committed to the Society, which is offered voluntarily and unremunerated. The Board has been stable for three years, and this has allowed good progress to be achieved in many areas. We now have a trustee representing each of the Devolved Nations. As notified last year, we held a joint meeting with the Behçet's Patients Centres Board to ensure we are moving forward in harmony and aligned with long-term goals, and this protocol will continue.

Annual Conference

The Annual General Meeting and Conference took place at Pavilions of Harrogate on 19 October. It was a highly successful conference, led by Dr Deva Situnayake's team from the Birmingham Centre of Excellence. A full summary of the proceedings was reported in the Winter 2019/20 Newsletter, Issue No. 50. The facilities were excellent, 130 registered of which 20 subsequently cancelled their booking and 26 did not show, leaving a robust figure of 84 attending. Feedback was most positive, and we have taken on suggestions for the future. The Judith Buckle Award was presented by Richard West to Dr Edmund Jessop, who was instrumental in advising on the National Commissioning process to establish the national Centres of Excellence, from his position within the Highly Specialised Services, NHS England.

The Behçet's Forum Meeting

The Behçet's Forum initiative remains problematic. It has not met since the 2016 Conference; a fundamental problem being overstretch amongst clinicians within respective NHS. Looking to the future, the Royal Society of Medicine (RSM) has, for the past 10 years, through the generosity of anonymous donors, put on a very successful series of events 'RSM Medicine and me: living with ...'. The aim of these programmes is to bring together those who have experience with a condition with those who are have clinical and/or research expertise in the condition. For these events the RSM teams up with a relevant charity. Just before the COVID pandemic lockdown we had started to work with Fiona Moss, RSM Dean to put together an in-person programme – RSM Medicine and Me: Living with Bechet's – in November 2020. Clearly, that is now not possible. But instead we will be working with the RSM to put on a 'Medicine and Me' webinar. Whilst this will not have the same networking opportunities as an in-person event, it will enable many more people to take part. The aim would be to schedule a live Face to Face event in 2021.

Behçet's Friends and Family Day

Unfortunately, the planned Friends and Family Day, to be held on 27 June 2020, at the Underbank Activity Centre, Stockbridge, had to be cancelled owing to 'lockdown'. These popular events will continue and members are strongly encouraged to support these events. They really are a great 'tonic' to all who attend, and offer patients much needed enjoyment.

Newsletter

Clare Griffith, ably assisted by Judi Scott, continues to craft fantastic Newsletters and contributors are thanked for their increasingly positive articles. This is a core product that the Society produces to include considerable input from the Behçet's Patients Centres. We continue to encourage the use of our electronic version, to save expense, but will continue the printed version where demand exists.

Medical Factsheets and Alert Card

These continue to be an important point of reference to patients and clinicians alike; the former particularly for those 'new to Behçet's' and are linked with all four Nations' NHS sites. I continue to strive to have these routinely updated annually, even though the vast majority of information will not change from year-to-year. It sends an important subliminal signal to anyone looking at them, that they are indeed up to date. The issue remains on ensuring they are taken note of in Primary and Secondary care, which is not always the case and exceedingly frustrating for patients.

The revised Alert Card has gone down well, but I still aim to get an official NHS logo on them, so they are routinely taken seriously (to align with The UK Strategy for Rare Diseases 2019 update (27 February 2019) which stated the intention to introduce Alert Cards for rare disease patients).

Medical Advisory Panel

A revised draft set of Terms of Reference for the Medical Advisory Panel still awaits implementation, with the aim of re-vitalising this important function, and ease reliance on the three Clinical Directors of the Centres of Excellence.

Fundraising and Membership

Generous individuals continue given much of their time and effort to boost our funds, and everyone involved, whatever the amounts collected (great or relatively small) are thanked most sincerely for their fantastic efforts. Membership is buoyant as reported elsewhere.

Research

Research Award Prizes

The Board-endorsed paper (our three Research Award Prizes; Behçet's UK Prize, Adamantiades Prize and The Patrons' Prize) noted last year remains on the books, but we have encountered difficulties with the Royal Societies in achieving endorsement – who prefer more non-specific awards. We continue to progress this initiative.

Prevalence and incidence of Bechet's Disease in England

This research, led by Dr Priyanka Chandratre and generously supported by Mrs Virginia Yee, has been delayed because of COVID-19. The detail was noted last year, suffice to say that this will be an important precursor to establishing a Behçet's Patient Registry leading to a study into the Natural History of Behçet's in the UK.

Supporting Initiatives

RAIRDA

Our associate status, at the time of writing, has lapsed thanks to a new management structure initiated and concomitant proposed membership fee, which trustees felt we could not afford as a proportion of our annual income.

BSR/BAD NICE accredited guideline

This joint initiative is progressing well and will be an important step to improve patient outcomes; consistent standards of care, treatment and conducting subsequent audits/Quality Assurance.

Communications Strategy

Our Communications Strategy, and particularly visibility on Social Media has improved, thanks to the conscientious efforts of our administrators, Gemma Darlow and Deborah Cardinal.

Social Media

The Behçet's UK Facebook page continues to attract followers, which now stands at 825 and our private Facebook groups, open to Behçet's UK members, are gradually attracting more members. Our Twitter page now has 659 followers, and Deborah Cardinal regularly tweets whenever opportunities arise. Instagram has 458 followers. Our online presence therefore continues to increase our visibility considerably among all age groups with followers steadily on the rise across all platforms.

Support Groups

Our previous six Local Support Groups, led by Yvonne Morris, Richard West, Andrea Williams, Tony Wright, Rachael Humphreys and Fionnuala McKinley are shrinking in size but we have been most grateful for the support offered by the aforesaid. We look to recruit new helpers as the function is valued by the participating members, even though small in numbers. Very much a local, and personal initiative.

Political Lobbying

This remains an important aspect, and members have been encouraged to get involved, as and where appropriate in a coordinated manner. Reduced activity has been evident in consequence of the pandemic. The groups with which we remain involved, for the record, 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.

Helpline

Incidence of calls remains relatively low, by comparison to the past, which on the one hand is a positive sign that the support patients (and members) need is forthcoming elsewhere. Nevertheless, the facility remains an important function, and as ever we continue to need volunteers. Gemma Darlow, Fionnuala McKinley, Tony Wright, Daniellea Boyle and Catherine O'Hara are thanked for their vital contributions.

Devolved Nations

Positive strides continue to be made in Northern Ireland, with Fionnuala McKinley and Ann Gough's enduring help in the background. Baroness Ritchie of Downpatrick has been instrumental in assisting the Northern Ireland patient cohort, and a most useful meeting was held on 21 February 2020 with Dr Miriam McCarthy, Director Commissioning, Ms. Veronica Gillen, Acting Director Commissioning Specialist Services, Ms. Christine Collins Chair the Patient Client Council and Ms. Rhoda Walker from the Northern Ireland Rare Disease Partnership. Subsequently, with the assistance of Dr Michael McBride (Chief Medical Officer) Northern Ireland, who has always supported our patients well, I have been put in touch with Public Health Agency's Health and Social Care Research and Development Division (PHA HSC R&D) to explore research opportunities. Catherine O'Hara is making progress in Scotland and Rachael Humphreys continues to move matters forward in Wales, utilizing her close links with colleagues in Genetic Alliance UK.

Conclusion

In sum, we have witnessed another productive and progressive year, albeit a bit unusual since mid-March 2020! In that regard I would particularly like to thank Gemma Darlow and Deborah Cardinal for their sustained efforts to keep ahead of the game with the latest (authoritative) information and guidance to inform members.

I will conclude similar to that I did last year, by thanking everyone who makes this Society the great institution that it is; ultimately for the purpose of supporting our Patient Members. This is a team effort starting with your trustees, the admin staff, Helpline, Local Support Group leads, and Clare Griffith. It includes carers and supportive family members, all the staff at, and supporting, the National Centres of Excellence led by the Clinical Directors Professor Rob Moots, Dr Deva Situnayake and Professor Farida Fortune CBE, supported by Jan Mather's magnificent team in Behçet's Patients Support, Jean Christians, Rebecca Hyder and Jackie Pooler (and their Board of Directors, trustees and John Mather the Operations Manager in the background), together with our Medical Advisory Panel.

Finally, at its core, the Society must achieve fulsome member engagement. The next stage on its development is to establish a Patient Registry leading to a study into the Natural History of Behçet's within the UK. The recent 2020 Quality of Life Survey saw 326 full survey questionnaires completed and another 133 partially completed. Our patient members number over 1000! If we are to move forward successfully we must improve engagement levels. A Priority Setting Partnership to promulgate agreed patient and clinician research questions has been initiated (which attracts interested researchers and in turn helps promote their careers, together with wider awareness of Behçet's). The final stage will be to get into the whole genome sequencing/genomic medicine and epigenetics space. Focused collegiate effort, and of course funding, is required to achieve all this but it is the area the Society can most help to shape. Basically, it is your data and you need to own it – and in so doing its proper use can considerably improve patient outcomes for all. I encourage members to support me in this endeavour.

Tony Thornburn OBE, Chair

October 2020

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 emergence of Covid 19 has had a significant impact upon fundraising opportunities for all charities and Behçet's UK is no exception. All major fundraising events have been cancelled: marathons, long-distance walks, park runs, sponsored swims, bike rides, all on hold until it is safe for people to participate. These events would usually represent a considerable boost to Behçet's UK's funds.

However, as always, we have some amazing members who haven't let this deter them from finding ways to support the charity.

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)



Stacey Rodger was determined to keep fit in 2020 and pledged to raise £1000 for Behçet's UK and signed up for various gruelling events.

Sadly, due to the pandemic the events were cancelled but, undeterred Stacey has completed many of the events virtually from home and has already raised over £500 to date.

Sian Wisson decided she needed a challenge and there doesn't come a bigger one than Powerlifting! Sian has now qualified for the British Championship having won her weight category at local level and has raised over £1800!



Makeup artist Jodie Stuart enlisted the help of The Body Shop in Aberdeen and organised a Pamper Evening with mini makeovers, food, drinks and prizes. Jodie raised over £670.



Malcolm Matthews continues to collect and sell postage stamps to raise funds.

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



Jan Mather and her mother produced their beautiful Christmas cards which sold out again! Almost £1000 was raised 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 £5382



In early May, **Cat Ray** and her friends from Evolution Choir organised an "epic weekend of online entertainment" to keep everyone upbeat during 'lockdown'. The Big Variety Weekend involved singers, comedians, impressionists and illusionists. They raised £1031- smashing the £500 target they set themselves!



Bike for Behçet's

13 weeks  226 miles

Run for the Rare



Trustee Rachael Humphreys is always looking for innovative ways to raise funds and this year is no exception. A keen runner, Rachael and friend and fellow member Laura Forrest devised a fantastic challenge.

'Bike for Behçet's Run for Rare' would involve running and/or cycling the distance between the 3 Behçet's Centres of Excellence over 13 weeks finishing before the date of the Behçet's UK Online AGM and Conference on October 17th; a distance of 226 miles!

Also taking part are Clare Gibson; Lauren Bradfield; Laura & Zoe Forrest; 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.

So far, this fantastic team have raised over £7,500!



Trustee, Catherine O'Hara has crocheted handbags which are for sale priced at £8 and all proceeds go to Behçet's UK.



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 2020

The trustees present their report along with the financial statements of the charity for the year ended 31 August 2020. 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 19. 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

Tony Thornburn OBE

Chair

5 October 2020

Staff and Trustees

Trustees

Tony Thornburn OBE (Chair)
Richard West (Vice-Chair)
(resigned 10 Aug 2020)
Judi Scott (Hon. Secretary)
Alan Lane (Hon. Treasurer)
Mark Friston
Rachael Humphreys
Fionnuala McKinley (from 3 Jan 2020)
Amanda Moseley
Catherine O'Hara

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

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Web: behcetsuk.org

Registered Charity No: 326679

Report on Financial Statement 2019/20

At this time last year, I reported that the Trustees had been able to expand the Society's range of activities by appointing a second part-time member of staff and by increasing our attendance and representation at events for medical professionals and others, in order to improve our profile and to share knowledge about Behçet's and its impact upon our members and their families.

I cautioned that the decision to reduce our reserves in this way might later need to be reconsidered if our income did not increase within the year, particularly if a hoped-for, but disputed, large bequest did not materialise.

The financial year just ended was very much one of 'two halves'! From September to February, Trustees noted with some concern that our monthly income was less than the corresponding expenditure and were conscious that some difficult decisions might have to be made at their planned Board meeting in March.

A few days before the planned date, we were all plunged into 'lockdown' and so a virtual meeting via the 'Cloud' was arranged. However, its agenda was transformed by the sudden resolution of the legal wrangles and the receipt of a cheque for £100 000 from the executors of the estate of a former member, representing the largest single donation received by the Society in its 37-year history!

The pandemic had the effect of reducing or cancelling some of the planned events and activities that would have usually happened during the summer. Nevertheless, some wonderful fund-raising did take place and is described earlier in this Annual Report.

The other effect was to reduce our ability to spend some of our resources, as it was difficult to finalise arrangements with university departments for several research projects that Trustees wished to support. Our balance sheet for 31 August 2020 shows a total of £48k in 'accrued expenses'. The bulk of this relates to these projects: two research grants totalling £9.5k to the University of Liverpool, £36k to Sandwell and West Birmingham Hospitals NHS Trust made possible by a very generous donation from a member in Hong Kong and £1.8k for a workshop funded by the British Association of Dermatologists. It is anticipated that these projects will all be able to go ahead in the next year.

The bulk of the bequest has also been earmarked to underwrite and expand our normal activities over the next three 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 General Fund received income this year of £148.0k, including £9.6k in subscriptions, £26.1k in donations, and activities and sales totalling £1.3k. Expenditure was £62.9k and there was a net surplus on the General Fund of £85.3k, leaving accumulated reserves of £113.5k.

The Restricted Fund had a total income of £36.7k, which was donated towards a particular research project. Allowing for this future expenditure, there remains £15.4k in reserves.

Membership

There has been a larger than usual increase in the number of members this year and in particular it is pleasing to note that there have been quite a few new Junior Members. Our membership has in fact increased by 23% over the last two years.

On 1 September 2020, we had 1186 full members, compared with 1045 on that date last year. In addition, there were 22 junior members and 80 associate members (mainly medical professionals).

The total number of names on our database was 1347, compared with 1220 the previous year, of whom 1084 were patients and 74% were female. The number in receipt of UK state benefits, including pensions, was 916, compared with 824 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

October 2020

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	
	£	£	£	£	
Income and endowments					
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
Total income and endowments	148 044	36 722	184 766	43 808	
Expenditure on charitable activities					
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	
Total expenditure	62 874	35 960	98 834	82 902	
Net income before gains on investments	85 170	762	85 932	-39 094	
Net gains on investments	116	26	142	104	
NET INCOME	85 286	788	86 074	-38 990	
Transfers between funds	749	-749	0	0	
Net movements in Funds after transfers	86 035	39	86 074	-38 990	
RECONCILIATION OF FUNDS					
Fund balance brought forward at 1 Sep 2019	27 475	15 339	42 814	81 804	
Fund balance carried forward at 31 Aug 2020	113 510	15 378	128 888	42 814	

Statement of Financial Activities 2018/19

Statement of Financial Activities for the year ended 31 August 2019

	General Fund	Restricted Fund	Total 2019	Total 2018
	£	£	£	£
Income and endowments				
Donations	21 439	455	21 894	27 882
Bequests and legacies	0	0	0	4 454
Subscriptions	8 881	0	8 881	10 148
Gift Aid tax reclaimed	2 760	34	2 794	2 261
Grants received	520	0	520	0
Fundraising activities	4 944	0	4 944	2 825
Sales of goods	658	0	658	1 104
Charitable activities income	531	0	531	1 061
Other	3 586	0	3 586	2 777
Total income and endowments	43 319	489	43 808	52 512
Expenditure on charitable activities				
Trading costs	201	0	201	316
Event costs	4 859	0	4 859	5 442
Fundraising costs	216	0	216	426
Staff recruitment	0	0	0	193
Staff training	354	0	354	0
Grants and bursaries	5 645	0	5 645	6 437
Research grants	0	9 535	9 535	0
Subscriptions to other organizations	661	0	661	434
Helpline costs	567	0	567	1 671
Salaries and wages	23 859	0	23 859	15 824
Social security and pensions	405	0	405	207
Travel and subsistence	8 069	0	8 069	5 310
Insurance	489	0	489	485
Telephone charges	637	0	637	500
Printing, postage, stationery etc.	2 627	0	2 627	1 447
Equipment purchases	519	0	519	922
Newsletter	8 404	0	8 404	8 358
Web site and publicity	2 450	0	2 450	1 616
AGM expenditure	5 833	0	5 833	7 492
Governance costs	6 950	0	6 950	2 757
Other	622	0	622	1 000
Total expenditure	73 367	9 535	82 902	60 837
Net income before gains on investments	-30 048	-9 046	-39 094	-8 325
Net gains on investments	79	25	104	43
NET INCOME	-29 969	-9 021	-38 990	-8 282
Transfers between funds	0	0	0	0
Net movements in Funds after transfers	-29 969	-9 021	-38 990	-8 282
RECONCILIATION OF FUNDS				
Fund balance brought forward at 1 Sep 2018	57 444	24 360	81 804	90 086
Fund balance carried forward at 31 Aug 2019	27 475	15 339	42 814	81 804

Balance Sheet

Balance Sheet as at 31 Aug 2020	General Fund	Research Fund	Total 2020	Total 2019	
	£	£	£	£	
Current Assets					
Stock in hand	979	0	979	1 170	<i>Note 9</i>
Debtors	41	0	41	28	<i>Note 10</i>
Prepayments	341	0	341	1 082	<i>Note 11</i>
Recoverable Gift Aid	767	27	794	647	
Deposit Accounts	113 318	54 086	167 404	49 262	
Current Accounts	1 302	6 759	8 061	2 243	
Petty Cash	350	0	350	350	<i>Note 12</i>
Total current assets	117 098	60 872	177 970	54 782	
Current Liabilities					
Creditors	269	0	269	9 832	<i>Note 13</i>
Deferred income	430	0	430	495	<i>Note 14</i>
Accrued expenses	2 889	45 494	48 383	1 641	<i>Note 15</i>
Total current liabilities	3 588	45 494	49 082	11 968	
Total net assets	113 510	15 378	128 888	42 814	
TOTAL FUNDS	113 510	15 378	128 888	42 814	

The financial statements were approved by the trustees on 5 October 2020

Signed

Alan Lane
Hon. Treasurer

Date: 5 October 2020

Notes to the Accounts

Notes forming part of the financial statements for the year ended 31 Aug 2020

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	113 510	15 378	128 888
Total	<u>113 510</u>	<u>15 378</u>	<u>128 888</u>

5. Research Fund

The Society received £35.7k towards a research project by Dr Priyanka Chandratre of Sandwell and West Birmingham Hospitals NHS Trust and a number of small donations during the year. Grants totalling £9.5k were agreed during to the University of Birmingham to support two research projects, which have yet to be drawn down.

6. Grants received

The Society received a grant from the British Association of Dermatologists, the bulk of which is to meet the costs of a planned workshop to be organized by the University of Liverpool.

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 2020 £	2019 £
Wages and salaries	25 777	23 859
National Insurance contributions	0	0 (after deduction of rebate)
Employer's pension contributions	<u>535</u>	<u>405</u>
	26 312	24 264

The average number of staff employed during the year was 2 persons (2019 2 persons). There are no employees earning above £60 000 (2019 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 amounting to £4508 (2019: £7169) during the year.

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 2019/20 that relates to 2020/21.

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 2020 salaries.
Research Fund: Grants awarded to University of Birmingham but not yet drawn down.

14. Deferred Income

Advance subscriptions for 2019/20 received before 1 September 2019.

15. Accrued expenses

Staff and trustees' expenses relating to August 2020 and provision for fees for independent examination of accounts, as well as funds committed to research projects to be undertaken in 2020/21.

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 2020 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
Ross Brooke Ltd

Suite 1
Windrush Court
Abingdon
OX14 1SY

.....8th October..... 2020