



TRUSTEES' REPORT AND ACCOUNTS

FOR THE YEAR ENDED 31st MARCH 2023



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Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2023.

Administration Details

Main Address: 43 Balton Way, Harwich, Essex, C012 4UP

Web: www.bbsuk.org.uk

Email: admin@bbsuk.org.uk

Registered Charity in England and Wales: 1181244

Bankers: Barclays Bank PLC

Independent Accounts Examiner: Amicus Accountancy Ltd

President: Professor Philip Beales BSc LMSSA MD FRCP

Board of Trustees:

Chair: Laura Dowswell

Secretary: Dianne Hand

Treasurer: Abbie Geeson

Trustee: Liam Wilkie

Trustee: Rachael Foley

Trustee: Stefan Crocker

Trustee: Dr Shehla Mohammed

Trustee: Azrat Mirza

Trustee: Chetan Meshram (co-opted November 2022)

Trustee: Gareth Owens (co-opted February 2023)

Trustee: Tazeem Abbas (co-opted February 2023)

Bardet-Biedl Syndrome UK

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Bardet-Biedl Syndrome

Bardet-Biedl syndrome is a rare, recessively inherited disorder which affects approximately 1 in 100,000 babies born. Features of the Syndrome include Rod-Cone Dystrophy, an eye disorder, characterised by tunnel vision and night blindness, which often leads to blindness; obesity; renal abnormalities; developmental delay; speech and language difficulties; extra fingers and/or toes and learning difficulties.

Not all of the features are always present in those diagnosed as having BBS and each one can vary in severity and appearance. The variability in presentation and severity of the Syndrome together with the rarity of the condition (there are approximately 650 diagnosed individuals known to us in the UK) can mean a delayed diagnosis and lack of adequate local health care.

Vision, Mission, Values

Vision: Our unique experience, knowledge and understanding of Bardet-Biedl syndrome, will ensure that everyone who accesses our services is supported, connected and informed about BBS and empowered to achieve the best possible outcome.

Mission: We are committed to promoting positive health and wellbeing within the BBS community; to improving knowledge and understanding amongst those affected, the medical and educational professionals and the wider public; and to supporting research and raising awareness of Bardet-Biedl syndrome.

Values:

- ✓ Committed and Passionate
- ✓ Inclusive and Community Minded
- ✓ Experienced and Understanding
- ✓ Positive and Forward Looking
- ✓ Collaborative

Structure, Governance and Management

Bardet-Biedl Syndrome UK (BBS UK), charity number 1181244 is a Charitable Incorporated Organisation (CIO) and was registered with the Charity Commission on the 18/12/2018. BBS UK is the only registered charity supporting people with Bardet-Biedl syndrome, their families and carers in the UK. The governing document of the Charity is a constitution. The CIO formally represents the incorporation of the unincorporated charity, Bardet-Biedl Syndrome UK (1027384), formerly known as Laurence-Moon-Bardet-Biedl Society and LMBBS which was established in 1993. The CIO is the successor body to the original Charity which was entered into the register of mergers on the 23/12/2020. The Board of Trustees is responsible for the governance of the Charity. The Charity now supports around

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650 individuals living with BBS, their families and carers, and also the professionals supporting them across health, education and social care. Full membership of the Charity is open to any adult who has Bardet-Biedl syndrome and his/her family and any family with one or more affected children, including their grandparents and carers.

Trustees

Trustees are elected during the Annual General Meeting (AGM) of the Charity. Trustees serve three-year terms and a trustee who has served for two consecutive terms of three years each may not be re-appointed for a third consecutive term unless approved by members but may be reappointed after an interval of at least three years. The members or the Trustees may at any time decide to appoint a new trustee in place of a trustee who has retired, been removed or as an additional trustee.

New trustees are given an opportunity to observe a board meeting, meet with the Chair of the Board of Trustees and Operations Manager. They are supported with an induction process and are provided with the following:

- ✓ Trustee Information Booklet
- ✓ Constitution
- ✓ Strategic Plan
- ✓ Core Policies and Procedures
- ✓ Recent minutes of meetings and accounts
- ✓ Core safeguarding and information security training

The Honorary Officers of the Charity hold office for one year but are eligible for re-election annually. All trustees give their time freely and receive no remuneration or other benefits, however, reasonable incurred expenses are reimbursed as appropriate.

The Board seeks to be representative of the people with whom the Charity works and individual trustees have sufficient knowledge, both of trusteeship in general and of the Charity's activities, to enable them to carry out their role and to represent the Charity.

Trustees are expected to undertake training to ensure they remain up to date with information and procedures. Courses attended have focused on developing governance skills, and include safeguarding, GDPR, recruitment and equality, diversity and inclusion training. The Charity Trustees will make available to each new trustee: a copy of the constitution and any amendments made to it; and a copy of the CIO's latest Trustees' Annual Report and Statement of Accounts.

BBS Clinics NHS Contract

Bardet-Biedl Syndrome UK has a contract with NHS England to facilitate the specialist multi-disciplinary clinics, which take place in Great Ormond Street Hospital and St Thomas' Hospital, London and Birmingham Children's Hospital and Queen Elizabeth Hospital, Birmingham. The requirements of the contract with the National Specialised Commissioning Team include:

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- To maximise access to NHS provided services for patients with Bardet-Biedl Syndrome (BBS).
- To provide emotional and practical support and advocacy services for patients affected by BBS and their families.
- To provide information relating to services provided for patients with BBS, including relevant health promotion and lifestyle information, to maximise the health and life chances of people living with BBS.

To achieve the above, information and support is provided to the patients and their families/carers before, during and after clinics. Accommodation is organised for patients when needed and assistance is given with travel arrangements. This service provision ensures patients, and their families are well informed about the syndrome and feel well supported to attend their clinic appointment. BBS UK has a presence at each clinic, offering emotional and practical support to patients and their families and ensuring they are aware of all relevant benefits and social support services. Post clinic, ongoing support and liaison services are available.

Additional Governance

Policies and Procedures

BBS UK has the following policies in place:

- Business Continuity
- Capability
- Child Protection
- Code of Conduct
- Complaints
- Conflict of Interest
- Dignity at Work
- Disciplinary
- Driving Whilst on Business
- Equal Opportunities
- Finance
- Grievance
- Health and Safety
- Home Working
- Lone Worker
- Management Structure
- Pay Review
- Research
- Research Statement and Pharma
- Reserves
- Risk Management
- Safeguarding Vulnerable Adults
- Scientific Advisory Board
- Staff Mobile Phone
- Social Media and Moderation
- Trustee Recruitment
- Volunteer
- Whistleblowing

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BBS UK has the following Information Security policies in place:

- Bring Your Own Device
- Confidentiality
- Data Protection
- Data Quality
- Data Security
- Data Retention and Disposal Schedule
- Email Use
- Facebook disclaimer
- Handling of DBS Certificate Information
- Information Governance Incident Process Stages
- Information Security Reporting and Auditing
- Information Sharing
- Privacy Notice
- Record Keeping (Data Retention)
- Subject Access Request.

BBS UK has the following handbooks in place:

- Health & Safety Handbook
- Information Governance Handbook
- Staff Handbook

Additional quality assurances

BBS UK has Cyber Essentials Certification which is an official UK wide government-backed scheme that provides protection against the most common cyber threats and demonstrates our commitment to cyber security.

BBS UK has completed and published NHS Digital's Data Security and Protection Toolkit, an online self-assessment tool that allows organisations to measure their performance against the National Data Guardian's 10 data security standards and to provide assurance they are practising good data security and personal information handling.

BBS UK has achieved PIF TICK accreditation following a thorough application and assessment process. The PIF TICK is a mark of quality and demonstrates that our health information has been through a professional and robust production process.

Disclosure and Barring Service checks (DBS) are carried out prior to commencement of employment, trusteeship, and volunteering duties. DBS checks are carried out regularly in line with statutory requirements. Child Protection Training and Safeguarding Vulnerable Adults Training is undertaken by those working or volunteering with children, young people and/or vulnerable adults, their line managers and their governing board.

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How we look after and safeguard information

BBS UK aims to provide members and patients with the highest quality support and information and to do this we need to collect, process and store information.

BBS UK processes and stores information in accordance with:

- The Data Protection Act 2018 incorporating UK GDPR.
- The Human Rights Act 1998
- The Common Law Duty of Confidentiality
- The Caldicott Principles
- NHS Code of Practice on Confidentiality

BBS UK maintains compliance via:

- Established and routinely maintained policies and procedures for the effective and secure management of information assets and resources
- Annual audits of its information and IT security arrangements
- Effective confidentiality and security practices promoted to staff through policies, procedures and training
- Incident reporting procedures and monitoring/investigation of all reported instances of actual or potential breaches of confidentiality and security
- BBS UK is registered with the Information Commissioner's Office (ICO) which ensures BBS UK comply with the Data Protection Act 2018 and GDPR regulations are processing personal information in a fair and transparent manner.

For this reporting period, BBS UK reported no breaches in security and no 'near misses'.

Objectives and Activities

BBS UK strives to bring together through our projects and services, support to our members. BBS UK Trustees have regard to the Charity Commission's public benefit guidance when exercising any powers or duties to which the guidance is relevant. The Trustees always ensure that the projects and services we undertake are in line with our charitable aims and objectives.

The main **objectives** of Bardet-Biedl Syndrome UK are:

1. To preserve and protect the health and promote the welfare of persons affected by Bardet-Biedl syndrome and their families.
2. To advance the education of the medical and educational professions and the general public on the subject of Bardet-Biedl syndrome and its implications for the family, and to promote research for the public benefit in all aspects of that subject and to publish the useful results.

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The main **activities** the charity undertakes in pursuance of its objectives for the public benefit are:

- BBS Clinic Support Team providing support, facilitation and advocacy services to NHS multi-disciplinary clinics.
- Advice Service supporting members with accessing local support across the areas of health, education, social care and benefits.
- Information booklets available in multiple formats, including:
 - Medical Information Booklet
 - Introducing Bardet-Biedl Syndrome
 - Booklet for Schools and Colleges
 - My Life, My Future (Transition Handbook)
 - Who We Are and How We Can Help
- Annual family conference weekend bringing beneficiaries together with interested professionals and experts, to provide access to the latest research and to participate in tailored workshops.
- BBS UK website: www.bbsuk.org.uk
- Regular newsletters and an annual conference report
- Social Media (including Facebook, Twitter, YouTube) in order to facilitate the development of an online community.
- Young People's Group (YPG) and Adult Focus Group (AFG).

Report from the Chair of BBS UK

Laura Dowswell, Chair

Like many smaller charities, BBS UK has faced numerous challenges over the last two or three years, not only with the pandemic but also in the tough economic times we now find ourselves facing. The Board of Trustees and staff team have worked incredibly hard to meet those challenges which include not only to maintain the delivery of the Charity's vital services, and to ensure that the Charity continues to be sustainable, but to develop our services to meet the increased needs of our community.

We have seen some positive changes and are delighted to welcome Natalie Braunton to the staff team in the role of Operations Assistant.

We've also recruited four new Trustees to the Board and welcome Azrat Mirza, Chetan Meshram, Gareth Owens and Tazeem Abbas who bring with them professional skills as well as lived experience of BBS.

The BBS UK Advice Service continues to provide high quality support with accessing local services across housing, social care, benefits, and education; the work that is being undertaken and the outcomes that are being achieved, continue to show that this is an essential core service and a primary funding focus for BBS UK.

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The Clinics Team have continued to provide excellent support to the service and to patients attending the face to face and telemedicine clinics.

There have been a number of team projects undertaken during the last year, including the IT Equipment Fund, our partnership with Slimming World, the Maypole Counselling Pilot Project and our newly formed Regional Group in Ireland. I was delighted to be invited to their first ever Information Day held in Belfast in May 2023. It was lovely meeting so many new families and seeing the support they were able to offer each other.

On behalf of the Board and personally, I would like to offer sincere thanks, firstly to the staff team who as always work so hard to support so many families, and also to my fellow trustees who freely and willingly give up their free time. Also, to all those who have continued to fundraise throughout and to those who have regularly contributed through the Friends scheme.

Team BBS UK is made up of trustees, staff, volunteers, members, supportive professionals, fundraisers, donors, campaigners, supporting charities and organisations, and that is how we have managed to continue our growth and provide the support and information services that our community needs: by continuing to work together and by developing new ways of working, in order to improve the lives of all those living with Bardet-Biedl syndrome.

Achievements and Performance

Tonia Hymers, Operations Manager

Introduction

In 2022, BBS UK published its three-year strategy following an extensive consultation process involving trustees, staff and the BBS community. Our three-year strategy sets out our vision, mission and values and establishes our aims and objectives for the period, which are:

1. Improve communication with our service users
2. Develop our support services and reduce isolation
3. Empower our membership to achieve
4. Strengthen governance and raise our profile
5. Support research and understanding of BBS

Following, is an overview of progress made towards these targets:

Improve communication with our service users

Database: It is important to us that we reach all members of our community in ways that are accessible and acceptable to them, in line with our data protection responsibilities and in support of this we have continued to develop our use of Charitylog (data management system) across all services. This has supported and improved internal and external communications and has improved the quality and accuracy of our data.

Social Media: We have increased our engagement on social media, in particular during the last quarter of the reporting period with a 45% increase in reach via Facebook:

- Facebook Page Followers: 847

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- Facebook (Closed) Group Members: 383
- Instagram Followers: 121
- Twitter Followers: 495
- LinkedIn Followers: 123

Newsletters: We have produced two bumper paper editions, also available in CD and Word. Looking ahead we are considering other ways of reaching our community including the introduction of e-newsletters.

Website management: The BBS UK website was largely unsupported, out of date and lacking accessibility and is now undergoing a rebuild. The website is essential to our communications with our service users and its development will support this target across the coming year.

Develop our support services and reduce isolation

This aspect of our work is of vital importance and following are some of the ways we have met our targets across the year:

Advice Service: Since its creation in 2021, demand for support from the BBS UK Advice Service has increased rapidly. This year has seen Rebecca and Shirin support **77** advice service users in a variety of areas including: navigating the increasingly complex social care system, education, housing, benefits, and future planning. They have completed **1044** contacts with both service users and external professionals to ensure that adults and children with BBS get the support that they are entitled to.

This year also saw the team complete their first social worker placement in partnership with London Metropolitan University by supporting a Year 2 student complete their 70-day placement as part of their degree in social work. They hope to complete another placement in the forthcoming year as it was such a positive experience for the team.

Looking forward, the team will continue to work in partnership with the clinics team to support adults and families the best way possible, in areas such as transition, social care, education and will continue to form positive working relationships with local authorities to ensure their professionals have knowledge and understanding of Bardet -Biedl syndrome.

Clinics Support Service: It has been a busy year for the clinics support team, logging **2666** actions/contacts for over **460** service users and providing support and facilitation services at approximately **55** clinics (virtual and face-to-face) across Birmingham and London. Amy, Angela, Laura and Shirin's work is consistently highly regarded by our NHS colleagues and NHS England and they are regularly cited as being essential to the running of the BBS clinics service. Outcomes include:

- The provision of an exceptional level of support to an anxious patient enabled them to attend an in-person appointment following repeated cancellations.
- The team supported parents at an Education, Health and Care Plan meeting where the school had refused to request funding for 1:1 support for the child, advocating for the child about why the support was essential. The school reversed their decision and requested funding.
- The parent of a young patient reported that the support they received in clinic gave them hope following their child's diagnosis.

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Patient evaluation data is also consistently high, with **99%** of patients rating the information and support received as 'Good' or 'Very Good'. Comments received include:

- "Incredible – the whole team have been so supportive both before and during the clinic."
- "The BBS support team are amazing to be honest... they are the only people who give us advice and information. We have no support in our area. I feel as if I am NOT alone when I attend this clinic."
- "The team gave great support in the lead up to the clinic and throughout the day. They couldn't have been better."

Conference 2022: In September we returned to the Hilton Hotel, Northampton for our annual family conference, the first in-person event since 2019. The weekend was a huge success as reflected in the following figures:

- **263** attended across weekend (in person)
- **180** delegates attended the formal conference programme
- **80** registered to join online; around **40-50** attended online
- **75** watched the event later via YouTube
- **20** Health Care Professionals/Researchers attended
- **20** New families attended – highest figure to date
- **23%** non-white British families attended (**7%** in 2018)
- **98%** rated their experience as very good (83%) or good (15%)
- **95%** said their reasons for attending were met:
 - Learn about research (95%)
 - Learn about support available (76%)
 - Meet others living with BBS (78%)
 - Professional development (20%)

Regional Group Ireland: We have established a regional group with our members in the Republic of Ireland and Northern Ireland with the aim of raising awareness and improving communications, information, and support. They have held two face-to-face meetings, one at Portlaoise in County Laoise and another in Belfast. Their feedback echoed what we have all felt which is how powerful it is to be in a room with people who understand exactly what you are going through. We are excited to continue working with this group and support their development which will benefit all those living with BBS across the Island of Ireland and in particular those who are newly diagnosed.

Counselling Pilot Project: We worked with The Maypole Project to provide counselling sessions for those struggling with social isolation. There is an ongoing need for this area of support and we are reviewing the outcomes of this project and considering how to take it forward.

IT Equipment Project: Our IT Equipment Project has continued to provide devices to those who have limited or no access to technology. Initially we support applicants to seek funding elsewhere and where this is unsuccessful, BBS UK will then fund and provide a computing device, which may be a laptop or tablet. This scheme has supported individuals to access education, medical appointments, and social opportunities.

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Slimming World on Referral: We have been really impressed with the determination and outcomes of those who joined our Slimming World on Referral group. Slimming World have submitted an abstract outlining our collaboration to the British Dietetic Association's annual 'research symposium' and included an article in their magazine for professionals. One of our members lost 5 stone and was voted 'Woman of the Year' by her fellow Slimming World members.

Empower our membership to achieve

Employment: In addition to the above projects, our Advice Team have started to look at the support that is available with gaining employment and are signposting and referring our service users as appropriate. We are following up these referrals and monitoring progress with the aim of seeking out the most appropriate schemes for potential collaboration and to better support our service users going forwards.

Health and Wellbeing: Those living with BBS are likely to experience difficulties maintaining a healthy weight and often struggle with their mental health and general wellbeing and therefore BBS UK has a responsibility to encourage a culture of positive health and wellbeing throughout its projects and services. During Conference 2022, we offered workshops with a dietitian and clinical psychologist and introduced our young people to the 'Five Ways to Wellbeing' which included a day at an outdoor activity centre and a session with British Blind Sports. Our main fundraising campaign has focused on being active, in whatever way suits the individual, with participants working together to achieve the goal of Carrying the Gene from John O Groats to Land's End. In the coming year we aim to develop a resource about healthy eating and exercise for those with BBS and those who support them.

Strengthen governance and raise our profile

We have simplified our organisational structure, bringing our NHS contract within the Charity and have continued growing and developing our Board of Trustees, with a focus on filling gaps identified in a skills audit. The BBS UK Board is now 11 strong and includes professional experience and skills across management/leadership, finance, project management, contract management, education, medical/genetics, human resources, and marketing/media/PR. We have established Finance, Fundraising and HR sub-committees and executive responsibility roles for safeguarding, risk, data protection and health and safety.

We are in the process of launching a Service User Advisory Group to ensure BBS UK strategy and operations remain service-user focused. We have established a terms of reference document and are about to commence recruitment. We have also introduced a 'Professionals Supporting BBS' group, with the aim of bringing together a network of professionals who have the skills to assist BBS UK in supporting our community.

We have a representative on the board of the Ciliopathy Alliance (CA), BBS International (BBSI) and CRIBBS, the Clinical Registry Investigating Bardet-Biedl Syndrome in the US and have represented the Charity at two Queen Alexandra College's Sight Villages, Retina UK Conference and Cilia Cologne.

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Support research and understanding of BBS

We have supported Rhythm Pharmaceuticals with the dissemination of a research questionnaire and information seeking to understand the lived experience of hyperphagia and have provided letters of support for other relevant research proposals/applications.

We have engaged with NICE in support of the appraisal process for Rhythm's application for Setmelanotide and completed a submission ahead of the appraisal due in July 2023.

Our presence on the boards of BBSI and the CA ensure we are aware of current research developments and are best placed to support and ensure our community is involved where appropriate.

Summary

This summary of our achievements and performance over the past year demonstrates our commitment to achieving the aims set out in our three-year strategic plan, towards which we have made good progress. We remain focused on continuous improvement and sustainability to ensure we can continue to meet the needs of our community into the future. Our deepest gratitude to all staff, trustees and volunteers for their exceptional work. It is through the collective efforts of this exceptional team that we are able to provide the services and projects that we do and why we are able to move forward with confidence and optimism.

Fundraising Review

Tonia Hymers, Operations Manager

Introduction

This reporting period has been a particularly challenging time for fundraising, not just for BBS UK but across the whole fundraising landscape. We marked two years since the start of the pandemic and have seen unprecedented challenges, not just with the continuing impact of living with Covid-19 but also the cost-of-living crisis that continues to affect us all. Across the fundraising sector, events, activities and giving in general have been massively impacted resulting in an inevitable drop in income, however the BBS community came through and together they fundraised/donated a fantastic £56,265 which was 87% of our community fundraising target.

Fundraising Goals and Strategy

A key aim across the year was to diversify income and develop a fundraising strategy to support BBS UK's three-year strategy and although we have moved significantly towards this goal, progress has been hampered by the loss of key staff.

Our aim is to gain multiple-year funding to secure and grow our Advice Service and this remains an ongoing target. A focus for the coming year is to work with industry experts to develop our skills and knowledge with the aim of improving our internal processes and the quality of our applications, to give us the best possible chance of securing long-term funding.

Income diversity and strategy development remain ongoing targets, to include a digital fundraising and communications strategy alongside the ongoing development of the Charity's general fundraising function.

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Fundraising Activities

Our community has once again walked, ran, cycled, knitted, baked, held quizzes and much more to raise funds for BBS UK. They are all BBS heroes, and our heartfelt thanks go to each and every one of them. The following three are this year's biggest fundraisers:

Cilia Cyclists: In September, a team of cyclists from the UK and Germany undertook an epic cycle ride to raise funds and awareness. Professor Helen May-Simera and her team of BBS researchers and members of BBS UK covered approximately 420 miles and 3 countries in five days: from Mainz University to the BBS UK Conference in Northampton, arriving on the Friday evening. Tim Ogden, president of the US BBS group joined the team for the UK leg of the trip; together the team raised a fantastic £5,000.

Marathon Runner: Tony Francis ran the Richmond Half Marathon for BBS UK on 9th October in support of his sister, Laura, and raised an incredible £14,500.

Carry the Gene: This BBS UK campaign aims to bring the BBS community together to 'Carry the Gene' from John O'Groats to Lands' End, via Northern Ireland, Ireland and Wales, with a focus on activity and exercise, and a target of raising £10K. Much of the preparation for this campaign was completed during the reporting period however the start was delayed until April 2023. The campaign is expected to exceed all expectations in terms of participation and fundraising.

Friends of BBS UK: We have continued to gain new 'Friends of BBS UK', bringing in a total of £9,472 across the year. This known, regular income enables BBS UK to provide its core services which are a lifeline for our community, and the promotion of this scheme is an ongoing focus for the coming months and years.

Conference Weekend: Our Conference Weekend provides an invaluable opportunity for us to connect with our community and demonstrate the value and impact of the Charity. We gave presentations about the past, present and future of BBS UK, an update of the Charity's services, an overview of our Advice Service and a fundraising round-up, launching the Carry the Gene campaign. Our community responded, generating record fundraising income across the weekend.

Donor and Supporter Engagement

A key aspect of BBS UK's three-year strategy is to improve our communications with our community, and this has extended to donor and supporter engagement. As mentioned elsewhere in this report, we have increased our engagement on social media and are now registered as a non-profit on Meta, which gives us fundraising tools, including a 'Donate' button on our Facebook profile and the ability to create charity fundraisers.

Donor stewardship is important to us, and we ensure that where possible, all donors and fundraisers receive a letter of thanks and a certificate where appropriate. At the end of the calendar year, an email of thanks was sent to everyone who had supported our work in some way, listing the ways in which we had put their money and efforts to good use. We do however acknowledge that we need to further develop the ways in which we engage with our supporters and will consider additional tools and strategies in the year ahead.

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Fundraising Income and Expenditure

As previously mentioned, this has been a challenging time for fundraising which is reflected in the figures below. Big local fundraising events were down, we had no runners in local or national marathons and were unable to secure funding from Trusts/Foundation.

	2022-2023
Donations/Fundraising	£39,555
Total Regular Givers	£ 9,472
Gift Aid	£ 7,238
Trusts/Foundation	£
Grants/Sponsorship (Pharma)	£ 7,000
Total	£63,265

Fundraising costs were minimal at £1,469

Pharmaceutical Industry: BBS UK believes it is important to maintain cooperative relationships with all industry partners and stakeholders in BBS, including the pharmaceutical industry. Such relationships are conducted in an open, transparent, and ethical way, in line with the strict guidelines provided by the Association of British Pharmaceutical Industry (ABPI) and guided by robust internal policies.

Our engagement facilitates our community's participation in research, surveys and focus groups and we contribute to regulatory and reimbursement processes to evidence the impact of the many aspects of Bardet-Biedl syndrome.

Pharmaceutical companies support the work that we do by providing grants and/or sponsorship for projects or services that benefit our community. In 2022-23 we were grateful to receive the following support:

Rhythm Pharmaceuticals: £7,000 towards our Annual Family Conference

Trusts and Foundations: BBS UK received no grants in the reporting year.

Impact and Future Plans

The generous support we have received from our donors and fundraisers has enabled BBS UK to maintain its core programmes and services which have had a significant impact on our beneficiaries as outlined elsewhere in this report. However, the drop in income has meant that we have been unable to develop or establish plans for long-term growth. This particularly impacts on our Advice Service provision, which often must implement a waiting list, and our aim is to secure funding to develop this provision going forwards.

Our Heartfelt Thanks

BBS UK has been called 'small but mighty' and that includes our community of fundraisers and donors; the Cilia Cyclists and Carry the Gene campaign have shown what can be achieved by a few individuals with big ambitions and our heartfelt thanks go to each and every person who has raised funds or donated to BBS UK this year. A big shout-out goes to the Wilkie family and their incredible supporters for inspiring and generating an impressive campaign for 2023.

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Special thanks go to the Sloane family who have been champion fundraisers for BBS UK for many years, holding quiz nights and afternoon teas; and to the Knitting Nannies who create beautiful, knitted toys all year round to sell and raffle for the Charity. We are seeing many more champion fundraisers emerging and look forward to continuing to work with them in the coming months and years.

This report shows the impact of the work of BBS UK and demonstrates the need for growth in service provision – this is only possible with the support of our donors and fundraisers and we encourage everyone to think about what they could do to help us to make a difference, for more information go to www.bbsuk.org.uk/fundraise-bbs/

Treasurer's Report

Abbie Geeson, Treasurer

BBS UK's financial period runs from the 1st April 2022 – 31st March 2023. The financial accounts are prepared on the accrual basis. It should be noted in the previous financial year BBS UK extended its financial year to incorporate 1st January 2021 – 31st March 22 and the financial statements reflected a 15-month period and were prepared on a receipts and payments basis.

On the 1st of April 2022 BBS UK took over the NHS Specialised Commissioned Services, third sector contract to provide the BBS Clinic Support Service, which was previously held by its now, dormant subsidiary company BBS UK Clinics Ltd, this meant an increase to income during the financial year. During the year the charity experienced the loss of two core key personnel. This impacted on both income generation of key grant funding and on project delivery. In January 2023 two new core employees were recruited and as such we expect to meet our budget outcomes next financial year.

The total Charity funds as of the 31st of March 2023 was £165,046 (21-22 £172,406). The General fund had a surplus of £30,465, transfers of £22,068 were made to other funds and the General fund stands at £129,600 (21-22 £121,203).

The Trustees made transfers from the General fund to the following designated funds:

- Annual Family Weekend and Conference £20,923
- Fixed Assets £1,145
- The Trustees also repurposed part of the designated IT Equipment Fund transferring £3,000 to the Chris Humphreys Memorial Fund.

The Trustees provided support of £955 from the Chris Humphreys Memorial Fund and £947 from the IT Equipment Fund. Further designated expenditure was £19,968 for the 2022 Annual Family Weekend and Conference and £5,955 for the Advice Service. The designated fund stands at £32,368 (21-22 £38,125).

The restricted fund stands at £3,078 (21-22 £13,078).

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2023.

Reserves Policy and Going Concern

Trustees regularly review the budget and the level of reserves, which are monitored monthly and reported at the quarterly board of trustee meetings to ensure that the appropriate levels are maintained considering the main risks to the organisation and future developments. Trustees have agreed unrestricted free reserves should be sufficient to cover six months expenditure.

The following designated reserves are set aside at year-end as follows:

- The Chris Humphreys Memorial Fund £3,000 – This subsidy fund is to support newly diagnosed individuals and their families to access our events based on assessment of need.
- The Annual Family Weekend and Conference £25,000 is committed future expenditure. The weekend brings together over 200 diagnosed individuals and their families.
- The IT Equipment Fund £3,223 - This fund was set up in response to an increasing need for people with BBS to access services through means of digital technology based upon an assessment of need.
- Fixed Assets Fund £1,445 which cannot be used to fund expenditure without being sold.

The remaining reserves of £129,600 are held in the General fund as free reserves and represent six months of expenditure.

The trustees have reviewed the circumstances of the Charity and consider that adequate resources continue to be available to fund its activities for the foreseeable future. The trustees are of the view that the charity is a going concern.

Management of risk

The Trustees have identified that the main risks to the charity are:

- The NHS England clinic contract
- Failing to secure sufficient funds
- The loss of income from reduced donations
- The loss of key personnel
- The Covid-19 Pandemic

Declaration

The Trustees approve this annual report and accounts.

Signed on behalf of the Board of Trustees:

L Dowswell

Laura Dowswell

Position: Chair

Date: 28/07/2023

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2023.

Accounts for year ended 31st March 2023



CHARITY COMMISSION
FOR ENGLAND AND WALES

BARDET-BIEDL SYNDROME UK			Charity No	1181244	CC17a
Annual accounts for the period					
Period start date	1-Apr-22	To	Period end date	31-Mar-23	

Section A Statement of financial activities

Recommended categories by activity	Unrestricted funds £	Restricted funds £	Endowment funds £	Total funds £	Prior year funds £
Incoming resources (Note3)					
Income and endowments from:					
Donations and legacies	56,265	-	-	56,265	101,615
Charitable activities	169,357	-	-	169,357	
Other trading activities	3,311	-	-	3,311	448
Investments	13,499	-	-	13,499	50,420
Other	349	-	-	349	2,081
Total	242,781	-	-	242,781	154,564
Resources expended (Note 5)					
Expenditure on:					
Raising funds	3,470	-	-	3,470	1,102
Charitable activities	236,671	10,000	-	246,671	92,437
Total	240,141	10,000	-	250,141	93,539
Net income/(expenditure) before investment gains/(losses)	2,640	- 10,000	-	- 7,360	61,025
Net gains/(losses) on investments	-	-	-	-	-
Net income/(expenditure)	2,640	- 10,000	-	- 7,360	61,025
Net movement in funds	2,640	- 10,000	-	- 7,360	61,025
Reconciliation of funds:					
Total funds brought forward	159,328	13,078	-	172,406	111,381
Total funds carried forward	161,968	3,078	-	165,046	172,406

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2023.

Section B Balance sheet

	Unrestricted funds £	Restricted funds £	Endowment funds £	Total this year £	Total last year £
Fixed assets					
Tangible assets (Note 10)	1,145	-	-	1,145	-
Total fixed assets	1,145	-	-	1,145	-
Current assets					
Debtors (Note 11)	34,378	-	-	34,378	-
Cash at bank and in hand (Note 12)	136,483	3,078	-	139,561	172,406
Total current assets	170,861	3,078	-	173,939	172,406
Creditors: amounts falling due within one year (Note 13)	10,038	-	-	10,038	-
Net current assets/(liabilities)	160,823	3,078	-	163,901	172,406
Total assets less current liabilities	161,968	3,078	-	165,046	172,406
Total net assets or liabilities	161,968	3,078	-	165,046	172,406
Funds of the Charity					
Restricted income funds (Note 14)	-	3,078	-	3,078	13,078
Unrestricted funds (Note 15)	161,968	-	-	161,968	159,328
Total funds	161,968	3,078	-	165,046	172,406
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval		
	A. Geeson	Abbie Geeson	28/07/23		

Section C

Notes to the accounts

Note 1: Basis of Preparation

1.1 Basis of accounting

These accounts have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant note(s) to these accounts. The accounts have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and with the Charities Act. The charity constitutes a public benefit entity as defined by FRS 102.

1.2 Going concern

There are no material uncertainties about the charity's ability to continue.

1.3 Change of accounting policy

The accounts present a true and fair view and the accounting policies adopted are those outlined in note 2.

1.4 Changes to accounting estimates

No changes to accounting estimates have occurred in the reporting period (3.46 FRS 102 SORP).

1.5 Material prior year errors

No material prior year error have been identified in the reporting period (3.47 FRS 102 SORP).

1.6 Fund accounting

- Unrestricted funds are available for use at the discretion of the trustees to further any of the charity purposes.
- Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.
- Restricted funds are subjected to restrictions of their expenditure declared by the donor or through the terms of an appeal and fall into one of two sub-classes: restricted income funds or endowment funds.

1.7 Disclosure exemptions

Under charities SORP (FRS102) the Charity is classes as a small charity and has therefore taken the exemption from the requirement to prepare a cashflow statement.

Note 2: Accounting Policies

2.2 Income

- Recognition of income is included in the Statement of Financial Activities (SoFA) when: the charity becomes entitled to the resources; it is more likely than not that the trustees will receive the resources; and the monetary value can be measured with sufficient reliability.
- There has been no offsetting of assets and liabilities, or income and expenses, unless required or permitted by the FRS 102 SORP or FRS 102.
- Grants and donations are only included in the SoFA when the general income recognition criteria are met (5.10 to 5.12 FRS102 SORP). In the case of performance related grants, income must only be recognised to the extent that the charity has provided the specified goods or services as entitlement to the grant only occurs when the performance related conditions are met (5.16 FRS 102 SORP).

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2023.

- Legacies are included in the SOFA when receipt is probable, that is, when there has been grant of probate, the executors have established that there are sufficient assets in the estate and any conditions attached to the legacy are either within the control of the charity or have been met.
- The charity has received no government grants in the reporting period.
- Gift Aid receivable is included in income when there is a valid declaration from the donor. Any Gift Aid amount recovered on a donation is considered to be part of that gift and is treated as an addition to the same fund as the initial donation unless the donor or the terms of the appeal have specified otherwise.
- Contractual Income and performance related grants is only included in the SoFA once the charity has provided the related goods or services or met the performance related conditions.

- Donated services and facilities are included in the SOFA when received at the value of the gift to the charity provided the value of the gift can be measured reliably. Donated services and facilities that are consumed immediately are recognised as income with an equivalent amount recognised as an expense under the appropriate heading in the SOFA.
- The value of any voluntary help received is not included in the accounts but is described in the trustees' annual report.
- Income from interest, royalties and dividends. This is included in the accounts when receipt is probable and the amount receivable can be measured reliably.
- Settlement of insurance claims. Insurance claims are only included in the SoFA when the general income recognition criteria are met (5.10 to 5.12 FRS102 SORP) and are included as an item of other income in the SoFA.

2.3 Expenditure and Liabilities

- Liabilities are recognised where it is more likely than not that there is a legal or constructive obligation committing the charity to pay out resources and the amount of the obligation can be measured with reasonable certainty.
- Support costs have been allocated between governance costs and other support. Governance costs comprise all costs involving public accountability of the charity and its compliance with regulation and good practice. Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, eg allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.
- No material item of deferred income has been included in the accounts.
- The charity has creditors which are measured at settlement amounts less any trade discounts
- The charity accounts for basic financial instruments on initial recognition as per paragraph 11.7 FRS102 SORP. Subsequent measurement is as per paragraphs 11.17 to 11.19, FRS102 SORP.
- Raising funds. These are costs incurred in attracting voluntary income and those incurred intrading activities that raise funds.
- Charitable Activities. Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

2.4 Assets

- Tangible fixed assets for use by charity are capitalised if they can be used for more than one year, and cost at least £300. They are valued at cost. The depreciation rates and methods used are disclosed in note 10.2.
- Debtors (including trade debtors and loans receivable) are measured on initial recognition at settlement amount after any trade discounts or amount advanced by the charity. Subsequently, they are measured at the cash or other consideration expected to be received.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2023.

Note 3: Analysis of income

Analysis		Unrestricted funds	Restricted funds	Endowment funds	Total funds	Prior year
		£	£	£	£	£
Donations and legacies:	Donations and gifts	39,555	-	-	39,555	58,038
	Gift Aid	7,238	-	-	7,238	2,096
	Regular Giving	9,472	-	-	9,472	9,877
	General grants provided by government/other charities	-	-	-	-	31,604
Total		56,265	-	-	56,265	101,615
Charitable activities:	Event Funding	7,000	-	-	7,000	-
	NHS - Commissioned Services	162,357	-	-	162,357	-
	Total	169,357	-	-	169,357	-
Other trading activities:	Fundraising Proceeds	2,207	-	-	2,207	-
	Sale of Merchandise	1,104	-	-	1,104	448
	Total	3,311	-	-	3,311	448
Income from investments	Interest income	123	-	-	123	8
	Dividend income	13,376	-	-	13,376	50,412
	Total	13,499	-	-	13,499	50,420
Other:	Other	349	-	-	349	2,081
	Total	349	-	-	349	2,081
Total Income		242,781	-	-	242,781	154,564

Note 4: Analysis of receipts of government grants

Description		This year	Last year
		£	£
Government grant 1	HMRC JRS	-	1,604
	Total	-	1,604

Note 5: Analysis of expenditure

Analysis	This year			Last year		
	Unrestricted funds	Restricted funds	Total funds	Unrestricted funds	Restricted funds	Total funds
Expenditure on raising funds:						
£						
Incurring seeking donations	1,268	-	1,268	1,102	-	1,102
Advertising, marketing, direct mail and publicity	201	-	201	-	-	-
Other trading activities	2,001	-	2,001	-	-	-
Total expenditure on raising funds	3,470	-	3,470	1,102	-	1,102

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2023.

Expenditure on charitable activities:

Advice Service	11,256	10,000	21,256	11,870	10,438	22,308
NHS - Commissioned Services	149,314	-	149,314	-	-	-
Annual Family Weekend and Conference	19,968	-	19,968	1,381	-	1,381
Chris Humphreys Memorial Fund	955	-	955	-	-	-
Information Support	4,034	-	4,034	7,776	-	7,776
IT Equipment Fund	947	-	947	2,830	-	2,830
Regional Groups	1,565	-	1,565	-	-	-
Wellbeing Support Service	3,000	-	3,000	10,000	-	10,000
Jeans 4 Genes	-	-	-	-	1,422	1,422
Breaking Down Barriers	-	-	-	-	1,804	1,804
Support Costs (Note 6)	45,632	-	45,632	44,916	-	44,916
Total expenditure on charitable activities	236,671	10,000	246,671	78,773	13,664	92,437

Other

	-	-	-	-	-	-
Total other expenditure	-	-	-	-	-	-
TOTAL EXPENDITURE	240,141	10,000	250,141	79,875	13,664	93,539

Analysis of expenditure on charitable activities:

Activity or programme	This year			Last year		
	Activities undertaken directly	Support Costs	Total this year	Activities undertaken directly	Support Costs	Total last year
	£	£	£	£	£	£
Advice Service	21,256	-	21,256	22,308	-	22,308
NHS - Commissioned Services	149,314	-	149,314	-	-	-
Annual Family Weekend & Conference	19,968	-	19,968	1,381	-	1,381
Chris Humphreys Memorial Fund	955	-	955	-	-	-
Information Support	4,034	-	4,034	7,776	-	7,776
IT Equipment Fund	947	-	947	2,830	-	2,830
Regional Groups	1,565	-	1,565	-	-	-
Wellbeing Support Service	3,000	-	3,000	10,000	-	10,000
Jeans 4 Genes	-	-	-	1,422	-	1,422
Breaking Down Barriers	-	-	-	1,804	-	1,804
Support Costs (note 6)	-	45,632	45,632	-	44,916	44,916
Total	201,039	45,632	246,671	47,521	44,916	92,437

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2023.

Note 6: Support Costs

Support cost	Support Costs	This year	Last Year
	£	£	£
Accountancy Fees	3,479	3,479	1,002
IT support	2,169	2,169	-
Database	650	650	-
Exhibition Fees	300	300	-
Finance Fees	5,814	5,814	3,740
Governance	767	767	704
Insurance	365	365	709
Postage, Stationary, Advertising	1,795	1,795	1,509
Staff costs	26,990	26,990	32,653
Subscriptions	793	793	2,816
Sundry	347	347	920
Telephone	745	745	-
Travel	163	163	-
Website	416	416	863
Partial Exemption VAT disallowed	838	838	-
Other	-	-	-
Total	45,632	45,632	44,916

Note 7: Details of certain items of expenditure

Fees for examination of the accounts

Independent examiner's fees
 Assurance services other than audit or independent examination
 Tax advisory fees
 Other fees (for example: financial advice, consultancy, accountancy services)
 paid to the independent examiner

This year £	Last year £
-	-
-	-
-	-
3,479	1,002

Note 8: Paid employees

8.1 Staff Costs

Salaries and wages
 Social security costs
 Pension costs (defined contribution scheme)
 Other employee benefits

This year £	Last year £
155,017	53,696
13,625	1,099
7,368	1,098
-	-
Total staff costs	55,893

No employees received employee benefits (excluding employer pension costs) for the reporting period of more than £60,000

8.2 Average head count in the year

The parts of the charity in which the employees work -part time basis.

	This year Number	Last year Number
Charitable Activities	10	3
Total	10	3

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2023.

Note 9: Defined contribution pension scheme or defined benefit scheme accounted for as a defined contribution scheme

	This year	Last year
	£	£
Amount of contributions recognised in the SOFA as an expense	7,368	1,098

Note 10: Tangible fixed assets

10.1 Cost or valuation

	Fixtures, fittings and equipment	Total
	£	£
At the beginning of the year	-	-
Additions	1,145	1,145
Revaluations	-	-
Disposals	-	-
Transfers *	-	-
At end of the year	1,145	1,145

10.2 Depreciation and impairments

**Basis SL or RB (Straight Line or Reducing Balance)

** Rate

	SL or RB	SL or RB
At beginning of the year	-	-
Disposals	-	-
Depreciation	-	-
Impairment	-	-
Transfers*	-	-
At end of the year	-	-

10.3 Net book value

Net book value at the beginning of the year	-	-
Net book value at the end of the year	1,145	1,145

Note 11: Debtors and prepayments

Analysis of debtors

	This year	Last year
	£	£
Trade debtors	32,893	-
Prepayments and accrued income	1,485	-
Total	34,378	-

Note 12: Cash at bank and in hand

	This year	Last year
	£	£
Cash at bank and on hand	139,561	172,406
Total	139,561	172,406

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2023.

Note 13: Creditors and accruals

Analysis of creditors

	Amounts falling due within one year		Amounts falling due after more than one year	
	This year £	Last year £	This year £	Last year £
Trade creditors	2,535	-	-	-
Taxation and social security	7,503	-	-	-
Total	10,038	-	-	-

Note 14: Charity funds

Details of material funds held and movements - Restricted Funds

Fund names	At 1st April 2022 £	Income £	Expenditure £	Transfers £	At 31st March 2023 £
Advice Service	10,000	-	(10,000)	-	-
Jeans 4 Genes	3,078	-	-	-	3,078
Total Funds	13,078	-	(10,000)	-	3,078

Fund names	At 1st January 2021 £	Income £	Expenditure £	Transfers £	At 31st March 2022 £
Advice Service	-	10,000	-	-	10,000
Pears	-	10,000	(10,438)	438	-
Jeans 4 Genes	4,500	-	(1,422)	-	3,078
Smaller restricted grants	2,242	-	(1,804)	(438)	-
Total Funds	6,742	20,000	(13,664)	-	13,078

Advice Service

Restricted donation set aside to support the development and growth of this new integral BBS service.

Pears

Funding our Advice service support.

Jeans 4 Genes

Funding to facilitate our transition work with Young People.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2023.

Note 15: Charity funds

Details of material funds held and movements – Unrestricted funds

Fund names	At 1st April 2022 £	Income £	Expenditure £	Transfers £	At 31st March 2023 £
General Funds	121,203	242,781	(212,316)	(22,068)	129,600
Chris Humphreys Memorial Fund	955	-	(955)	3,000	3,000
Annual Family Weekend & Conference	24,045	-	(19,968)	20,923	25,000
IT Equipment Fund	7,170	-	(947)	(3,000)	3,223
Advice Service	5,955	-	(5,955)	-	-
Fixed Assets	-	-	-	1,145	1,145
Total Funds	159,328	242,781	(240,141)	-	161,968

Fund names	At 1st January 2021 £	Income £	Expenditure £	Transfers £	At 31st March 2022 £
General Funds	83,683	134,564	(78,493)	(18,551)	121,203
Chris Humphreys Memorial Fund	955	-	-	-	955
Annual Family Weekend & Conference	20,000	-	(1,381)	5,426	24,045
IT Equipment Fund	-	-	-	7,170	7,170
Advice Service	-	-	-	5,955	5,955
Total Funds	104,638	134,564	(79,874)	-	159,328

General Funds

General funds are donations and other incoming resources receivable or generated for the objects of the charity without a specific purpose and which the charity may use for its own purpose at its discretion.

Chris Humphreys Memorial Fund

This subsidy fund was set up in 2020 to support newly diagnosed individuals and their families to access our events.

Annual Family weekend & Conference

This is committed future expenditure. The weekend brings together over 200 diagnosed individuals and their families.

IT Equipment Scheme

This fund was set up in 2021 in response to an increasing need for people with BBS to access services through means of digital technology based upon an assessment of need.

Advice Service

Amount set aside to support the development and growth of this new integral BBS service.

Fixed Assets

Fixed Assets which cannot be used to fund expenditure without being sold

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2023.

Note 16: Transactions with trustees and related parties

16.1 Trustee remuneration and benefits

This year none of the trustees have been paid any remuneration or received any other benefits from an employment with their charity or a related entity (2022: none)

16.2 Trustees' expenses

Type of expenses reimbursed	This year	Last year
	£	£
Travel	438	-
Other (please specify):	-	-
TOTAL	438	-

Please provide the number of trustees reimbursed for expenses or who had expenses paid by the charity

4

16.3 Transaction(s) with related parties

This year there have been no related party transactions in the reporting period (2022: none)

Independent Examiners Report



**CHARITY COMMISSION
FOR ENGLAND AND WALES**

**Independent examiner's
report on the accounts**

Section A Independent Examiner's Report

Report to the trustees/ members of	BARDET-BIEDL SYNDROME UK (BBS UK)		
On accounts for the the	12 Months ended 31 MARCH 2023	Charity no (if any)	1181244
	Set out on pages 18 TO 22 OF THE CHAIR'S REPORT AND ACCOUNTS		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the period ended 31/03/2023.

Responsibilities and basis of report As the charity trustees of the Trust, 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 Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed 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 which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Signed:  **Date:** 25/7/2023

Name: MICHAEL BANNISTER

Relevant professional qualification(s) or body (if any): Director, Amicus Accountancy Ltd
Chartered Certified Accountants

Address: THE STABLES, GOBLANDS FARM BUSINESS CENTRE,
CEMETERY LANE, HADLOW,
KENT, TN11 0LT

Section B Disclosure

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2023.

Give here brief details of any items that the examiner wishes to disclose.

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