



*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 2019

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 inflammatory diseases of the central nervous system



## Clive B Archer

**Job title:** Cons Dermatologist & Hon Clinical Snr Lecturer  
**Qualifications/ Post Nominals:** BScMD, PhD, MSc Med Ed (Lond), FRCP Edin, FRCP (Lond)  
**Where qualified:** Guy's Hospital Medical School, University of London  
**Year of initial qualification:** 1978  
**Currently practising at:** Bristol Dermatology Centre, University Hospitals Bristol NHS Foundation Trust, Bristol  
**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



## Reuben C S Ayres

**Job title:** Consultant Gastroenterologist

**Qualifications/Post Nominals:** BM, DM, FRCP

**Where qualified:** Southampton

**Year of initial qualification:** 1982

**Currently practising at:** Royal Devon & Exeter Foundation Trust

**Special interests:** Colorectal cancer, inflammatory bowel disease



## Paul Brogan

**Job title:** Senior Lecturer in Paediatric Vasculitis

**Qualifications/Post Nominals:** BSc(Hon), MBChB(Hon), MRCPCH, MSc, PhD

**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



## Dr 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

**Special interests:** HIV and genital dermatology



## 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





## Farida Fortune CBE

**Qualifications/Post Nominals:** BDS, MBBS, FRCS, FRCP, FDSRCS, FGDP, DipEdTMD, PhD

**Job title:** Dean for Dentistry; Director, Clinical Academic Unit

**Where qualified:** University College London

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

**Currently practicing at:** Dental Institute, Barts and The London NHS Trust

**Special interests:** Oral manifestations of systemic disease including immune related/autoinflammatory conditions such as Behçet's disease, Sjogren's syndrome, orofacial granulomatous and oral Crohn's disease, pemphigus and pemphigoid. Clinical research in inflammatory mucosal disease. Undergraduate and postgraduate dental and medical education, specialising in teaching the medical support subjects for dentistry.



## Desmond Kidd

**Job title:** Consultant Neurologist

**Qualifications/Post Nominals:** 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



## Dr Jane Setterfield

**Job title:** Senior Lecturer/Consultant Dermatologist

**Qualifications/Post Nominals:** BDS, DCH, DRCOG, MD, FRCP

**Where qualified:** University College Hospital, London

**Year of initial qualification:** Dentistry 1980, Medicine 1987

**Currently practising at:** Guy's Hospital 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 disease and vulval dermatology



## 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:** School of Immunity and Infection, 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. He is now retired but was formerly Clinical Director for Rheumatology at The Royal London Hospital. He is Honorary Life President of the International Society for Behçets'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). He is a member of the British Society for Rheumatology and has a special interest in clinical rheumatology and, of course, Behcet's syndrome



### **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. She has a special interests in Uveitis in adults and children, infective eye disease, ocular inflammation of all types associated with systemic disease

# Chair's Report

## Overview

I can report on another a highly successful year, based on stability within the Board and this last year the employment of both an Administrator and Assistant Administrator; whereby a number of the tasks we set out to achieve have been executed, thereby allowing the Society to support its members more efficiently and effectively.

The Annual General Meeting and Conference in Bristol was a great success where we witnessed a majority of members who had not attended a conference previously reflecting, we believe, the benefit of moving locations around the country each year. Another successful Families Day was held, this year at the Skreens Activity Centre in Essex.

Once more generous individuals have given much of their time and effort to boost our funds, which is highly commended; and a legacy remains elusive on the horizon. As noted last year, notwithstanding these marvellous efforts' expenditure is overtaking income and a major fundraising initiative is required in the next year, which also needs to achieve a more enduring and predictable outcome into the future.

A number of initiatives, particularly on the research front are being developed, and to achieve them significant funding will be required. We continue to seek a President and patrons to act as an enabler in this regard. I remain confident that, akin to the 'rolling snowball effect' once the right person is secured at the top the remainder will follow.

The 'big event', in its 36th year, was the Society successfully changing its title to Behçet's UK with an accompanying new logo that has been most popularly received. The rebranding, for the reasons summarised in last year's report, was highly effective and carried out at minimum cost – the credit to which must go to Gemma Darlow and Deborah Cardinal, our administrators. Our Social Media presence has also increased considerably thanks also to their efforts.

Representation at the major conferences (RCGP, BSR, BDNG, BAD, RSPCH) has accompanied this rebranding exercise, which has cost the Society but, just as other charities accept, if one does not get out and about one's voice will not be heard; and raising awareness of Behçet's within the UK remains a top priority.

## Governance

We continue to improve on what was already good governance including registering with the Fundraising Regulator and now checking we comply with their strict and detailed guidance. There is work to do here but we are making progress. The trustees have tightened up on documenting the procedure for the proper allocation of grants, including adjusting the upper limit in line with inflation and to allow a responsive, but controlled and flexible process to match individual requests in time of need.

With the able assistance of our part-time administrators we are making excellent progress in our business processes and procedures to ensure we reduce 'single points of failure' and facilitate smooth succession as and when it may be required in the future. The chair has joined the Association of Chairs, who produce much excellent guidance, which is being reviewed to ensure we are following best practice.

The trustees continue to devote their valuable time, voluntarily, to the Society always with the interests of the members to the forefront of their minds, and how they can be best supported. There is a healthy dynamic in moving the Society forward coherently. We seek to encourage a trustee from Northern Ireland to join the Board to balance representation across the UK. We will formally hold a joint meeting with the Behçet's Patients Centres Board this year to ensure we are both moving forward in harmony and aligned with long-term goals.

A number of 'names in the frame' have been identified, and indeed approached, to build a structure with a President and Patrons but is taking longer than hoped. It is a sad reflection that being a small society supporting people with a very rare disease does not naturally attract 'high profile' individuals



such as the larger health-related charities enjoy - linked to common and widespread diseases that most individuals in time will directly come across, affecting either them or their relatives. To a degree this is holding up the Fund-Raising Strategy which has still to be articulated.

### **Annual Conference**

The Annual General Meeting and Conference took place at the Doubletree by Hilton in Bristol on 20 October which was well received. Originally, 133 signed-up to attend, of which 13 subsequently cancelled and a further 27 did not turn up on the day. The AGM ran swiftly to time during which the chair introduced the new administration team, Gemma Darlow and Deborah Cardinal, as well as new Trustee Catherine O'Hara. The Judith Buckle Award was presented by Richard West to Julie Collier, who stood down as BSS Administrator earlier in the year, noting amongst other things the enormous contribution she had made to the Society during her tenure as the first, part-time, administrator the Society has employed.

The Medical presentations, sponsored this year by the London national Behçet's Syndrome Centre of Excellence were introduced by Professor Farida Fortune CBE, who covered the important topic of nutrition during her opening talk. Professor Miles Stanford, Consultant Ophthalmologist at the London Centre, covered Behçet's and the Eye which was followed by Dr Amal Senusi talking about why are Behçet's patients always tired? Dr Steve Higgins then covered psychological aspects of living with BD explaining that psychologists can help with coping with the psychological effects of BD; managing home, family and work life; living with pain and fatigue; improving sexual wellbeing and enjoyment; and cognitive assessment.

An informative update from The Behçet's Patients Centres followed presented by John Mather supported by Jackie Pooler and Jean Christians covering, amongst other things; patient support and provision of information, long-term conditions as an NHS England priority recognizing 'patient activation' as the knowledge, skills and confidence a person has in managing their own health and care, and the importance of physical activity built into a patient's daily routine. Dr Graham Wallace of the University of Birmingham covered microbes in the human gut, and the day finished with the popular question and answer session with the medical speaker panel.

### **The Behçet's Forum Meeting**

The Behçet's Forum, ordinarily running alongside our Conference, did not meet, as in 2017, and this function is being reviewed. Terms of Reference need to be developed. One of the fundamental problems is overstretch within respective NHS's and thus clinicians freeing up time to attend such initiatives. One option would be to 'piggy-back' the larger society conferences (e.g. BSR, BAD etc) offering a brief Continuous Personal Development session on Behçet's; which would also have the advantage of promoting wider visibility amongst clinicians. The national Centres of Excellence run Behçet's in a Day briefings, which to a degree covers aspects of what the Forum previously carried out, including patient engagement.

### **Behçet's Families Day – Skreens Activity Centre**

Another highly successful Families Day was held, this year at Skreens Activity Centre in Essex, with 27 attendees. Enjoyed by all, with trustees Rachael Humphreys and Amanda Page supporting, events kicked-off with refreshments in a 'day hut', the base for the day, before groups headed off for archery or kayaking. Followed by a leisurely lunch and some 'giant games', archery or tomahawk throwing was then undertaken followed by another break and finally kayaking or bushcraft. The day flew-by quickly and Gemma Darlow is again congratulated on 'bringing it all together' which made for such a successful event. The amount of Health and Safety procedures with which one has to comply in advance are considerable and take time to cover methodically.

### **Newsletter**

Clare Griffith has crafted a revised format for the Newsletter, with our new logo and colour scheme, and we have received many complementary remarks particularly about how it comes across in a more friendly and supportive manner – one of the aims of the rebranding exercise. This is a core product that the Society produces to include considerable input from the Behçet's Patients Centres.

## **Medical Factsheets and Alert Card**

Once again, I report that we have nearly achieved the aim of routinely updating our Behçet's Medical Factsheets annually. It is vital to ensure they remain current, particularly in perceptual terms, to ensure confidence in the information the Society provides is seen to be up-to-date. An 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, and unprofessional actually.

Regarding Alert Cards, we have revised the former BSS Patient Member Card to align with a forthcoming initiative embraced within The UK Strategy for Rare Diseases 2019 update (27 February 2019) to introduce Alert Cards for rare diseases. RAIRDA are also pushing to accelerate this initiative. Ultimately, they need the NHS logo on them if they are to be taken seriously.

## **Medical Advisory Panel**

A revised draft set of Terms of Reference for the Medical Advisory Panel awaits implementation, with the aim of re-vitalising this important function. Currently too much reliance rests on consulting with the three Clinical Directors of the Centres of Excellence, and as they are extremely busy this is iniquitous.

## **Fundraising and Membership**

A fuller report follows, but in sum generous individuals have again given much of their time and effort to boost our funds, which is highly commended and all are thanked most sincerely for their fantastic efforts. A relatively significant legacy remains elusive, locked in challenge to a disputed Will.

Notwithstanding these marvellous efforts' and generous (often unexpected) donations expenditure is overtaking income and a major fundraising initiative needs to be encourage in the forthcoming year. Indeed, we need to devise a more enduring and predictable outcome into the long-term future. Income from membership fees continues to decline. That said, our administration team have done an excellent job in significantly improving our fundraising promotional area within the website and as we embark with our new branding hope to increase revenue in this regard.

As last year Membership remains buoyant, with 1219 names on our database. We do not seem to know how many of these have been seen by the Centres of Excellence, and how many of those that have attended are not members and will address that over the next year. I would urge members to encourage further additions to our 'community' in future years.

## **Research**

### **Research Award Prizes**

The Board has endorsed the paper Mark Friston prepared articulating our three Research Award Prizes; Behçet UK Prize, Adamantiades Prize and The Patrons' Prize. With the assistance of the Chair and President of the RCGP, Helen Stokes-Lampard and Professor Mayur Lakhani respectively, we are confident that the Behçet's Prize will be initiated this year, on the proposed theme of a collaborative approach that aims to stimulate knowledge, discussion, standards, collaboration and pathways, perhaps between GPs and Dentists, and to encourage general practitioners to give thought as to how patients can better be managed in a primary healthcare setting.

### **Prevalence and incidence of Bechet's Disease in England**

The trustees have endorsed 'match funding', that has generously been pledged by Mrs Virginia Yee, to support a research proposal to be led by Dr Priyanka Chandratre, into the 'Prevalence and incidence of Bechet's Disease in England: A multi-centre retrospective observational study', starting in January 2020. The research will enable the Centres of Excellence (collegiately) to gather key information about the Behçet's burden in England – this will include the incidence and prevalence of all cases identified by examining databases from the three National Centres and satellite treatment centres plus additional data enquiry from what is called the GP THIN database and Hospital Episode Statistics (HES).

This data will then enable identification of the associated morbidity, mode of presentation and mortality of the disease and enable us to look much more precisely at the disease phenotype and

the clustering of the key elements and complications of Behçet's within this phenotype. This is the underpinning data needed for subsequent drug trials and treatment regimes, and will be the first time we have been able to do this on a very large sample in the UK.

In consequence we hope, as one outcome, to be able to effectively replicate the work of the Japanese group who have studied this in detail in Japan and who have identified that there are 3 or 4 typical clusters of complications in Japan which do not all behave the same way in terms of prognosis and progression over time. The Japanese group have identified that there has been a change in the disease over time with the emergence of a greater proportion of patients with a GI phenotype. This will obviously lead to a better understanding of the patterns of disease presentation and how best to target therapy selectively through a more personalised / individualised approach - i.e. treatment. Again, to do this properly one has to have the underpinning data - and becomes the start of articulating the Natural History of Behçet's in the UK.

## **Supporting Initiatives**

### **RAIRDA**

I continue to represent the Society at the Rare Autoimmune Rheumatic Diseases Alliance (RAIRDA), and we remain as Affiliate Members, alongside the British Society of Rheumatology, LUPAS UK, SCLERODERMA & RAYNAUD'S UK, VASCULITIS UK, British Sjögren's Syndrome Association (BSSA).

Their aim remains to improve care for people living with rare autoimmune rheumatic diseases by: raising the profile of the needs of people living with rare autoimmune diseases and their access to timely effective treatment; promoting the implementation of best practice care and pathways; increasing knowledge about patient care through better data.

Progress on some initiatives is slower than anticipated, but it is beneficial to be supporting RAIRDA, and if more advances are made I would be recommending full membership.

### **BSR/BAD NICE accredited guideline**

At this year's British Society of Rheumatology, it was announced that a NICE accredited guideline, sponsored jointly by the British Society of Rheumatology and British Association of Dermatologists, is to be compiled. We have two representatives acting as 'the Patient Voice' (one of whom on behalf of children with Behçet's) and Richard West. I have asked to attend with no executive function; to become better informed about Behçet's and treatment and this has been agreed. Once produced this will be a significant step to help improve more consistent standards of care, treatment and conduct subsequent audits/Quality Assurance. Once 'England' has produced it we need to encourage Wales, Scotland and Northern Ireland's respective NHS's to adopt the principles in accordance with their own processes.

## **Political Lobbying**

Political lobbying groups are an important area from which small charities, such as ourselves, can benefit. Often set up by larger enterprises, such as Genetic Alliance UK or National Voices. I have now started to enter this space. Cross-Party Groups aim to provide an opportunity for politicians and members of the public to meet and discuss a shared interest in a particular cause or subject.

### **All Party Group on Skin (APPGS)**

This committee is chaired by David Davies MP, who has written to the Health Secretary on the back of the latest meeting. Members in the Devolved Nations were contacted and encourage to send personalised prepared letters to their local MP or Assembly Member in advance, to ask them to 'pop into the meeting'; but it had a secondary and more important motive, as an excuse to make those individuals aware of Behçet's. We are not sure that the take-up was that prominent and is a matter all need to support when asked.

## **Cross Party Group on Rare, Genetic and Undiagnosed Conditions (CPG RGUC) in The National Assembly for Wales**

Usefully, there has been another opportunity as Genetic Alliance UK are in the process of setting up this group and members from Wales have been encouraged to write to their Assembly Member and ask them to pledge their support to the establishment of this group.

## **The Scottish Parliament Cross-party Group on Rare, Genetic and Undiagnosed conditions**

Genetic Alliance UK provides the Secretariat to this Cross Party Group, and Catherine O'Hara is monitoring what goes on and attending meetings when appropriate. The CPG aims to:

- Act as a channel of communication between the Scottish Parliament and families affected by rare, genetic and undiagnosed conditions.
- Act as a channel of communication between the Scottish Parliament and those working in the fields of research, treatment, care and prevention of rare, genetic and undiagnosed conditions.
- Monitor and contribute to the implementation of the Scottish Plan for Rare Diseases in Scotland.
- Identify areas where inequalities exist in provision of care for rare, genetic and undiagnosed conditions and campaigning for improvement.
- Examine areas of health and social care policy or service provision relating to rare, genetic and undiagnosed conditions.

Again, members in Scotland will variously be asked to 'lobby' when appropriate.

## **Prescription Charges Coalition**

This group, which the Society joined in 2007, was set up with Asthma UK leading in 2006. The work of the group has been re-energised and it is timely to be involved again; seeking to achieve free prescriptions for all people with long-term conditions.

I have attended two meetings, and with a potential election in the offing, this offers another opportunity to lobby potential parliamentary candidates (and another opportunity to raise awareness of Behçet's). This is an important area because NHS England have already initiated a couple of what are cost-cutting exercises, for example "*Conditions for which over the counter items should not routinely be prescribed in primary care and Items which should not be prescribed in primary care*", and there will doubtless be more to come. As the British Association of Dermatology briefed, the APPGS has been alerted to short-term savings, such as with emollients, will undoubtedly have a long-term impact with inflammatory skin conditions when patients, who cannot afford provision, do not 'nip symptoms in the bud' with simple but regular treatment before the symptoms become more extreme.

## **Communications Strategy**

The Communications Strategy has yet to be written and formalised, but already considerable advances have been made by our administrators, Gemma Darlow and Deborah Cardinal. We now offer a clear message, with the prime goal of raising awareness and reducing time to diagnosis for patients. Initially, in correspondence we refer to Behçet's as a syndrome/disease and thereafter just Behçet's.

## **Social Media**

A new Behçet's UK Facebook business page has been created, which already has 401 followers, which also hosts 12 peer-to-peer support groups. These groups are exclusively for Behçet's UK members as an alternative to local support groups. We are now registered for Facebook Fundraising which allows Facebook users to raise funds for a charity of their choice. We have already had 15 birthday fundraisers which not only raises funds for Behçet's UK but also raises awareness of the condition and what we do.

Our twitter page currently has 490 followers, and Deborah Cardinal regularly tweets when opportunities arise. More recently we have also launched on Instagram gaining 145 followers already.

Our online presence has increased our visibility considerably among all age groups with followers steadily on the rise across all platforms. All one needs is something to go viral and we will have plenty more!

### **Support Groups**

Our six Local Support Groups, led by Yvonne Morris, Richard West, Andrea Williams, Tony Wright and Fionnuala McKinley are thanked once more for everything they do. The function is most valued by the participating members.

### **Helpline**

Evidence seems to be emerging that the Helpline may not necessarily be required on every day of the week, or certainly throughout the whole day; which one trustee observed might be due to the existence of the Behçet's Syndrome Centres of Excellence (together with the provision of more effective online help and guides). Our Helpline continues to be a most important function, so we will continue to refine the requirement to its demand. We are most grateful to Julie Collier, Tony Wright and Daniella Boyle for their continued support, and to Fionnuala McKinley joining the team. Gemma Darlow manages the line on one day of the week, as do I actually, but this must only be a temporary expedient whilst we find an enduring solution.

### **Rebranding - The Society change in name**

Our rebranding was a great success, and achieved at relatively little cost compared to many organisations who go through this necessary process from time to time - credit to which firmly rests with Gemma Darlow and Deborah Cardinal. Updating of associated brochures and merchandise is evolving, and in the process evaluating the cost-effectiveness and necessity of replicating previous items for sale.

As noted last year, renaming the Society 'Behçet's UK' sends a clear message that the Society exists for the benefit of all members in the UK – the very intention when the Society was formed by Judith Buckle in 1983.

### **Devolved Nations**

It is thus apposite to note, as the final part of my report, that positive strides are being made in Northern Ireland, with the assistance of Fionnuala McKinley and Ann Gough. I have now engaged with the Northern Ireland Health Board (NIHB) and on their direction the Northern Ireland Rare Disease Partnership (NIRDP), to whom the responsibility has been delegated to assist with championing the cause of rare disease provision in the Province. Meetings with the Chief Medical Officer, Dr Michael McBride, who was very helpful with the Northern Ireland Mapping Study in 2016, and Andrew Dougal, Chair of the Public Health Agency, together with the chair of the Patient and Client Council Ms Christine Collins MBE are being set up with the assistance of Margaret Ritchie (an ex Northern Ireland MP, now appointed a Life Peer and has been thanked for all that she has done to help the Society in the Province).

The aim of these meetings is to elicit support for proposed research – so that clinicians cannot make comments like 'it is not my job to fill in forms' as happened during the Mapping Study.

With the assistance of a researcher who works in the NIRDP, Dr Kerry Moore, I am engaging to explore opportunities to effectively replicate Dr Priyanka Chandratre's study in England. The aim is to establish: who are all the people in Northern Ireland that have and 'maybe have' Behçet's?; what is the criterion they are using to diagnose?; who are they being treated by (specific names, where based - and their specialty)?; what are they being treated with - and is it working?; for those who are frustrated by their standard of care (quality and coordination or lack of it etc.) why have they not been referred to a Centre of Excellence in England?

There are some pretty challenging governance issues preoccupying Northern Ireland currently, so it appears an opportune moment for the Society to offer to help to the NIHB to promote improvement in patient care; and what should already be happening anyway of course! Identifying evidence of what is going on is the key, and hence the importance of this work. More pound signs come to mind



though, thus the research will need to be achieved in stages - affordability being one driver. Nevertheless, if we do not establish the foundations, we are just going to continue to 'go round in circles' and pay lip-service to what our constitution says we need to achieve (3.2 The area of the benefit of the Society shall be the United Kingdom). We need hard facts in order that we can hold meaningful 'conversations' with those in positions of influence, and who control the 'purse strings'!

## **Conclusion**

In sum, we have witnessed another busy year with a number of initiatives gaining momentum. Increasing our fundraising capability from now and into 2020 and thereafter needs to be a priority.

I will conclude as I did last year by thanking everyone who makes this Society the great institution that it is; with the purpose of supporting our Patient Members. The message needs reinforcing, as I have stated consistently since taking over as chair, that this is a team effort: starting with your trustees, and particularly the Treasurer Alan Lane, 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 Leads, Professor Rob Moots, Dr Deva Situnayake and Professor Farida Fortune CBE, supported by Jan Mather's magnificent team in Behçet's Patients Support (and their Board of Directors and trustees in the background, and the Medical Advisory Panel).

I have again got 'out-and-about' this last year, principally to reinforce our rebranding but also to take advice and make contacts, and to avoid nugatory effort by learning from other charities and organisations. A good deal of research into Behçet's is being conducted in the UK, but by nature of the 'academic and research-funding' process it tends to be conducted within isolated competitive groups, which is the way the 'academic process' and funding mechanism has evolved over centuries (effectively pitting one group of researchers against another, the theory being to encourage excellence).. If we are to crack the Behçet's problem in the UK, the consistent message I have been receiving is that we need a Patient Register, leading to establishing the Natural History of Behçet's within the UK, a Priority Setting Partnership to promulgate agreed patient and clinician research questions (which then attract interested researchers, which in turn helps promote their careers) and finally get into the whole genome sequencing/genomic medicine and epigenetics space that is fast becoming de rigueur. This all requires a focused collegiate effort, and of course funding, and is this is the area the Society can most help to shape and influence if we can secure the resources.

Whilst a lengthy report, I trust our Patient Members will welcome what collectively has been achieved this past year, and offers much hope for the future. I encourage suggestions and feedback, and indeed ask for more engagement to enable us to support you even better. Please get in touch direct should you wish. Particularly, when requested to do so please complete any formal correspondence and research-related questionnaire (and 'lobbying' request letters) that we send to you. It really is vital to help back up what we demand in a very overstretched and resource constrained NHS.

**Tony Thornburn OBE, Chair**

**October 2019**

# Fundraising Activities

A new name, a new logo but the primary aim of the Society is still the same.

*Behçet's UK: Caring for all affected by this rare, complex and lifelong condition*

This statement now appears on the front of our newsletter and it encapsulates the commitment Behçet's UK has to support its members.

However, we receive no external funding and therefore rely 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.

Therefore, 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! This year has been no exception.

**Jodie Eardley raised over £300 when she shaved her head on her 27<sup>th</sup> birthday.**



**'The adventure of a lifetime', was how Kayleigh Atherton described the challenge she and her husband Steve signed up for; the Machu Picchu Trek. They raised over £600.**



**A raffle held at the book launch of Trustee Mark Friston's book on the law of costs raised over £450.**



**Paul Weston's amazing, ongoing efforts mean that he has now raised more than £10 000.**

**Corey Hawkins held a bake sale, raised over £330 and is planning his next project for Behçet's UK.**



**The London to Brighton Ultra Marathon is a 100k challenge. Ross Wakely decided to run the distance and with help from his wife Jo and support from his father Chris, raised over £1100.**



**The Prudential Ride London 46 is a bike ride around the capital. Simon Millard signed up and raised over £600.**



**The creative duo of Jan Mather and her mother produced their beautiful Christmas cards again and sold out! They raised £1000.**



**Chris Sundborg raised £2120 holding the Lee Pearcey Charity Cup (for the second year running) and a sponsored head / beard shave!**



**In April Darren raised over £1400 running the London Marathon.**



**Malcolm Matthews continues to collect and sell postage stamps to raise funds. Details of where to send your old stamps can be found in the newsletter.**

Behçet's UK also raises much needed funds from the sale of merchandise including a new range of greeting cards, Amazon Smile, Facebook birthday pledges and bequests in wills.



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)**



## Report of the Trustees for the year ended 31 August 2019

The trustees present their report along with the financial statements of the charity for the year ended 31 August 2019. 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.

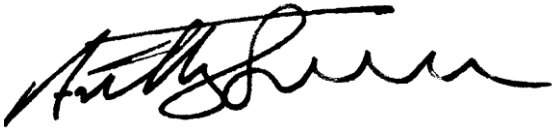
### Risks and public benefits

The trustees do not consider that the Society faces any significant risks in the near future, but they are mindful that the level of subscriptions and donations has tended to drop recently as more members have become eligible for free membership from being in receipt of UK state benefits and will continue to monitor the situation closely.

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

3 October 2019

# Staff and Trustees

## Trustees

Tony Thornburn OBE (Chair)  
Richard West (Vice-Chair)  
Judi Scott (Hon Secretary)  
Alan Lane (Hon Treasurer)  
Mark Friston  
Rachael Humphreys  
Hazel McLachlan (Resigned Jan 2019)  
Amanda Moseley  
Catherine O'Hara (Appointed Nov 2018)

## 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  
Dr Reuben Ayres  
Dr Paul Brogan  
Dr Andrew de Burgh-Thomas  
Prof Farida Fortune  
Prof Dorian Haskard  
Dr Desmond Kidd  
Prof Phil Murray  
Dr Catherine Nelson-Piercy  
Dr Jane Setterfield  
Dr Graham Wallace

## Banks

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

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

## Independent Examiner of Accounts

Ross Brooke Ltd  
Suite I, Windrush Court  
ABINGDON  
OX14 1SY

## Administration Office

Behçet's UK  
Kemp House  
152-160 City Road  
LONDON  
EC1V 2NX

Office Tel: 0345 130 7328  
Helpline Tel: 0345 130 7329  
Email: [info@behcetsuk.org](mailto:info@behcetsuk.org)  
Web: [www.behcetsuk.org](http://www.behcetsuk.org)

**Registered Charity No: 326679**

# Report on Financial Statement 2018/19

In the last annual report, I explained that the Society's reserves had increased well beyond the margin we needed to hold to meet any unexpected contingencies and that therefore the Trustees were expanding our activities to improve our services to members.

We are now seeing the benefit of having two excellent part-time staff, not only dealing with members' queries and routine administration, but also playing an active part in the organization of activities, such as the Family Days mentioned earlier in this report.

The other major area of growth in our activities has been our attendance and representation at a whole series of events for medical professionals and others, which has contributed greatly in improving the profile of the Society and in sharing knowledge about Behçet's and its impact upon our members and their families.

In setting their budget for 2018/19, the Trustees made a clear decision to draw upon our reserves to finance additional activities, including charitable grants to members. It was also decided, once again, not to increase the annual subscription, which has remained at £20 (except for those in receipt of UK benefits, an increasing proportion of our membership) for nearly ten years. The budgeted deficit for the year was £38.7k and the eventual figure was within £300 of that figure.

Of course, reducing reserves cannot continue indefinitely, so Trustees will have to look carefully over the next few months at our financial estimates. At the time of writing, this is particularly difficult. We know that one of our members, who sadly passed away last year, left a potentially large legacy to the Society, but it has been subject to a legal challenge that has not yet been resolved. In the short term, we have incurred legal fees, but within months our financial situation could be transformed.

The Society continues to rely almost totally on the subscriptions, donations and fund-raising efforts of our members and their families and friends. Do please read our most recent quarterly newsletter for details of the many ways in which you can help. As well as traditional ways, such as through donations and legacies and by Gift Aiding subscriptions, it is now very easy (and painless!) to get on-line suppliers of goods to pay small commissions to nominated charities, and all these soon add up to worthwhile amounts.

**The General Fund** received income this year of £43.3k, including £8.9k in subscriptions, £21.4k in donations, and activities and sales totalling £6.1k. Expenditure was £73.4k, so there was a net deficit on the General Fund of £30.0k, leaving accumulated reserves of £27.5k.

**The Restricted Fund** had an total income of £0.5k, as there were no large donations this year. Grants were approved to the University of Birmingham totalling £9.5k, leaving £15.3k in reserves.

## Membership

On 1 September 2019, we had 1045 full members, compared with 1014 on that date last year. In addition, there were 13 junior members and 76 associate members (mainly medical professionals).

The total number of names on our database was 1220, compared with 1186 the previous year, of whom 974 are patients. The number in receipt of UK state benefits, including pensions was 824, compared with 728 the previous year. These are entitled to free membership, but many make donations when they can, for which we are very grateful. It has been particularly noticeable this year that, whereas we continue have a wide range of ages amongst our membership, the large majority of recently joined members, as well as 73% of the Society as a whole, are female. It would be interesting to know if this reflects the gender balance of Behçet's patients or if we should endeavour to make our activities more attractive to the men who might benefit from joining our Society!

Finally, may I express my sincere thanks to our staff, who have taken over some of the routine work of membership administration from me this year!

**Alan Lane, Hon. Treasurer**

**October 2019**

## Statement of Financial Activities for the year ended 31 August 2019

	General Fund	Restricted Fund	Total 2019	Total 2018	
	£	£	£	£	
<b>Income and endowments</b>					
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	Note 6
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	Note 7
<b>Total income and endowments</b>	<b>43 319</b>	<b>489</b>	<b>43 808</b>	<b>52 512</b>	
<b>Expenditure on charitable activities</b>					
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	Note 8
Social security and pensions	405	0	405	207	Note 8
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	
<b>Total expenditure</b>	<b>73 367</b>	<b>9 535</b>	<b>82 902</b>	<b>60 837</b>	
<b>Net income before gains on investments</b>	<b>-30 048</b>	<b>-9 046</b>	<b>-39 094</b>	<b>-8 325</b>	
Net gains on investments	79	25	104	43	
<b>NET INCOME</b>	<b>-29 969</b>	<b>-9 021</b>	<b>-38 990</b>	<b>-8 282</b>	
Transfers between funds	0	0	0	0	
<b>Net movements in Funds after transfers</b>	<b>-29 969</b>	<b>-9 021</b>	<b>-38 990</b>	<b>-8 282</b>	
<b>RECONCILIATION OF FUNDS</b>					
Fund balance brought forward at 1 Sep 2018	57 444	24 360	81 804	90 086	
<b>Fund balance carried forward at 31 Aug 2019</b>	<b>27 475</b>	<b>15 339</b>	<b>42 814</b>	<b>81 804</b>	

## Statement of Financial Activities for the year ended 31 August 2018

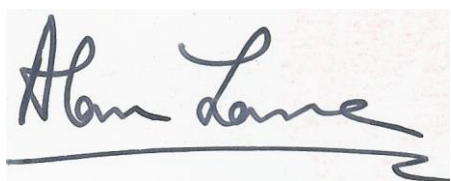
	General Fund	Restricted Fund	Total 2018	Total 2017	
	£	£	£	£	
<b>Income and endowments</b>					
Donations	17 367	10 515	27 882	26 124	
Bequests and legacies	4 454		4 454	0	
Subscriptions	10 148		10 148	9 135	
Gift Aid tax reclaimed	2 201	60	2 261	2 425	
Grants received	0		0	11 756	Note 6
Fundraising activities	2 825		2 825	10 875	
Sales of goods	1 104		1 104	1 019	
Charitable activities income	1 061		1 061	337	
Other	2 777		2 777	3 152	Note 7
<b>Total income and endowments</b>	<b>41 937</b>	<b>10 575</b>	<b>52 512</b>	<b>64 823</b>	
<b>Expenditure on charitable activities</b>					
Trading costs	316		316	844	
Event costs	5 442		5 442	11 103	
Fundraising staff costs	5 097		5 097	7 361	Note 8
Fundraising other costs	426		426	216	
Staff recruitment	193		193	0	
Grants and bursaries	6 437		6 437	3 073	
Research grants	0		0	14 000	
Subscriptions to other organizations	434		434	315	
Helpline costs	1 671		1 671	1 239	
Charitable support staff costs	1 699		1 699	2 851	Note 8
Other staff costs	6 387		6 387	0	Note 8
Employment rebate	-649		-649	-830	Note 8
Travel and subsistence	5 310		5 310	3 607	
Insurance	485		485	481	
Administrative staff costs	1 699		1 699	2 454	Note 8
Telephone charges	500		500	319	
Printing, postage, stationery etc.	1 447		1 447	2 614	
Equipment purchases	922		922	50	
Newsletter	8 358		8 358	8 081	
Web site and publicity	1 616		1 616	1 190	
Public relations staff costs	1 798		1 798	2 454	Note 8
AGM expenditure	7 492		7 492	4 351	
Governance costs	2 757		2 757	2 819	
Other	1 000		1 000	107	
<b>Total expenditure</b>	<b>60 837</b>	<b>0</b>	<b>60 837</b>	<b>68 699</b>	
<b>Net income before gains on investments</b>	<b>-18 900</b>	<b>10 575</b>	<b>-8 325</b>	<b>-3 876</b>	
Net gains on investments	30	13	43	114	
<b>NET INCOME</b>	<b>-18 870</b>	<b>10 588</b>	<b>-8 282</b>	<b>-3 762</b>	
Transfers between funds	0	0	0	0	
<b>Net movements in Funds after transfers</b>	<b>-18 870</b>	<b>10 588</b>	<b>-8 282</b>	<b>-3 762</b>	
<b>RECONCILIATION OF FUNDS</b>					
Fund balance brought forward at 1 Sep 2017	76 314	13 772	90 086	93 848	
<b>Fund balance carried forward at 31 Aug 2018</b>	<b>57 444</b>	<b>24 360</b>	<b>81 804</b>	<b>90 086</b>	



Balance Sheet as at 31 Aug 2019	General Fund	Research Fund	Total 2019	Total 2018	
	£	£	£	£	
<b>Current Assets</b>					
Stock in hand	1 170	0	1 170	147	Note 9
Debtors	28	0	28	101	Note 10
Prepayments	1 082	0	1 082	4 680	Note 11
Accrued income	0	0	0	0	
Recoverable Gift Aid	143	504	647	584	
Deposit Accounts	25 202	24 060	49 262	79 159	
Current Accounts	1 933	310	2 243	2 186	
Petty Cash	350	0	350	350	Note 12
<b>Total current assets</b>	<b>29 908</b>	<b>24 874</b>	<b>54 782</b>	<b>87 207</b>	
<b>Current Liabilities</b>					
Creditors	297	9 535	9 832	4 000	Note 13
Deferred income	495	0	495	480	Note 14
Accrued expenses	1 641	0	1 641	923	Note 15
<b>Total current liabilities</b>	<b>2 433</b>	<b>9 535</b>	<b>11 968</b>	<b>5 403</b>	
<b>Total net assets</b>	<b>27 475</b>	<b>15 339</b>	<b>42 814</b>	<b>81 804</b>	
<b>TOTAL FUNDS</b>	<b>27 475</b>	<b>15 339</b>	<b>42 814</b>	<b>81 804</b>	

The financial statements were approved by the trustees on 3 October 2019

Signed



Alan Lane  
Hon. Treasurer

Date: 3 October 2019

## Notes forming part of the financial statements for the year ended 31 Aug 2019

### 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	27 505	15 309	42 814
Total	<u>27 505</u>	<u>15 309</u>	<u>42 814</u>

### 5. Research Fund

The Society has received a number of small donations during the year to augment the Research Fund. Grants totalling £9.5k were agreed during the year to the University of Birmingham to support two research projects, which have yet to be drawn down.

### 6. Grants received

The Society has received a grant this year to assist the University of Liverpool in publicising a research trial.

### 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	2019	2018
		£	£
Wages and salaries		23 859	15 824
National Insurance contributions		0	0 (after deduction of rebate)
Employer's pension contributions		<u>405</u>	<u>207</u>
		24 264	16 031

The average number of staff employed during the year was 2 persons (2018 1 person). There are no employees earning above £60 000 (2018 none).

None of the trustees, nor any persons connected with them, has received any remuneration during the year. Seven trustees received expenses for travel and subsistence costs amounting to £7169 (2018: £2079) 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 the Annual Conference in October 2019 and part of the insurance premium paid in 2018/19 that relates to 2019/20.

### 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 2019 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 2019 and provision for fees for independent examination of accounts.

**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 2019 which are set out on pages 21 to 24.

**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 I  
Windrush Court  
Abingdon  
OX14 1SY

..... 2019