

BARDET-BIEDL SYNDROME UK (BBS UK)

England & Wales · Charity number 1181244

Details

Other names BARDET-BIEDL SYNDROME UK, BBS UK

Status Registered

Legal form CIO

Registered 2018-12-18

Register [View on the Charity Commission register](#)

Contact

Address 43 Balton Way
Harwich
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Website www.bbsuk.org.uk

Activities

Objects: THE OBJECTS OF THE CIO ARE:(A) TO PRESERVE AND PROTECT THE HEALTH AND PROMOTE THE WELFARE OF PERSONS DIAGNOSED WITH BARDET-BIEDL SYNDROME AND THEIR FAMILIES;(B) 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.

Activities: BBS UK provides support, information and advocacy services. It organises an annual family conference, a family activity weekend and social weekend for adults living with the syndrome. The charity maintains a website and produces twice-yearly newsletters, an annual Conference Report, information leaflets and online resources.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£395,748	£294,676	-	-
2024-03-31	£315,787	£279,165	-	-
2023-03-31	£242,781	£250,141	-	-
2022-03-31	£154,564	£93,539	-	-
2020-12-31	£53,704	£55,174	-	-

Trustees

Name	Role	Appointed
Bilal Ali		2024-11-09
Chetankumar Meshram		2023-09-24
DIANNE JULIE HAND		2018-12-18
Dr Shehla Mohammed		2021-07-13
Emma Hughes		2024-11-09
Gareth Owens		2023-09-24
Liam Wilkie		2021-07-13
Natasha Murray		2025-11-08
RACHAEL ANNE Zimblar		2018-12-18

BARDET-BIEDL SYNDROME UK (BBS UK)

England & Wales - Charity number 1181244

Accounts

Charity registration number: 1181244



Bardet-Biedl Syndrome UK

Annual Report and Financial Statements

for the Year Ended 31 March 2025



Bardet-Biedl Syndrome UK

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Bardet-Biedl Syndrome UK

Reference and Administrative Details

Trustees:

- Emma Hughes, Chair (appointed 9 November 2024)
- Laura Dowswell, Chair (resigned 9 November 2024)
- Chetan Meshram, Vice Chair
- Dianne Hand, Secretary
- Tazeem Abbas, Treasurer
- Liam Wilkie
- Rachael Zimblar
- Dr Shehla Mohammed
- Gareth Owens
- Bilal Ali (appointed 9 November 2024)
- Stefan Crocker (resigned 9 November 2024)

Charity Registration Number 1181244

Principal Office 43 Balton Way
Harwich
Essex
C012 4UP

Independent Examiner Westcotts (SW) LLP
Chartered Accountants & Statutory Auditors
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

Bankers Barclays Bank PLC
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Bardet-Biedl Syndrome UK

Trustees' Report

The Trustees present the annual report together with the financial statements of the Charity for the year ended 31 March 2025.

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 720 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

Charity Structure

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 (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 over 720 individuals living with BBS, and their families, carers, and 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 their family, and any family with one or more affected children, including their grandparents and carers.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Governance

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, UK 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.

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:

- 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.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Environmental Commitment and Carbon Reduction

As a supplier to the NHS, we are committed to supporting the NHS Net Zero agenda and the UK Government's Procurement Policy Note (PPN 06/21). In the next reporting year, we will publish our first Carbon Reduction Plan, establishing a baseline footprint, covering homeworking and essential travel by our remote team.

From this we will set a clear trajectory toward Net Zero by 2045, with interim targets and practical measures already underway, including:

- Prioritising public transport for all NHS-related travel
- Reducing reliance on printing and in-person meetings
- Promoting energy-efficient homeworking practices

We recognise our role in contributing to a more sustainable health and care system and will continue to review and report on our progress annually.

Additional Governance

Policies and Procedures

BBS UK has the following policies in place:

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

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

BBS UK has the following Information Security policies in place:

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

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, where appropriate and 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.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

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 about 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.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

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

- Advice Service supporting members with accessing local support across the areas of health, education, social care, and benefits.
- BBS Clinic Support Team providing support, facilitation, and advocacy services to NHS multi-disciplinary clinics.
- 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)
- Annual family conference, bringing beneficiaries together with interested professionals and experts, to provide access to the latest research and to participate in tailored workshops
- Support given to, and engagement with, the BBS research community
- BBS UK website: www.bbsuk.org.uk
- Regular newsletters and an annual conference report
- Social media (including Facebook, Twitter, YouTube) to facilitate the development of an online community
- Service User Advisory Board
- Young People's Group (YPG)

Report from the Chair of BBS UK

Emma Hughes, Chair of BBS UK

It is a great honour to present my first Chair's report for BBS UK. As a small, user-led charity, BBS UK continues to punch well above its weight—delivering life-changing support to individuals and families affected by Bardet-Biedl syndrome across the UK and beyond. The scale and depth of what has been achieved over the past year is nothing short of extraordinary. This success is rooted in the passion, expertise, and unwavering commitment of our staff team, who provide vital information, practical help, and emotional support—often in very complex circumstances. On behalf of the Board, I would like to thank each one of them for their dedication and hard work.

A Year of Progress and Renewal

This has been a year of transition and renewal at Board level. I'd like to express our sincere gratitude to Laura Dowswell, who stepped down as Chair in November 2024 after 9 years of dedicated service. Laura helped guide the organisation through significant growth, and her legacy is evident in the strength and stability we enjoy today. We also thank Stefan Crocker, who stepped down after 9 years of valued contribution as a trustee, serving as Vice-Chair and Chair in his time. We are very pleased to have welcomed Bilaal Ali to the Board, bringing new perspectives and energy to our work. Staffing changes also brought both challenge and opportunity. We said farewell to Samantha Serido, our Fundraising and Communications Officer, and thank her for her contribution.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Strengthening Our Services

Thanks to a transformational legacy gift, we are now in the position to expand our Advice Service with the recruitment of two new Advice Workers—ensuring that we can meet growing need and support more individuals and families navigating complex health, social care, and education systems.

Our Clinics Support Service continues to be a cornerstone of what we do. Now in our 15th year, the impact of this service is clear, with the professionalism and empathy of our staff frequently praised by patients, carers, and clinicians alike.

Our Counselling Project, in partnership with Rareminds, continues to offer specialist mental health support. This free and confidential service recognises the emotional impact of living with a rare condition.

We are also proud of the ways we have supported digital inclusion through our IT Fund, helping individuals access education, work, and healthcare through technology—something that is increasingly essential to wellbeing and independence.

Together, these services reflect our commitment to holistic, person-centred support—offering both practical help and emotional care when it matters most.

Coming Together as a Community

A real highlight of the year was our Annual Conference in June 2024, which brought together over 130 attendees from across the UK and around the world for a packed programme of expert presentations and inspiring lived experience stories. This online event was a powerful reminder of the strength of our community, and of the importance of staying connected—even at a distance. The overwhelmingly positive feedback showed just how valuable and empowering the event was for so many.

Our commitment to inclusion also extended beyond our borders. We strengthened our international partnerships, with our Operations Manager, Tonia, representing BBS UK at BBS and rare disease summits in Chicago and Dublin, helping ensure that the voices of patients and families remain central in global conversations around BBS research and treatments.

Looking Forward

This reporting year also marked the conclusion of our three-year strategic plan. With thoughtful input from all our stakeholders, we are developing a new strategy to take us forward with confidence, sustainability, and clarity. We will continue to champion the voices of those with lived experience, expand our reach, and advocate for improved care and understanding of Bardet-Biedl syndrome.

A Final Thank You

As I reflect on my first year as Chair, I feel incredibly proud to be part of this vibrant, compassionate, and determined community. To our staff, thank you for your skill and care.

To our members, families, volunteers, fundraisers, and partners, thank you for the trust you place in us and the energy you bring. And to my fellow trustees, thank you for your support and guidance.

Everything we do is powered by people—people who care deeply, give generously, and believe in a better future for those affected by BBS. Together, we are not only delivering services and support, we are building connections, confidence, and hope.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Achievements and Performance

Aims and Objectives

BBS UK's 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:

1. Improving 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 and reach on social media:

Facebook Page Followers:	1079 (5.17% increase)
Facebook (Closed) Groups* Members:	576
BBS UK	448 (3.9% increase)
BBS Adults Social Group	74
Ireland Regional Group	54
Instagram Followers:	312 (36.8% increase)
X Followers:	527 (6.5% increase)
LinkedIn Followers:	231 (33.5% increase)

*BBS UK have three closed groups; BBS UK, BBS Adults Social and Ireland Regional Group. Some individuals are members in multiple groups. Only statistics from the BBS UK closed group were recorded previously.

Newsletters

We have produced two bumper paper editions, also available on CD and in PDF, Word and Plain Text formats, alongside a digital Conference report.

Website management

The BBS UK website is continually updated with new and relevant information. To improve accessibility and keep all our audiences informed, we have integrated a live social media feed directly onto the site. This ensures that even those who do not use social media platforms can stay up to date with our latest news, updates, and community highlights in real time.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

2. 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

As we enter the fifth year of the BBS UK Advice Service, demand for support continues to grow. This year, our team has supported **125** individuals across a wide range of areas, including:

- Navigating the social care system
- Education support and advocacy
- Housing issues
- Accessing benefits
- Issues with college transport post-16
- Future planning for both children and adults with BBS

Over the past year, we've observed that cases are becoming increasingly complex, with local authorities more frequently resisting requests for care and support, beyond the bare minimum. As a result, individual cases are taking longer to resolve, and the overall workload has intensified. In total, we recorded **817** contacts through the service this year.

Team Update

At the beginning of the year, Shirin transitioned into her new role as Patient Liaison Officer (PLO) for the London Children's Clinic. Following a gradual handover, Shirin is now fully focused on her PLO responsibilities and is no longer taking on advice cases, inevitably resulting in an increase in our waiting list.

Despite this challenge, 2024 also brought positive developments. We were pleased to host another social work student on a 70-day placement, which concluded successfully:

"Rebecca, I came back to say thank you for the guidance you gave me in my first placement. Your recommendations helped me incredibly for the better."

- London Metropolitan University, MA Social Work Student, 2024

Unfortunately, we have not been able to offer a placement in 2025, but we hope to recommence the student placement programme in 2026.

Thanks to a legacy grant, we have been able to recruit two new advisors, who joined the team in June 2025. We are delighted to welcome Alis and Beatrice, who bring with them a wealth of experience in social care and education. Their addition will significantly enhance our capacity, streamline processes, and help reduce waiting times for those seeking support. Both are excited to begin working with and supporting the BBS community.

Rareminds Counselling Service – Pilot Project

We launched a specialised and bespoke counselling service project with Rareminds in June 2024, initially rolling it out as a pilot project in London to help bridge the gap in access to counselling for people with Bardet-Biedl Syndrome (BBS).

Following the success of this pilot, BBS UK is delighted to confirm that we will be expanding counselling support countrywide to more individuals with BBS who meet the eligibility criteria.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

IT Equipment Scheme

BBS UK continues to run its IT Equipment Project, providing practical and financial support to help individuals purchase essential devices such as laptops, tablets, and computers. The scheme aims to support children and adults in accessing education, medical and social care appointments, and social opportunities—all of which are vital for maintaining both mental and physical health, and for reducing feelings of isolation and loneliness.

Feedback from recipients highlights the real-life impact of the project:

“... I feel less isolated, and I can take positive steps towards looking for employment.”

“I am incredibly happy as I can now contact other people, something I was unable to do before. I am going to set up a Facebook account to connect with others.”

We are proud to continue offering this vital support and look forward to helping more individuals overcome barriers to connection and opportunity in the coming year.

Virtual Meet-Ups for Adults with BBS

Our Zoom social meet-ups are especially important for those living with Bardet-Biedl Syndrome (BBS) who may feel isolated or are unable to meet others with similar lived experiences in person—particularly as our community is spread across the UK.

The monthly sessions are participant-led, providing a welcoming space for 10 to 15 people to meet online, chat about everyday life, and explore shared topics such as travel, transport, and of course, enjoy the occasional quiz.

We are incredibly grateful to our facilitator, Maria, and all those who attend, for helping build a warm and inclusive virtual space for the BBS UK community. We look forward to building this project over the year, following on from a successful in person meetup at Conference.

Clinics Support Service

Our Clinics Support Service provides support, facilitation, and advocacy services to those attending specialised BBS clinics. Our Patient Liaison Officers (PLO) play an essential role within the NHS multi-disciplinary clinic framework, including facilitating access, advocating for patient-centred care, supporting continuity across services, and maintaining close relationships with healthcare professionals, liaising with patients to maximise health outcomes. The number of new referrals into the service continues to increase year on year and, as demand rises, our team continues to deliver high-level, tailored support to all new service users and their families.

Across the reporting year, the team logged **2,889** actions or contacts on behalf of over **536** service users and provided support and facilitation services at approximately **60** clinics (virtual and face-to-face) across Birmingham and London. The team's presence at each clinic—from the point of diagnosis onward—ensures that support is accessible and immediate. Our work is consistently highly regarded by NHS colleagues and NHS England and is frequently described as essential to the successful running of the BBS clinics service.

The team continues to develop and strengthen its transition service, offering enhanced support for young people and their families as they move from paediatric to adult services. This involves coordination with the adult clinics service to ensure a smooth handover, continuity of care, and a positive first experience in adult services. We work closely with families to ensure each young person is fully prepared for their first adult clinic appointment.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Our PLO team collaborates with local authorities to support the development and integration of Education, Health, and Care (EHC) plans for our young service users. We attend and contribute to key meetings, ensuring that health needs are accurately represented and effectively met within wider care planning structures.

Our team supports service users in understanding and accessing innovative treatments and clinical trials. By facilitating their involvement in this area, we empower individuals to engage in initiatives that could meaningfully enhance their quality of life and overall care experience.

Beyond the clinic setting, the Clinics Support Team provides ongoing support between appointments via email and telephone, ensuring continuity of care year-round. We recognise the emotional and psychological impact of living with a rare condition, and work to provide reassurance, empathy, and guidance, especially during key transitions or times of uncertainty.

The team supports not just individuals with BBS, but also their parents, carers, and families, acknowledging the vital role they play in care and decision-making. We offer practical advice and emotional support to help families feel confident and well-informed throughout the care journey.

We also strive to ensure our services are inclusive and accessible to all. This includes providing culturally sensitive support, addressing language needs, and working to reduce barriers that may prevent engagement with clinic services.

Our work is rooted in collaborative practice, with strong relationships across the NHS multi-disciplinary team. This integrated approach ensures holistic care and better outcomes for our service users.

Patient evaluation data is consistently high, with **93%** of patients rating the support received from our team as **'Excellent'**. Comments received include:

"A team of remarkable people who help to reassure and guide you for the next year ahead."

"BBS UK were very helpful and accommodating on managing people's conditions."

"Very good and I felt supported. The clinic has kept me at peace about my BBS."

"The support provided by BBS UK is a lifeline for us and the clinic is an important part of this support where our child's care is brought together."

"Really well coordinated, it ran smoothly and the support team were helpful and empathetic."

"Excellent care, I was treated as an individual that not all care fits one bracket and that they are there for support"

Conference 2024

We held an online conference on 8th June which was incredibly well attended and supported. We had 203 register to attend the event with 130 joining us on the day. Of those who registered, 135 were based in the UK and 68 registered from across 26 countries.

Included in our programme were presentations from Dr Arlene Drack, who joined us from the US, and Professor Phil Beales, both of whom shared exciting updates about their gene therapy research. We also heard from Dr Elizabeth Forsythe about hyperphagia in BBS and a potential treatment, and were privileged to hear two personal perspectives about the lived experience of Bardet-Biedl syndrome, one of which focused on the sibling perspective.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Conf 2024 Feedback

- 97% felt better informed about ongoing research into BBS
- 82% felt better informed about the management of BBS
- 76% had greater awareness of the support and information available
- 64% felt more confident managing the challenges of BBS
- 76% felt more connected to the BBS community
- 97% would attend or recommend attendance at a BBS UK event in future

Comments received:

“I was really doubtful that I would enjoy this conference as much because I like the community of our in-person conferences. However, I have to say that the quality of the information presented was fantastic. What I also liked was that my daughter with BBS was able to sit in on some of the presentations which normally she would not have been able to as she would have been out on the activity day. Thank you! “

“Well done everyone that helped to organise or took part in presenting, what a fabulous job! Really interesting, informative and professional. I especially look forward to hearing the personal perspectives, which are always inspiring and so heart-warming. Thank you!”

Regional Group Ireland

Our Ireland Regional Group continues to make meaningful progress in improving access to healthcare, support, and information for people living with Bardet-Biedl syndrome across the island of Ireland.

In 2024, the group carried out an audit of BBS patient access to healthcare services, highlighting key challenges such as fragmented care and the burden of multiple appointments. These findings are directly informing ongoing efforts to develop a dedicated multi-disciplinary team (MDT) clinic in Ireland.

The group also formalised its structure and future plans, strengthening its capacity to advocate effectively and support families. Plans are underway for a second Information Day in October 2025, aiming to bring families and clinicians together for learning and connection.

We are grateful to all those who continue to give their time, energy, and expertise to this work. The commitment of volunteers and supporters is driving real and positive change.

3. Empower our membership to achieve

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.

Earlier we reported on our Rareminds Counselling Service project, our virtual ‘meet-ups’, our IT Equipment Fund, our Clinics Support Service and Annual Conference, all of which promote positive health and wellbeing in our community. During the year we also held a Young Person’s Activity Weekend and a Social Event in London for adult service users.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Our Young Person's Weekend in Birmingham, provided a variety of challenges, including a day at Bear Grylls Activity Centre and plenty of social time to connect with others living with BBS. Parents found it invaluable having time with other parents who are on the same journey.

For our older members a two-day event in London was built around attendance at Sight Village, an exhibition for people affected by sight loss, showcasing a wide range of technology and support services. We also visited the Natural History Museum and enjoyed meals out and social time together.

Service User Advisory Group

We have established a Service User Advisory Group, to ensure that the voice and needs of the wider BBS community are accounted for and can directly feed into strategy and service improvements. The group meets every 2-3 months and consists of up to six BBS patients and six parents with experience of using BBS UK services. Over the past year, the SUAG members have helped review our newsletters, the online conference programme (including accessibility of materials), the conference report, and the Community Audit 2024. The group also shared ideas for the 2025 annual conference, upcoming newsletters, and fundraisers.

4. Strengthen governance and raise our profile

We have continued growing and developing our Board of Trustees, with a focus on filling gaps identified in a skills audit. For the first time we engaged a specialised recruitment organisation to fill our Chair position and were delighted to welcome Emma Hughes to our Board at our AGM in November 2024. We also welcomed new Trustee, Bilaal Ali to our Board.

The Board now includes professional experience and skills across management/leadership, finance, project management, contract management, education, medical/genetics, human resources, and marketing/media/PR. We currently have two spaces unfilled and are seeking skills and experience as follows:

- Legal including charity law
- Marketing, media, PR
- Fundraising/funding
- Human Resources/employment legislation

This reporting year brought us to the end of our three year strategic plan and we invested considerable time in its review and the development of a strategy for the next three years. We are in the process of finalising it and aim to publish it towards the Autumn of 2025.

In October 2024, we attended the European Cilia research meeting in Dublin, during which our Operations Manager, gave a presentation about BBS UK and the importance of collaboration, and patient and patient group engagement in research. In March 2025, Tonia attended a BBS summit in Chicago, connecting with key stakeholders in the global BBS research network.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

5. Support research and understanding of BBS

BBS UK continues to play a vital role in fostering, supporting, and influencing research related to Bardet-Biedl syndrome. We are committed to ensuring that people living with BBS are meaningfully involved in all stages of the research process, from shaping questions to reviewing outcomes.

Throughout the year, we have supported a number of research initiatives through:

- Letters of support for funding applications
- Acting as co-applicants on grant proposals
- Assisting in the development of research protocols and patient information materials to ensure accessibility and clarity for participants
- Disseminating research findings to our community via newsletters, the website, and at key events
- Providing input into the design of research questions, particularly those that address lived experience, service improvement, or unmet needs
- Welcoming researchers at our Annual Family Conference, providing them with space to engage with attendees, gather insight, and share their work in an accessible and collaborative environment

To ensure scientific rigour and effective collaboration with the academic and pharmaceutical sectors, our Scientific Advisory Board meets two to three times a year. The Board:

- Keeps BBS UK informed of the latest scientific and clinical developments
- Provides oversight of research activity and pharma engagement, ensuring alignment with our values and the needs of the BBS community
- Contributes to the development and review of educational materials and publications
- Offers expert input into the programme and content of our Annual Family Conference, helping to ensure it reflects current priorities in BBS research and treatment

In addition, we maintain active connections with BBS organisations internationally and other UK-based rare disease groups, including through memberships and collaborations. These relationships allow us to stay informed about emerging research, influence strategic research priorities, and advocate for opportunities that are inclusive of people living with BBS.

Summary

In conclusion, this year has been one of meaningful progress and connection for BBS UK, as we continued to deliver on the goals outlined in our three-year strategic plan, whilst developing our plan for the next three years. We have improved communication through inclusive, accessible channels; expanded and diversified our support services; created new opportunities for empowerment; strengthened our governance structures; and deepened engagement with research and scientific understanding of Bardet-Biedl Syndrome.

Our sincere thanks go to our staff, trustees, volunteers, and partners whose dedication and collaboration make this work possible. Their efforts have enabled us to meet growing needs with compassion, innovation, and resilience. As we look ahead, we remain committed to continuous improvement and long-term sustainability, ensuring we support every individual and family living with BBS to live well, feel connected, and thrive.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Fundraising Review

Introduction

The national fundraising landscape continues to reflect a challenging macroeconomic climate, with rising living costs and donor fatigue placing pressure on income generation across the third sector. Nevertheless, BBS UK experienced a strong fundraising year, significantly outperforming our income targets. This was driven largely by a transformational legacy donation and a series of community-led initiatives that exceeded expectations.

Total fundraising income for the year exceeded **£170,000**, equating to more than **200%** of our original budget. Notably, excluding the legacy gift, income still reached **92%** of target - a remarkable achievement given the external environment.

Statutory funding from the NHS England continues to support our core Clinics Service, providing stable income.

Fundraising Goals and Strategy

This year, our primary goal was to further diversify income streams while developing our fundraising strategy. We successfully met our corporate giving target and exceeded expectations in individual, regular, and legacy giving. Currently, we are finalising our strategy, with a clear focus on expanding community fundraising, corporate partnerships, and regular giving in the year ahead. It continues to be our aim to register with the Fundraising Regulator, reinforcing our commitment to best-practice and ethical fundraising.

Community Fundraising

The dedication of our community fundraisers continues to inspire us. From extreme physical challenges to intimate family-led gatherings, every event made a difference. This year's highlights include:

- Michael O'Sullivan raised nearly £7,500, whilst training for the London Marathon. Unfortunately, Michael sustained an injury, and his place has rolled over to 2026; we wish him the best of luck with his training, and look forward to cheering him on, over the finish line.
- Fintan Cruse raised over £4,500 completing the Royal Canal Extreme Challenge, running 150km in 24 hours.
- Community events including the Sloane Family Afternoon Tea, Knitting Nannies, St Edwards Church fundraiser, Graeme Roache's Golf Tournament, Wilkie Family's Kilt Walk and many more.

We saw a surge in engagement following a call for help at our conference, leading to a noticeable uptick in new event planning, with skydive, bungee, and running challenges already scheduled.

Friends of BBS UK

The Friends of BBS UK regular giving programme raised over **£11,000**, an increase of more than £1,000 from the previous year. Promoting Regular Giving will remain a priority for the year ahead, to promote long-term sustainability.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Pharmaceutical Industry

Maintaining open, ethical and transparent relationships with pharmaceutical industry partners is an important element of BBS UK's funding, governance and strategic approach. These partnerships are managed in accordance with the guidelines of the Association of the British Pharmaceutical Industry (ABPI) and our internal policies.

We are deeply grateful to Rhythm Pharmaceuticals (£10,000) and Axovia Therapeutics (£5,000) for their generous support of the BBS UK Conference through unrestricted educational grants. In line with ABPI guidelines, these funds supported non-promotional educational activities, helping to increase awareness and understanding of Bardet-Biedl syndrome among patients and carers.

Trusts and Foundations

Grants and trust income, received into our account, totalled **£19,150**, representing **59%** of our target; our heartfelt thanks go to:

- The National Lottery Community Fund
- Sir Jules Thorn Charitable Trust
- Douglas Arter Foundation
- Kaye Charitable Trust
- The Eveson Trust

We are pleased to share that we have been awarded a three-year grant from BBC Children in Need, which will commence in the next financial year. In line with accruals accounting principles, this grant has been recognised in the current year's accounts. We continue to strengthen our funding pipeline, with a focus on increasing both the scale and sustainability of our grant income in the years to come.

Legacy Giving

This year saw the extraordinary impact of a legacy gift from the estate of Jackie Farrington. The BBS UK Board of Trustees has designated the funds to be used across three years to support the development of the Advice Service, a cornerstone of support for individuals and families living with Bardet-Biedl syndrome.

We are deeply grateful to Jackie and her family for this generous gift, which will have far reaching benefits for our community.

Looking ahead, we will build on this momentum by launching our first legacy awareness campaign, helping supporters understand the lasting impact of gifts in wills. Legacy giving represents a vital opportunity to strengthen the future of BBS UK, and we are committed to ensuring our community has the information and inspiration needed to consider this special form of support.

Fundraising Income Breakdown

Corporate Giving	£ 16,588
Events/Campaigns	£ 18,078
Gift Aid	£ 4,391
Individual Giving	£ 4,706
Regular Giving	£ 11,121
Legacy	£ 97,052
Grants/Trusts	£ 33,518
Total Income	£ 185,454

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Campaigns and Communications

Once again, our internally created campaigns received limited uptake, with the 'Countdown to Conference' campaign generating just £280. As in previous years, community-led events vastly outperform branded campaigns. Our strategic focus will shift towards encouraging and empowering fundraisers, rather than leading centralised campaigns.

To improve engagement and accessibility, we are trialling membership of the Run for Charity platform, which provides access to 800+ running events, including marathons, fun runs, muddy and inflatable events, enabling us to cover registration costs with ease and streamlining event registration.

Summary

In a year where many charities continued to face financial uncertainty and increased pressure on fundraising, the BBS UK community responded with remarkable generosity, determination, and heart. Thanks to the unwavering commitment of our fundraisers, donors, partners and volunteers, we exceeded expectations and secured income that will directly benefit those living with Bardet-Biedl syndrome.

This success is about much more than figures, every act of support reflects the strength and solidarity of our rare disease community. We are especially grateful for those who gave their time, shared their stories, and rallied others to get involved — their dedication has been truly inspiring.

To everyone who has supported us, in ways both big and small, we offer our heartfelt thanks. Your generosity has helped sustain vital services and given us the confidence to plan ambitiously for the future. We remain firmly committed to using every pound raised wisely, and to building on this year's achievements with integrity, purpose and care.

Treasurer's Report

Tazeem Abbas, Treasurer

As we have heard, this year marked a period of financial stability and operational progress for BBS UK. Alongside strong fundraising and prudent financial management, key developments included:

- The change of accountants at the end of the financial year from Amicus Accountancy Ltd to Westcotts Chartered Accountants.
- The completion of Kevin Sales' tenure as bookkeeper in March; Kevin has been a valued supporter of the Charity for many years, and we give our heartfelt thanks for his dedication and service.
- Our finance policy remains under review and will be prioritised in the next quarter.

BBS UK's financial period runs from 1st April 2024 to 31st March 2025, with accounts prepared on an accrual basis.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

As of the 31st March 2025, total Charity funds stood at **£302,739** (2023-24: £201,667). During the year, transfers of £18,114 were made from the General Fund to designated funds:

- £11,451 to the Annual Family Weekend and Conference
- £1,455 to the IT Equipment Fund
- A net £750 to the Rareminds Counselling Project, comprising £13,650 transferred to the designated fund, and £12,900 returned to the General Fund, following receipt of a restricted grant.
- £4,458 to Fixed Assets, reflecting capitalised expenditure.

General Funds increased to **£267,203** (2023-24: £190,949) with a surplus for the year of £76,254

Designated Funds stood at **£9,868** (2023-24: £7,928*)

Restricted Funds stood at **£25,668** (2023-24: £2,790).

The Trustees provided support from designated funds during the financial year:

- Chris Humphreys Memorial Fund: £2,167 (23-24: £1,407)
- Annual Family Weekend and Conference: £9,498 (23-24: £23,951)
- IT Equipment Fund: £1,197 (23-24: £2,178)
- Rareminds Counselling Project: £750.00

Reserves Policy and Going Concern

Trustees regularly review budget and reserves, monitored monthly and reported quarterly, 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 **6** months expenditure.

At 31st March 2025, the total unrestricted funds were **£277,071** including £9,868 of designated funds remaining at year end. After year-end as part of the 2025-26 budget approval, the trustees designated **£114,000** from the General Fund towards the following key priorities:

- £3,000 to the Chris Humphreys Memorial Fund, to support newly diagnosed individuals and their families to access our events based on assessment of need.
- £5,000 to the IT Equipment Fund, to improve digital access to services.
- £12,000 to the Rareminds Counselling Project, providing specialist counselling for BBS patients.
- £94,000 to fund the Advice Service over three-years* (2025-2028)

This leaves estimated free reserves of **£157,933**, equivalent to **5.5** months' core expenditure. The trustees consider that the Charity has adequate resources to continue its activities for the foreseeable future and therefore deem it a going concern.

**Designation of Unrestricted Legacy for Advice Service

At the end of 2024-25, Trustees designated £94,000 from an unrestricted legacy gift to support the Advice Service over three years. This strategic designation supports immediate growth and capacity building, while the Charity continues to seek sustainable funding sources. Although this designation provides temporary financial support, it does not fully cover the costs of the Advice Service, and additional funding is sought. These funds remain unrestricted and may be reallocated if necessary, in line with maintaining appropriate free reserves and financial stability.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

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

Summary

This year has been one of financial strength and strategic progress for BBS UK. Thanks to generous fundraising support, a significant legacy gift, and improved financial processes, we are well-positioned to meet current needs and invest in future growth. The Board remains committed to strong governance and prudent reserves management, ensuring our long-term sustainability. We are deeply grateful to our dedicated trustees, staff, volunteers, fundraisers and donors, whose continued support makes our work possible.

Statement of Trustees' Responsibilities

The Trustees are responsible for preparing the Trustees' report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations.

The law applicable to charities requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charity and of the incoming resources and application of resources of the Charity for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in business.

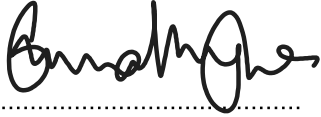
The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008, and the provisions of the constitution. The Trustees 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.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

The annual report was approved by the Trustees of the Charity on^{23/9/25} and signed on its behalf by:



.....
Emma Hughes
Chair and Trustee

Bardet-Biedl Syndrome UK

Independent Examiner's Report to the trustees of Bardet-Biedl Syndrome UK

I report to the Trustees on my examination of the accounts of Bardet-Biedl Syndrome UK for the year ended 31 March 2025.

Responsibilities and basis of report

As the Charity Trustees of Bardet-Biedl Syndrome UK 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 Bardet-Biedl Syndrome UK's accounts carried out under section 145 of the 2011 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

Since Bardet-Biedl Syndrome UK's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the ICAEW, which is one of the listed bodies.

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 Bardet-Biedl Syndrome UK 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 accounting 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.



.....
Catherine Williams FCA DChA
Independent Examiner
Westcotts (SW) LLP
Chartered Accountants & Statutory Auditors
47 Boutport Street
Barnstaple
Devon
EX31 1SQ

Date: 3rd October 2025

Bardet-Biedl Syndrome UK

Statement of Financial Activities for the Year Ended 31 March 2025

	Note	Unrestricted funds £	Restricted funds £	Total 2025 £	Total 2024 £
Income and Endowments from:					
Donations and legacies	2	140,436	30,018	170,454	130,082
Charitable activities	3	223,444	-	223,444	181,107
Other trading activities	4	-	-	-	2,534
Investment income	5	850	-	850	664
Other income	6	1,000	-	1,000	1,400
Total income		<u>365,730</u>	<u>30,018</u>	<u>395,748</u>	<u>315,787</u>
Expenditure on:					
Raising funds	7	(1,919)	-	(1,919)	(1,094)
Charitable activities	8	<u>(285,617)</u>	<u>(7,140)</u>	<u>(292,757)</u>	<u>(278,072)</u>
Total expenditure		<u>(287,536)</u>	<u>(7,140)</u>	<u>(294,676)</u>	<u>(279,166)</u>
Net income		<u>78,194</u>	<u>22,878</u>	<u>101,072</u>	<u>36,621</u>
Net movement in funds		78,194	22,878	101,072	36,621
Reconciliation of funds					
Total funds brought forward		<u>198,877</u>	<u>2,790</u>	<u>201,667</u>	<u>165,046</u>
Total funds carried forward	20	<u><u>277,071</u></u>	<u><u>25,668</u></u>	<u><u>302,739</u></u>	<u><u>201,667</u></u>

All of the Charity's activities derive from continuing operations during the above two periods.

The funds breakdown for 2024 is shown in note 20.

Bardet-Biedl Syndrome UK

(Registration number: 1181244)
Balance Sheet as at 31 March 2025

	Note	2025 £	2024 £
Fixed assets			
Tangible assets	15	5,137	3,241
Current assets			
Debtors	16	91,502	19,861
Cash at bank and in hand	17	<u>226,878</u>	<u>194,231</u>
		318,380	214,092
Creditors: Amounts falling due within one year	18	<u>(20,778)</u>	<u>(15,666)</u>
Net current assets		<u>297,602</u>	<u>198,426</u>
Net assets		<u>302,739</u>	<u>201,667</u>
Funds of the Charity:			
Restricted income funds			
Restricted funds		25,668	2,790
Unrestricted income funds			
Unrestricted funds		<u>277,071</u>	<u>198,877</u>
Total funds	20	<u>302,739</u>	<u>201,667</u>

The financial statements on pages 23 to 38 were approved by the Trustees, and authorised for issue on23/9/25..... and signed on their behalf by:



.....
Emma Hughes
Trustee

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025

1 Accounting policies

Statement of compliance

The financial statements have been prepared in accordance with the second edition of the Charities Statement of Recommended Practice issued in October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011.

Basis of preparation

Bardet-Biedl Syndrome UK meets the definition of a public benefit entity under FRS 102. The accounts (financial statements) 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 financial statements have been prepared in sterling which is the functional currency of the charity.

Going concern

The Trustees consider that there are no material uncertainties about the Charity's ability to continue as a going concern.

Income and endowments

Voluntary income including donations, gifts, legacies and grants that provide core funding or are of a general nature is recognised when the Charity has entitlement to the income, it is probable that the income will be received and the amount can be measured with sufficient reliability.

Donations and legacies

Donations and legacies are recognised on a receivable basis when receipt is probable and the amount can be reliably measured.

Grants receivable

Grants are recognised when the Charity has an entitlement to the funds and any conditions linked to the grants have been met. Where performance conditions are attached to the grant and are yet to be met, the income is recognised as a liability and included on the balance sheet as deferred income to be released.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Raising funds

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025 (continued)

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.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Taxation

The Charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the Charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Tangible fixed assets

Individual fixed assets are initially recorded at cost, less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

Depreciation and amortisation

Depreciation is provided on tangible fixed assets so as to write off the cost or valuation, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Depreciation method and rate
Fixtures, fittings and equipment	33.3% Straight line

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Fund structure

Unrestricted income funds are general funds that are available for use at the Trustees discretion in furtherance of the objectives of the Charity.

Restricted income funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025 (continued)

Pensions and other post retirement obligations

The Charity operates a defined contribution pension scheme which is a pension plan under which fixed contributions are paid into a pension fund and the Charity has no legal or constructive obligation to pay further contributions even if the fund does not hold sufficient assets to pay all employees the benefits relating to employee service in the current and prior periods.

Contributions to defined contribution plans are recognised in the Statement of Financial Activities when they are due. If contribution payments exceed the contribution due for service, the excess is recognised as a prepayment.

Financial instruments

Classification

Financial assets and financial liabilities are recognised when the Charity becomes a party to the contractual provisions of the instrument.

Financial liabilities and equity instruments are classified according to the substance of the contractual arrangements entered into. An equity instrument is any contract that evidences a residual interest in the assets of the Charity after deducting all of its liabilities.

Recognition and measurement

All financial assets and liabilities are initially measured at transaction price (including transaction costs), except for those financial assets classified as at fair value through profit or loss, which are initially measured at fair value (which is normally the transaction price excluding transaction costs), unless the arrangement constitutes a financing transaction. If an arrangement constitutes a financing transaction, the financial asset or financial liability is measured at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Financial assets and liabilities are only offset in the statement of financial position when, and only when there exists a legally enforceable right to set off the recognised amounts and the Charity intends either to settle on a net basis, or to realise the asset and settle the liability simultaneously.

Financial assets are derecognised when and only when a) the contractual rights to the cash flows from the financial asset expire or are settled, b) the Charity transfers to another party substantially all of the risks and rewards of ownership of the financial asset, or c) the Charity, despite having retained some, but not all, significant risks and rewards of ownership, has transferred control of the asset to another party.

Financial liabilities are derecognised only when the obligation specified in the contract is discharged, cancelled or expires.

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025 (continued)

2 Income from donations and legacies

	Unrestricted funds General £	Restricted funds £	Total 2025 £
Donations and Gifts	24,372	-	24,372
Legacies	97,052	-	97,052
Gift aid	4,391	-	4,391
Grants Received	3,500	30,018	33,518
Regular Giving	11,121	-	11,121
	<u>140,436</u>	<u>30,018</u>	<u>170,454</u>

	Unrestricted funds General £	Total 2024 £
Donations and Gifts	97,695	97,695
Gift aid	3,931	3,931
Grants Received	18,500	18,500
Regular Giving	9,956	9,956
	<u>130,082</u>	<u>130,082</u>

3 Income from charitable activities

	Unrestricted funds General £	Total 2025 £
Event Funding	18,236	18,236
NHS - Commissioned Services	205,208	205,208
	<u>223,444</u>	<u>223,444</u>

	Unrestricted funds General £	Total 2024 £
Event Funding	10,000	10,000
NHS - Commissioned Services	171,107	171,107
	<u>181,107</u>	<u>181,107</u>

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025 (continued)

4 Income from other trading activities

	Unrestricted funds General £	Total 2024 £
Sale of Merchandise	942	942
Fundraising Proceeds	1,592	1,592
	<u>2,534</u>	<u>2,534</u>

5 Investment income

	Unrestricted funds General £	Total 2025 £
Interest receivable on bank deposits	<u>850</u>	<u>850</u>

	Unrestricted funds General £	Total 2024 £
Interest receivable on bank deposits	<u>664</u>	<u>664</u>

6 Other income

	Unrestricted funds General £	Total 2025 £
Other income	<u>1,000</u>	<u>1,000</u>

	Unrestricted funds General £	Total 2024 £
Other income	<u>1,400</u>	<u>1,400</u>

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025 (continued)

7 Expenditure on raising funds

a) Costs of generating donations and legacies

	Unrestricted funds General £	Total 2025 £
Donations expenses	433	433

	Unrestricted funds General £	Total 2024 £
Donations expenses	289	289

b) Costs of trading activities

	Unrestricted funds General £	Total 2025 £
Other trading activities	1,486	1,486

	Unrestricted funds General £	Total 2024 £
Other trading activities	805	805

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025 (continued)

8 Expenditure on charitable activities

		Unrestricted funds General £	Restricted funds £	Total 2025 £
Charitable activities		242,080	7,140	249,220
Allocated support costs	9	43,537	-	43,537
		<u>285,617</u>	<u>7,140</u>	<u>292,757</u>

		Unrestricted funds General £	Restricted funds £	Total 2024 £
Charitable activities		230,419	288	230,707
Allocated support costs	9	47,365	-	47,365
		<u>277,784</u>	<u>288</u>	<u>278,072</u>

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025 (continued)

9 Analysis of support costs

Support costs allocated to charitable activities

	Support costs £	Total 2025 £	Total 2024 £
Office expenses	6,434	6,434	3,110
Staff costs	5,238	5,238	26,734
Travelling	6,648	6,648	534
Insurance	1,994	1,994	495
Telephone and fax	1,480	1,480	822
IT security and support	4,678	4,678	1,798
Database	675	675	150
Website	733	733	1,550
Printing, postage and stationery	552	552	344
Exhibition Fees	1,123	1,123	928
Trade subscriptions	929	929	1,120
Sundry expenses	623	623	399
Accountancy fees	4,774	4,774	5,280
Partial Exemption VAT disallowed	-	-	1,429
Independent examiner's fee	5,094	5,094	2,672
Depreciation	2,562	2,562	-
	<u>43,537</u>	<u>43,537</u>	<u>47,365</u>

10 Net incoming/outgoing resources

Net incoming resources for the year include:

	2025 £
Depreciation of fixed assets	<u>5,124</u>

11 Trustees remuneration and expenses

No Trustees, nor any persons connected with them, have received any remuneration from the Charity during the year.

During the year expenses were reimbursed to 3 Trustees totalling £830 (2024: £438) in respect of travel costs.

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025 (continued)

12 Staff costs

The aggregate payroll costs were as follows:

	2025	2024
	£	£
Staff costs during the year were:		
Wages and salaries	186,050	167,127
Social security costs	17,060	14,331
Pension costs	10,022	8,642
	<u>213,132</u>	<u>190,100</u>

The average number of persons employed by the Charity during the year was as follows:

	2025	2024
	No	No
Charitable activities	<u>8</u>	<u>9</u>

No employee received emoluments of more than £60,000 during the year

13 Independent examiner's remuneration

	2025	2024
	£	£
Examination of the financial statements	<u>5,094</u>	<u>2,672</u>

14 Taxation

The Charity is a registered charity and is therefore exempt from taxation.

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025 (continued)

15 Tangible fixed assets

	Furniture and equipment £	Total £
Cost		
At 1 April 2024	3,241	3,241
Additions	4,458	4,458
At 31 March 2025	<u>7,699</u>	<u>7,699</u>
Depreciation		
Charge for the year	2,562	2,562
At 31 March 2025	<u>2,562</u>	<u>2,562</u>
Net book value		
At 31 March 2025	<u>5,137</u>	<u>5,137</u>
At 31 March 2024	<u>3,241</u>	<u>3,241</u>

16 Debtors

	2025 £	2024 £
Trade debtors	88,193	17,867
Prepayments	2,996	1,994
Other debtors	313	-
	<u>91,502</u>	<u>19,861</u>

17 Cash and cash equivalents

	2025 £	2024 £
Cash at bank	<u>226,878</u>	<u>194,231</u>

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025 (continued)

18 Creditors: amounts falling due within one year

	2025 £	2024 £
Trade creditors	375	2,768
Taxation and social security	15,801	11,063
Other creditors	2,142	1,835
Accruals	2,460	-
	<u>20,778</u>	<u>15,666</u>

19 Pension and other schemes

Defined contribution pension scheme

The Charity operates a defined contribution pension scheme. The pension cost charge for the year represents contributions payable by the Charity to the scheme and amounted to £10,022 (2024 - £8,642).

20 Funds

	Balance at 1 April 2024 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 March 2025 £
Unrestricted funds					
General					
General Funds	190,949	365,730	(271,362)	(18,114)	267,203
Chris Humphreys Memorial Fund	2,593	-	(2,167)	-	426
Conference Weekend	1,049	-	(9,498)	11,451	3,002
IT Equipment Fund	1,045	-	(1,197)	1,455	1,303
Fixed Assets	3,241	-	(2,562)	4,458	5,137
Rareminds Counselling	-	-	(750)	750	-
	<u>198,877</u>	<u>365,730</u>	<u>(287,536)</u>	<u>-</u>	<u>277,071</u>
Restricted funds					
Jeans 4 Genes	2,790	-	-	-	2,790
The National Lottery (Rareminds Counselling Project)	-	13,650	(5,185)	-	8,465
The Eveson Trust (Transition Project)	-	2,000	(1,955)	-	45
BBC Children in Need	-	14,368	-	-	14,368
	<u>2,790</u>	<u>30,018</u>	<u>(7,140)</u>	<u>-</u>	<u>25,668</u>

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025 (continued)

	Balance at 1 April 2024 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 March 2025 £
Total funds	<u>201,667</u>	<u>395,748</u>	<u>(294,676)</u>	<u>-</u>	<u>302,739</u>
	Balance at 1 April 2023 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 March 2024 £
Unrestricted funds					
<i>General</i>					
General Funds	129,600	315,787	(251,342)	(3,096)	190,949
Chris Humphreys Memorial Fund	3,000	-	(1,407)	1,000	2,593
Conference Weekend	25,000	-	(23,951)	-	1,049
IT Equipment Fund	3,223	-	(2,178)	-	1,045
Fixed Assets	1,145	-	-	2,096	3,241
	<u>161,968</u>	<u>315,787</u>	<u>(278,878)</u>	<u>-</u>	<u>198,877</u>
Restricted funds					
Jeans 4 Genes	<u>3,078</u>	<u>-</u>	<u>(288)</u>	<u>-</u>	<u>2,790</u>
Total funds	<u>165,046</u>	<u>315,787</u>	<u>(279,166)</u>	<u>-</u>	<u>201,667</u>

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025 (continued)

Unrestricted Funds

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.

Conference Weekend

The BBS UK Conference Weekend brings together over 200 service users and interested professionals for a weekend of learning and sharing experiences.

IT Equipment Fund

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.

Fixed Assets

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

Rareminds Counselling Service

BBS UK is working with Rareminds to provide specialised counselling sessions for those with BBS, who would otherwise find it difficult to access the support needed.

Restricted Funds

Jeans 4 Genes

Funding to facilitate our work with young people

The National Lottery (Rareminds Counselling Project)

Funding for our Rareminds Counselling Service

The Eveson Trust (Transition Project)

Funding for development of transition project to support young adults as they transition to adult health care.

21 Analysis of net assets between funds

	Unrestricted funds General £	Restricted funds £	Total funds at 31 March 2025 £
Tangible fixed assets	5,137	-	5,137
Current assets	292,712	25,668	318,380
Current liabilities	<u>(20,778)</u>	<u>-</u>	<u>(20,778)</u>
Total net assets	<u>277,071</u>	<u>25,668</u>	<u>302,739</u>

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2025 (continued)

	Unrestricted funds	Restricted funds	Total funds at 31 March 2024
	General		
	£	£	£
Tangible fixed assets	3,241	-	3,241
Current assets	211,302	2,790	214,092
Current liabilities	(15,666)	-	(15,666)
Total net assets	<u>198,877</u>	<u>2,790</u>	<u>201,667</u>

22 Related party transactions

There were no related party transactions in the year.

BARDET-BIEDL SYNDROME UK (BBS UK)

England & Wales - Charity number 1181244

Accounts



TRUSTEES' REPORT AND ACCOUNTS

FOR THE YEAR ENDED 31st MARCH 2024



Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

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Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

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

Vice-Chair: Chetan Meshram

Secretary: Dianne Hand

Treasurer: Tazeem Abbas

Trustee: Liam Wilkie

Trustee: Rachael Foley

Trustee: Stefan Crocker

Trustee: Dr Shehla Mohammed

Trustee: Gareth Owens

Trustee: Azrat Mirza (Resigned 25/1/24)

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

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 over

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

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:

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

- 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

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

BBS UK has the following Information Security policies in place:

- Bring Your Own Device
- Confidentiality
- Data Protection
- Data Quality
- Data Retention and Disposal Schedule
- Data Security
- Email Use
- Facebook disclaimer
- Handling of DBS Certificate Information
- 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.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

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.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

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)

Report from the Chair of BBS UK

Laura Dowswell, Chair

Like many smaller charities, BBS UK has continued to face challenges 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, 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 Samantha Serido to the staff team, in the role of Fundraising and Communications Officer.

Azrat Mirza left the Board of Trustees and we thank him for his contribution in the time served.

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.

The Clinics Support Service Team have continued to provide excellent support to the NHS highly specialised multi-disciplinary service, and to patients attending the face to face and telemedicine clinics. Our NHS colleagues are very clear that the service could not run

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

without the work undertaken by the BBS UK team, and we were delighted to secure a further four year contract at the end of this reporting period.

There have been a number of projects undertaken during the last year, which included rebuilding the website and increasing our reach across social media platforms, both of which should help increase awareness of BBS UK's services and improve accessibility.

We supported the development of the first Patient Information Day in Ireland, with many of the team attending and forging good links with patients, families and professionals alike. We received excellent feedback, which highlighted that families really appreciated the opportunity to get together with professionals to learn more about Bardet-Biedl syndrome.

The Board of Trustees and the staff team held a two-day workshop to start the process of reviewing and updating BBS UK's strategy for 2025-2028; a working party was formed to take this forwards.

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

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

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 and reach on social media:

- Facebook Page Followers: 1026 (up 151%)
- Facebook (Closed) Group Members: 431 (up 13%)
- Instagram Followers: 228 (up 88%)
- X (Twitter) Followers: 495 (up 8%)
- LinkedIn Followers: 173 (up 41%)

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

Website management: The BBS UK website has undergone a rebuild and is now fully supported and accessible.

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 2020, demand for support from the BBS UK Advice Service has increased rapidly. This year has seen our team support **141** 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 **927** contacts to ensure that adults and children with BBS get the support that they are entitled to.

In partnership with the London Metropolitan University, the team completed their second student social worker placement, supporting a Year 1 student with a 70-day placement as part of their degree in social work.

Looking forward, the team will continue to work in partnership with the Clinics Support Service team, to support adults and families across areas such as transition, social care, and education. They will continue to form positive working relationships with local authorities, to ensure they have knowledge and understanding of Bardet-Biedl syndrome.

Clinics Support Service: Across the reporting year, the clinics support service team, logged **3022** actions/contacts for over **507** service users and provided support and facilitation services at approximately **63** clinics (virtual and face-to-face) across Birmingham and London. Our team'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.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

This year saw the introduction of an extended transition service, which included a group site visit and Q&A, followed by a social activity, to better prepare young people for their first clinic in adult services.

Patient evaluation data is also consistently high, with 97% of patients rating the information and support received as 'Good' or 'Very Good'. Comments received include:

- "I received support from BBS patient liaison officers who helped me to be open about my feelings and get the support I need physically, mentally and emotionally"
- "BBS UK team made sure that [my child] and I were informed of the clinic process. We knew exactly what time we were due to see which clinician and when we would be finished for the day. The clinic ran like clockwork, fantastic!"
- "At every step I was asked about any support needed and I am so glad about caring attitude by staff at BCH/BBS clinic."

Conference 2023: The annual family conference at the Hilton Hotel, Northampton, was a significant success:

- 231 attendees (in person)
- 166 delegates attended the formal program
- 118 registered for online participation; 58 attended
- 46-380 watched the event later via YouTube
- 24 Healthcare Professionals/Researchers attended
- 24 new families attended (highest to date)
- 23% non-white British families attended (7% in 2018)
- 94% rated their experience as very good (76%) or good (18%)
- 98% reported their reasons for attending were met:
 - Learn about research (92%)
 - Learn about available support (85%)
 - Meet others with BBS (58%)
 - Professional development (21%)

Workshops on health and wellbeing, including sessions with a dietitian, clinical psychologist, and British Blind Sports, were well received.

Regional Group Ireland: We supported our Regional Group: Ireland to organise an Information Day in Belfast in May, 2023, closely modelled on the BBS UK Annual Conference. For many, this was the first time that they had connected with others with BBS or with BBS UK, and the day enabled them to share their experiences with each other and learn more about the syndrome.

An attendee told us, "we were made to feel so welcome and seeing how it was set up, all the information available, it was brilliant. Really informative and supportive. Certainly helped us as we felt completely lost after the diagnosis but meeting everyone and seeing other families at our first conference was an absolute blessing and helped us move forward as a family "

Bardet-Biedl Syndrome UK

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A Regional Group member told us, “the regional group in Ireland has been life changing for us. When we received our daughter’s diagnosis two years ago, we knew of one other person in the country with BBS. Now, thanks to the group, we know over 30 families”.

The group are now formalising their structure, leadership board and future plans. A significant concern for the group is the difficulty that those who live in the south are having, with accessing the BBS clinics service and a key aim is to advocate for and support the development of a multi-disciplinary service in the Republic of Ireland to ensure comparable care.

Counselling Project: During the reporting period, our pilot with The Maypole Project to provide counselling sessions for those struggling with social isolation came to a close. The outcomes from this project demonstrated that there is an ongoing need for this area of support and, on the recommendation of our BBS clinics colleagues, we will be taking this forward with RareMinds, a non-profit specialising in rare disease counselling.

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.

Slimming World on Referral: Our partnership with Slimming World came to a close and, although we have been impressed with the determination and positive outcomes, take-up has been very limited and we will not be taking this project forward in the coming year.

Empower our membership to achieve

Employment: In addition to the above projects, our Advice Service team continue to evaluate 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 2023, we offered workshops with a dietitian and clinical psychologist and built a programme around the ‘Five Ways to Wellbeing’ for the children and young people in attendance, including a trip to an indoor 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.

Service User Advisory Group: We have established a Service User Advisory Group, to ensure that the voice and needs of the wider BBS community are accounted for and can directly feed into strategy and service improvements. The group meets every 2-3 months and consists of up to six BBS patients and six parents with experience of using BBS UK services.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Strengthen governance and raise our profile

We have continued growing and developing our Board of Trustees, with a focus on filling gaps identified in a skills audit. The Board now includes professional experience and skills across management/leadership, finance, project management, contract management, education, medical/genetics, human resources, and marketing/media/PR. We currently have two spaces unfilled and are seeking skills and experience as follows:

- Legal including charity law
- Marketing, media, PR
- Fundraising/funding
- Human Resources/employment legislation

We have a representative on the board of the Ciliopathy Alliance (CA) and BBS International (BBSI) and have represented the Charity at Queen Alexandra College's Sight Village, Birmingham and Retina UK Conference, London.

We attended Rare Disease Day events at St Thomas' Hospital, London and Queen Elizabeth Hospital (QEH), Birmingham, exhibiting at both and speaking with interested medical and research professionals about BBS UK and our services. It was the first event held at QEH and we were the only rare disease charity to attend, making it onto the hospital website and newsletter.

Support research and understanding of BBS

Our Scientific Advisory Board meets two to three times a year and ensures we are kept up to date with the latest scientific developments. It also provides a useful mechanism for ensuring oversight of research and pharma collaboration and feeds into relevant projects including our annual conference and the development and review of publications.

We have engaged with NICE in support of the appraisal process for Rhythm's application for Setmelanotide, completing submissions and attending meetings as required. We were delighted to see the treatment receive approval for prescribing in those aged 17 years and under and will continue working with NICE and Rhythm to support its approval for use in adults.

Our continued 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

In conclusion, the past year has been one of significant progress and achievement for BBS UK, demonstrating our commitment to the goals outlined in our three-year strategic plan. We have made positive strides in improving communication, enhancing support services, empowering our members, strengthening governance, and supporting vital research.

Our database and website development and comprehensive newsletters ensure our community stays informed and connected, and increased social media engagement have

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

improved our reach and accessibility. Our IT Equipment Project has provided the technology needed to connect socially, educationally and medically.

Our support services have grown, with the BBS UK Advice Service providing invaluable support to individuals in navigating complex systems and our clinics support team providing excellent clinic facilitation and patient support, and maintaining high levels of patient satisfaction. Successful events, such as the annual conference and regional information day, have fostered a stronger sense of community and reduced isolation.

Governance improvements have strengthened our Board of Trustees, ensuring robust oversight and strategic direction. Our involvement in professional networks and research initiatives keeps us at the forefront of scientific developments, directly benefiting our community.

Our deepest gratitude goes to our dedicated staff, trustees, and volunteers. Their collective efforts have enabled us to provide exceptional services and move forward with confidence and optimism. As we look to the future, we remain focused on continuous improvement and sustainability, ensuring we meet the evolving needs of our community.

Fundraising Review

Samantha Serido, Fundraising and Communications Officer

Introduction

The macroeconomic climate, including the cost-of-living crisis, has presented significant challenges to fundraising efforts, as reported by Charity Digital and other third-sector researchers. Despite these obstacles, most UK charities, including ours, have experienced more growth than decline in income compared to the previous year. This positive outcome is largely attributed to one exceptionally successful fundraising campaign. Additionally, we continue to benefit from multi-year, statutory funding from the National Health Service, although these funds are restricted to supporting our Clinics Support Service.

Fundraising Goals and Strategy

A primary objective for the year was to diversify income streams and develop a robust fundraising strategy to align with BBS UK's three-year strategic plan. With the addition of a new Fundraising and Communications Officer, we have made significant progress towards this goal.

We successfully formulated a comprehensive fundraising strategy for the upcoming financial year, focusing on expanding our income sources. This strategy includes developing a pipeline of grants and trusts, some of which offer multi-year funding. Such funding will be crucial for our intended expansion of our Advice Service and initiating new projects, including a Wellbeing Support Service and a Transition Support Service.

Community Fundraising

Our community has once again demonstrated immense support through various fundraising activities such as walking, running, cycling, knitting, baking, and holding quizzes. We extend our heartfelt gratitude to each participant, recognising them as BBS UK heroes. Special thanks go to those who supported the following key initiatives:

Bardet-Biedl Syndrome UK

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‘Carry the Gene’ Campaign: This BBS UK campaign united the community as participants carried the BBS gene baton from John O’Groats to Land’s End, via Scotland, England, Northern Ireland, Ireland, and Wales, emphasising activity and exercise with a fundraising target of £10K. The campaign more than surpassed expectations, raising over £80,000. It was inspiring to witness so many dedicated fundraisers – friends, family members, colleagues, and more – achieve such a remarkable feat for our community.

Friends of BBS UK: The Friends of BBS UK initiative continues to grow, generating £6,025 over the year. This reliable income stream is vital for maintaining BBS UK’s core services, which are essential to our community. Promoting this scheme remains a key focus for the coming months and years.

Pharmaceutical Industry

Maintaining cooperative relationships with industry partners, including the pharmaceutical sector, is crucial for BBS UK. These relationships are managed transparently and ethically, adhering to the guidelines of the Association of the British Pharmaceutical Industry (ABPI) and our internal policies.

We are deeply grateful to Rhythm Pharmaceuticals for their £10,000 contribution towards our annual family conference weekend, which unites families across the UK to share the latest advancements in BBS management and potential treatments from leading researchers.

Trusts and Foundations

We extend our deepest gratitude to the following organisations for their support this year:

- Lillie Johnson Charitable Trust
- The National Lottery Community Fund

Fundraising Income and Expenditure

The table below outlines the prioritised income streams for the previous financial year. Complete income figures are available in our audited accounts within this report.

2023-2024

Individual Giving/Events/Campaigns	£ 97,695.39
Gift Aid	£ 3,930.50
Regular Giving	£ 9,956.18
Grants and Trusts	£ 18,500.00
Corporate Giving (Event Funding)	£ 10,000.00
Statutory Funding	£171,107.79
Other	£ 4,596.85

Total **£315,786.71**

Impact and Future Plans

The generous support from our donors and fundraisers has enabled BBS UK to sustain its core programmes and services, significantly supporting our beneficiaries, as detailed in this report. Additionally, we have initiated steps towards registering with the Fundraising Regulator, ensuring our fundraising practices meet the highest ethical standards.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Our Heartfelt Thanks

The Bardet-Biedl Syndrome UK community continues to inspire us each year. Despite representing a relatively small population, the impact of our community members' fundraising efforts is monumental. We also extend our gratitude to the organisations that recognise and support the value of our work, contributing to supporting the best possible life outcomes for our rare-disease community.

Treasurer's Report

Tazeem Abbas, Treasurer

BBS UK's financial period runs from the 1st April 2023 – 31st March 2024.

The financial accounts are prepared on the accrual basis.

Total Charity funds as of the 31st March 2024 stand at **£201,666.46** (22-23 £165,045.11)

- Transfers of £3,096 were made during the year from the General Fund as follows:
 - £1,000 to Chris Humphreys Memorial Fund, in respect of a donation received
 - £2,096 to Fixed Assets
- General Fund stands at **£190,947.79** (22-23 £129,599.11)
 - General Fund surplus: £61,348.68
- The designated fund stands at £7,928.49 (22-23 £32,368)
- The restricted fund stands at £2,790.18 (22-22 £3,078)

The Trustees provided support from designated funds during the financial year:

- Chris Humphreys Memorial Fund: £1,407
- IT Equipment Fund: £2,178
- Annual Family Weekend and Conference: £23,951

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:

- £2,593: The Chris Humphreys Memorial Fund, to support newly diagnosed individuals and their families to access our events based on assessment of need.
- £1,049: Remaining from Annual Family Weekend and Conference to carry forward
- £1045: The IT Equipment Fund, to support access to services through means of digital technology based upon an assessment of need.
- £3,241: Fixed Assets Fund, which cannot be used to fund expenditure without being sold.

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Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

The remaining reserves of **£190,948** are held in the General fund as free reserves and represent **6.6** 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

Declaration

The Trustees approve this annual report and accounts.

Signed on behalf of the Board of Trustees:



Laura Dowswell

Position: Chair

Date: 17th October 2024

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Accounts for year ended 31st March 2024



CHARITY COMMISSION
FOR ENGLAND AND WALES

BARDET-BIEDL SYNDROME UK		Charity No	1181244	CC17a
Annual accounts for the period				
Period start date	01-Apr-23	To	Period end date	

Section A

Statement of financial activities

Recommended categories by activity	Unrestricted funds £	Restricted income funds £	Endowment funds £	Total funds £	Prior year funds £
Incoming resources (Note 3)					
Income and endowments from:					
Donations and legacies	130,082	-	-	130,082	56,265
Charitable activities	181,107	-	-	181,107	169,357
Other trading activities	2,534	-	-	2,534	3,311
Investments	664	-	-	664	13,499
Other	1,400	-	-	1,400	349
Total	315,787	-	-	315,787	242,781
Resources expended (Note 5)					
Expenditure on:					
Raising funds	1,094	-	-	1,094	3,470
Charitable activities	277,783	288	-	278,071	246,671
Total	278,878	288	-	279,165	250,141
Net income/(expenditure) before investment gains/(losses)	36,909	-	-	36,621	-
Net gains/(losses) on investments	-	288	-	-	7,360
Net income/(expenditure)	36,909	288	-	36,621	7,360
Net movement in funds	36,909	-	-	36,621	-
		288		36,621	7,360

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Reconciliation of funds:

Total funds brought forward	161,968	3,078	-	165,046	172,406
Total funds carried forward	198,877	2,790	-	201,667	165,046


Section B Balance sheet

	Unrestricted funds £	Restricted income funds £	Endowment funds £	Total this year £	Total last year £
Fixed assets					
Tangible assets (Note 10)	3,241	-	-	3,241	1,145
Total fixed assets	3,241	-	-	3,241	1,145
Current assets					
Debtors (Note 11)	19,861		-	19,861	34,378
Cash at bank and in hand (Note 12)	191,153	3,078	-	194,231	139,561
Total current assets	211,014	3,078	-	214,092	173,939
Creditors: amounts falling due within one year (Note 13)	15,666	-	-	15,666	10,038
Net current assets/(liabilities)	195,348	3,078	-	198,426	163,901
Total assets less current liabilities	198,589	3,078	-	201,667	165,046
Total net assets or liabilities	198,589	3,078	-	201,667	165,046
Funds of the Charity					
Restricted income funds (Note 14)	2,790			2,790	3,078
Unrestricted funds (Note 15)		198,877	-	198,877	161,968
Total funds	2,790	198,877	-	201,667	165,046

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Signed by one or two trustees on behalf of all the trustees

	Laura Dowswell	03/10/2024

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:

- and 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) issued on 16 July 2014
- and with*

--

 the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102)
- and with the Charities Act 2011.

The charity constitutes a public benefit entity as defined by FRS 102.*

✓

* -Tick as appropriate

1.2 Going concern

If there are material uncertainties related to events or conditions that cast significant doubt on the charity's ability to continue as a going concern, please provide the following details or state "Not applicable", if appropriate:

An explanation as to those factors that support the conclusion that the charity is a going concern;

Not applicable - There are no material uncertainties about the charity's ability to continue.

Disclosure of any uncertainties that make the going concern assumption doubtful;

Not applicable

Where accounts are not prepared on a going concern basis, please disclose this fact together with the basis on which the trustees prepared the accounts and the reason why the charity is not regarded as a going concern.

Not applicable

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

1.3 Change of accounting policy

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

Yes*	<input checked="" type="checkbox"/>	* -Tick as appropriate
No*	<input type="checkbox"/>	

Please disclose:

<i>(i) the nature of the change in accounting policy;</i>	Not applicable
<i>(ii) the reasons why applying the new accounting policy provides more reliable and more relevant information; and</i>	Not applicable
<i>(iii) the amount of the adjustment for each line affected in the current period, each prior period presented and the aggregate amount of the adjustment relating to periods before those presented, 3.44 FRS 102 SORP.</i>	Not applicable

1.4 Changes to accounting estimates

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

Yes*	<input checked="" type="checkbox"/>	* -Tick as appropriate
No*	<input type="checkbox"/>	

Please disclose:

<i>(i) the nature of any changes;</i>	Not applicable
<i>(ii) the effect of the change on income and expense or assets and liabilities for the current period; and</i>	Not applicable
<i>(iii) where practicable, the effect of the change in one or more future periods.</i>	Not applicable

1.5 Material prior year errors

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

Yes*	<input checked="" type="checkbox"/>	* -Tick as appropriate
No*	<input type="checkbox"/>	

Please disclose:

<i>(i) the nature of the prior period error;</i>	Not applicable
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Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

<i>(ii) for each prior period presented in the accounts, the amount of the correction for each account line item affected; and</i>	Not applicable
<i>(iii) the amount of the correction at the beginning of the earliest prior period presented in the accounts.</i>	Not applicable

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

This standard list of accounting policies has been applied by the charity except for those ticked "No" or "N/a". Where a different or additional policy has been adopted then this is detailed in the box below.

Recognition of income	<p>These are included in the Statement of Financial Activities (SoFA) when:</p> <ul style="list-style-type: none"> 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. 	<table border="1"> <tr> <td>Yes</td> <td>No</td> <td>N/a</td> </tr> <tr> <td style="text-align: center;">✓</td> <td></td> <td></td> </tr> </table>	Yes	No	N/a	✓		
Yes	No	N/a						
✓								
Offsetting	<p>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.</p>	<table border="1"> <tr> <td>Yes</td> <td>No</td> <td>N/a</td> </tr> <tr> <td style="text-align: center;">✓</td> <td></td> <td></td> </tr> </table>	Yes	No	N/a	✓		
Yes	No	N/a						
✓								
Grants and donations	<p>Grants and donations are only included in the SoFA when the general income recognition criteria are met (5.10 to 5.12 FRS102 SORP).</p>	<table border="1"> <tr> <td>Yes</td> <td>No</td> <td>N/a</td> </tr> <tr> <td style="text-align: center;">✓</td> <td></td> <td></td> </tr> </table>	Yes	No	N/a	✓		
Yes	No	N/a						
✓								
Legacies	<p>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). 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.</p>	<table border="1"> <tr> <td>Yes</td> <td>No</td> <td>N/a</td> </tr> <tr> <td style="text-align: center;">✓</td> <td></td> <td></td> </tr> </table>	Yes	No	N/a	✓		
Yes	No	N/a						
✓								

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Government grants	The charity has received government grants in the reporting period	Yes	No	N/a
			✓	
Tax reclaims on donations and gifts	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.	Yes	No	N/a
		✓		
Contractual income and performance related grants	This is only included in the SoFA once the charity has provided the related goods or services or met the performance related conditions.	Yes	No	N/a
		✓		
Donated services and facilities	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.	Yes	No	N/a
		✓		
	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.	Yes	No	N/a
		✓		
Support costs	The charity has incurred expenditure on support costs.	Yes	No	N/a
		✓		
Volunteer help	The value of any voluntary help received is not included in the accounts but is described in the trustees' annual report.	Yes	No	N/a
		✓		
Income from interest, royalties and dividends	This is included in the accounts when receipt is probable and the amount receivable can be measured reliably.	Yes	No	N/a
		✓		
	Membership subscriptions which gives a member the right to buy services or other benefits are recognised as income earned from the provision of goods and services as income from charitable activities.	Yes	No	N/a
		✓		
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.	Yes	No	N/a
		✓		
2.3 EXPENDITURE AND LIABILITIES				
Governance and support costs	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.	Yes	No	N/a
		✓		
	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.	Yes	No	N/a
		✓		
Deferred income	No material item of deferred income has been included in the accounts.	Yes	No	N/a
		✓		
Creditors	The charity has creditors which are measured at settlement amounts less any trade discounts	Yes	No	N/a
		✓		

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Basic financial instruments	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.	Yes	No	N/a
		✓		

2.4 ASSETS

Tangible fixed assets for use by charity

These are capitalised if they can be used for more than one year, and cost at least

They are valued at cost.

The depreciation rates and methods used are disclosed in note 10.2.

Tangible fixed assets for use by the charity are capitalised if they can be used for more than one year, and cost at least £300.

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.

Yes	No	N/a
✓		

Debtors

Yes	No	N/a
✓		

POLICIES ADOPTED ADDITIONAL TO OR DIFFERENT FROM THOSE ABOVE

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.

Note 3: Analysis of income

Analysis		Unrestricted funds	Restricted income funds	Endowment funds	Total funds £	Prior year £
Donations and legacies:	Donations and gifts	97,695	-	-	97,695	39,555
	Gift Aid	3,931	-	-	3,931	7,238
	Regular Giving	9,956	-	-	9,956	9,472
	General grants provided by government/other charities	18,500	-	-	18,500	-
	Total	130,082	-	-	130,082	56,265
Charitable activities:	Event Funding	10,000	-	-	10,000	7,000
	NHS - Commissioned Services	171,107	-	-	171,107	162,357
	Total	181,107	-	-	181,107	169,357

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Other trading activities:	Fundraising Proceeds	1,592	-	-	1,592	2,207
	Sale of Merchandise	941	-	-	941	1,104
	Total	2,534	-	-	2,534	3,311

Income from investments:	Interest income	664	-	-	664	123
	Dividend income		-	-	-	13,376
	Total	664	-	-	664	13,499

Other:	Other	1,400	-	-	1,400	349
	Total	1,400	-	-	1,400	349

TOTAL INCOME	315,787	-	-	315,787	242,781
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Note 4: Analysis of receipts of government grants

	Description	This year £
Government grant 1		-
Other		-
	Total	-

	Description	Last year £
Government grant 1		
Other		-
	Total	-

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Note 5: Analysis of expenditure

Analysis	This year				Last year			
	Un-restricted funds	Re-restricted income funds	Endowment funds	Total funds	Un-restricted funds	Re-restricted income funds	Endowment funds	Total funds
Expenditure on raising funds:				£				£
Incurring seeking donations	289	-	-	289	1,268	-	-	1,268
Advertising, marketing, direct mail and publicity		-	-	-	201	-	-	201
Other trading activities	805	-	-	805	2,001			2,001
Total expenditure on raising funds	1,094	-	-	1,094	3,470	-	-	3,470

Expenditure on charitable activities:

Advice Service	24,613	-	-	24,613	11,256	10,000	-	21,256
NHS - Commissioned Services	163,428	-	-	163,428	149,314	-	-	149,314
Events	26,357	288	-	26,645	19,968	-	-	19,968
Chris Humphreys Memorial Fund	1,407	-	-	1,407	995	-	-	995
Information Support	5,189	-	-	5,189	4,037	-	-	4,037
IT Equipment Fund	2,178	-	-	2,178	947	-	-	947
Regional Groups	7,247	-	-	7,247	1,565	-	-	1,565
Wellbeing Support Service		-	-	-	3,000	-	-	3,000
Jeans 4 Genes	-	-	-	-	-	-	-	-
Breaking Down Barriers	-	-	-	-	-	-	-	-
Support Costs (Note 6)	47,364	-	-	47,364	45,632		-	45,632
Total expenditure on charitable activities	277,783	288	-	278,071	236,714	10,000	-	246,714

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Other

		-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-
Total other expenditure	-	-	-	-	-	-	-	-
TOTAL EXPENDITURE	278,877	288	-	279,165	240,184	10,000	-	250,184

Other information:

Analysis of expenditure on charitable activities

Activity or programme	This year				Last year			
	Activities undertaken directly	Grant funding of activities	Support Costs	Total this year	Activities undertaken directly	Grant funding of activities	Support Costs	Total last year
	£	£	£	£	£	£	£	£
Advice Service	24,613	-	-	24,613	21,256	-	-	21,256
NHS - Commissioned Services	163,428			163,428	149,314			149,314
Annual Family Weekend & Conference	26,645			26,645	19,968			19,968
Chris Humphreys Memorial Fund	1,407			1,407	955			955
Information Support	5,189			5,189	4,034			4,034
IT Equipment Fund	2,178			2,178	947			947
Regional Groups	7,247			7,247	1,565			1,565
Wellbeing Support Service	-			-	3,000			3,000
Jeans 4 Genes	-			-	-			-
Breaking Down Barriers	-	-	-	-	-	-	-	-
Support Costs (Note 6)	-	-	47,364	47,364	-	-	45,632	45,632
Total	230,707	-	47,364	278,071	201,039	-	45,632	246,671

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Note 6: Support Costs

	Support Costs	Grand total 2024	Total 2023
Support cost	£	£	£
Accountancy Fees	2,672	2,672	3,479
IT security/support	1,798	1,798	2,169
Database	150	150	650
Exhibition Fees	928	928	300
Finance Fees	5,280	5,280	5,814
Governance	3,110	3,110	767
Insurance	495	495	365
Postage, Stationary, Advertising	344	344	1,795
Staff costs	26,734	26,734	26,990
Subscriptions	1,120	1,120	793
Sundry	398	398	348
Telephone	822	822	745
Travel	534	534	163
Website	1,550	1,550	416
Partial Exemption VAT disallowed	1,429	1,429	838
Other	-	-	-
Total	47,364	47,364	45,632

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

	This year £	Last year £
Independent examiner's fees	-	-
Assurance services other than audit or independent examination	-	-

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Tax advisory fees	-	-
Other fees (for example: financial advice, consultancy, accountancy services) paid to the independent examiner	2,672	3,479

Note 8: Paid employees

8.1 Staff Costs

	This year £	Last year £
Salaries and wages	167,127	155,017
Social security costs	14,331	13,625
Pension costs (defined contribution scheme)	8,642	7,368
Other employee benefits	-	-
Total staff costs	190,099	176,010

Please give details of the number of employees whose total employee benefits (excluding employer pension costs) fell within each band of £10,000 from £60,000 upwards. If there are no such transactions, please enter 'true' in the box provided.

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

0	0
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Band	Number of employees	
	This year	Last year
£60,000 to £69,999	-	-
£70,000 to £79,999	-	-
£80,000 to £89,999	-	-
£90,000 to £99,999	-	-
£100,000 to £109,999	-	-

8.2 Average head count in the year

The parts of the charity in which the employees work

	This year Number	Last year Number
Fundraising	-	-
Charitable Activities	9	10
Governance	-	-
Other	-	-
Total	9	10

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

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

Amount of contributions recognised in the SOFA as an expense

This year	Last year
£	£
8,642	7,368

Note 10: Tangible fixed assets

10.1 Cost or valuation

At the beginning of the year

Additions

Revaluations

Disposals

Transfers *

At end of the year

Fixtures, fittings and equipment	Total
£	£
1,145	1,145
2,096	2,096
-	-
-	-
-	-
3,241	3,241

10.2 Depreciation and impairments

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

**** Rate**

At beginning of the year

Disposals

Depreciation

Impairment

Transfers*

At end of the year

SL	SL
33.30%	33.30%
-	-
-	-
-	-
-	-
-	-
-	-

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
3,241	3,241

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Note 11: Debtors and prepayments

Analysis of debtors

Trade debtors

Prepayments and accrued income

Total

This year	Last year
£	£
17,867	32,893
1,994	1,485
19,861	34,378

Note 12: Cash at bank and in hand

Cash at bank and on hand

Total

This year	Last year
£	£
194,231	139,561
194,231	139,561

Note 13: Creditors and accruals

Analysis of creditors

Trade creditors

Business credit card

Taxation and social security

Total

Amounts falling due within one year		Amounts falling due after more than one year	
This year £	Last year £	This year £	Last year £
2,768	2,535	-	-
1,835	-	-	-
11,063	7,503	-	-
15,666	10,038	-	-

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Note 14: Charity funds

14 Details of material funds held and movements

Restricted Funds

Fund names	At 1st April 2023 £	Income £	Expenditure £	Transfers £	Gains and losses £	At 31st March 2024 £
Advice Service				-	-	-
Jeans 4 Genes	3,078		288	-	-	2,790
Other funds	-	-	-	-	-	-
Total Funds	3,078	-	288	-	-	2,790

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

Advice Service

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

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 2024.

Note 15: Charity funds

Details of material funds held and movements

Unrestricted Funds

Fund names	At 1st April 2023 £	Income £	Expenditure £	Transfers £	Gains and losses £	At 31st March 2024 £
General Funds	129,600	315,787	-251,342	-3,096	-	190,949
Chris Humphreys Memorial Fund	3,000		-1,407	1,000	-	2,593
Conference Weekend	25,000		-23,951		-	1,049
IT Equipment Fund	3,223		-2,178		-	1,045
Advice Service	-				-	-
Fixed Assets	1,145			2,087	-	3,232
Office Equipment				9		9
Other funds	-	-	-	-	-	-
Total Funds	161,968	315,787	- 278,878	-	-	198,877

Fund names	At 1st April 2022 £	Income £	Expenditure £	Transfers £	Gains and losses £	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
Conference Weekend	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

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.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Conference Weekend

Events includes the BBS UK conference, which brings together over 200 service users and interested professionals.

IT Equipment Fund

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

Core service set up In 2020 to support service users with accessing local health, education and social care services.

Fixed Assets

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

Note 16: Transactions with trustees and related parties

If the charity has any transactions with related parties (other than the trustee expenses explained in guidance notes) details of such transactions should be provided in this note. If there are no transactions to report, please enter "True" in the box or "False" if there are transactions to report.

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 (True or False)

TRUE

In the period the charity has paid trustees remuneration and benefits. Please give the amount of, and legal authority for, any remuneration or other benefits paid to a trustee by the charity or any institution or company connected with it.

Name of trustee	Legal authority (e.g. order, governing document)	Amounts paid or benefit value				
		Remuneration	Pension contribution	Redundancy (including loss of office)/ex gratia	Other	TOTAL
		£	£	£	£	£
		-	-	-	-	-
		-	-	-	-	-

Please give details of why remuneration or other employment benefits were paid.

Where an ex gratia payment has been made to a trustee, provide an explanation of the nature of the payment.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

Last 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 (True or False)

TRUE

In the period the charity has paid trustees remuneration and benefits. Please give the amount of, and legal authority for, any remuneration or other benefits paid to a trustee by the charity or any institution or company connected with it.

Name of trustee	Legal authority (eg order, governing document)	Amounts paid or benefit value				
		Remuneration	Pension contribution	Redundancy (including loss of office)/ex gratia	Other	TOTAL
		£	£		£	£
		-	-	-	-	-
		-	-	-	-	-

Please give details of why remuneration or other employment benefits were paid.

Where an ex gratia payment has been made to a trustee, provide an explanation of the nature of the payment.

16.2 Trustees' expenses

If the charity has paid trustees expenses for fulfilling their duties, details of such transactions should be provided in this note. If there are no transactions to report, please enter "True" in the box below. If there are transactions to report, please enter "False".

No trustee expenses have been incurred (True or False)

FALSE

Type of expenses reimbursed	This year	Last year
	£	£
Travel	438	-
Subsistence	-	-
Accommodation	-	-
TOTAL	438	-

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

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

4	
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16.3 Transaction(s) with related parties

Please give details of any transaction undertaken by (or on behalf of) the charity in which a related party has a material interest, including where funds have been held as agent for related parties. If there are no such transactions, please enter 'true' in the box provided.

This year

There have been no related party transactions in the reporting period (True or False)

TRUE

Name of the trustee or related party	Relationship to charity	Description of the transaction(s)	Amount	Balance at period end	Provision for bad debts at period end	Amounts written off during reporting period
			£	£	£	£

In relation to the transactions above, please provide the terms and conditions, including any security and the nature of any payment (consideration) to be provided in settlement.

For any related party, please provide details of any guarantees given or received.

Last year

There have been no related party transactions in the reporting period (True or False)

Name of the trustee or related party	Relationship to charity	Description of the transaction(s)	Amount	Balance at period end	Provision for bad debts at period end	Amounts written off during reporting period
			£	£	£	£

In relation to the transactions above, please provide the terms and conditions, including any security and the nature of any payment (consideration) to be provided in settlement.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2024.

For any related party, please provide details of any guarantees given or received.

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**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 year
ended** 31 MARCH 2024 **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 31/03/2024.

**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:** 15/10/2024

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 2024.

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

A large, empty rectangular box with a thin black border, intended for providing details of items that the examiner wishes to disclose. The box is currently blank.

BARDET-BIEDL SYNDROME UK (BBS UK)

England & Wales - Charity number 1181244

Accounts



TRUSTEES' REPORT AND ACCOUNTS

FOR THE YEAR ENDED 31st MARCH 2023



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Bardet-Biedl Syndrome UK

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

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

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

Bardet-Biedl Syndrome UK

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

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:

Bardet-Biedl Syndrome UK

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

- 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

Bardet-Biedl Syndrome UK

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

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.

Bardet-Biedl Syndrome UK

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

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.

Bardet-Biedl Syndrome UK

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

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.

Bardet-Biedl Syndrome UK

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

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).

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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

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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

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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	-
<i>Total fixed assets</i>	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
<i>Total current assets</i>	170,861	3,078	-	173,939	172,406
Creditors: amounts falling due within one year (Note 13)	10,038	-	-	10,038	-
<i>Net current assets/(liabilities)</i>	160,823	3,078	-	163,901	172,406
<i>Total assets less current liabilities</i>	161,968	3,078	-	165,046	172,406
<i>Total net assets or liabilities</i>	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
<i>Total funds</i>	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).

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- 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.

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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
	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.

--

BARDET-BIEDL SYNDROME UK (BBS UK)

England & Wales - Charity number 1181244

Accounts



TRUSTEES' REPORT AND ACCOUNTS

FOR THE YEAR ENDED 31st MARCH 2022



Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

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Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

Administration Details

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

Tel: 07421 312 731

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

President: Professor Philip Beales BSc LMSSA MD FRCP

Board of Trustees:

Chair: Laura Dowswell

Vice-Chair: Vacant

Secretary: Dianne Hand

Treasurer: Abbie Geeson

Trustee: Judith Aylott

Trustee: Rachael Foley

Trustee: Stefan Crocker

Trustee: Virginia Cashin (Retired 05/03/21)

Trustee: Emma Oates (Retired 13/07/21)

Trustee: Liam Wilkie (Elected: 13/07/21)

Trustee: Dr Shehla Mohammed (Elected: 13/07/21)

Trustee: Azrat Mirza (Co-opted: 23/09/21)

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 600 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

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

Trustees is responsible for the governance of the Charity. The Charity now supports around 600 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.

BBS UK Clinics Ltd is a Private Company Limited by Shares and is a wholly owned subsidiary of BBS UK.

Prior to BBS UK becoming a CIO, it was unable to trade according to the terms of its constitution. BBS UK Clinics Ltd was set up in 2010 following professional advice, and since then, the contract with NHS England to facilitate the specialist multi-disciplinary clinics has been managed through this subsidiary.

Since the Charity has become Incorporated, the Board of Trustees have reviewed whether it is necessary to continue trading via the Company, or whether it would be beneficial for the Charity to undertake its own trading, weighing up the risks, implications, and benefits of such a change.

On the 23rd September 2021, a resolution was put to the Board which was unanimously approved by the Trustees. From the 1st April 2022, the Company will cease trading and become dormant and the NHS England contract will transfer to the Charity. BBS UK will be receiving the remaining assets of the Company over the next 12 months and all employees of the Company will transfer to the Charity under TUPE (transfer of undertakings, protection of employment).

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 Service 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.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

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:

- 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
- Bring your own device
- Child Protection
- Code of Conduct
- Complaints
- Handling of DBS Certificate Information
- Health and Safety
- Lone Worker
- Management Structure
- Pay Review

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

- Conflict of Interest
- Dignity at Work
- Disciplinary
- Driving Whilst on Business
- Equal Opportunities
- Finance
- Grievance
- Reserves
- Safeguarding Vulnerable Adults
- Social Media
- Trustee Recruitment
- Volunteer
- Whistleblowing

BBS UK has the following Information Security policies in place:

- Anonymisation & Pseudonymisation Information
- Collection and Recording of Service User Data
- Confidentiality / Code of Conduct
- Data Impact Assessment Procedure
- Data Protection
- Data Retention and Disposal
- Email Use
- Handling of DBS Certificate Information
- Home Working - Handling
- Information Governance
- Information Sharing
- Information Security Reporting and Auditing
- Privacy Notice
- 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.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

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.

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.

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

The last couple of years have presented many challenges for our charity and for our community, and the BBS UK Board of Trustees and staff team have worked incredibly hard to meet those challenges. 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 during this difficult time, and to ensure we can meet those needs into the future, all within the very tough economic environment we have faced.

We have been very fortunate to be able to extend the support available with the creation of two new Assistant Patient Liaison roles and an Admin, Engagement & Events Co-ordinator role; we are delighted to welcome Laura, Shirin and Léonie to the team.

In response to the needs of our members, we developed the BBS UK Advice Service 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 have quickly shown that this is an essential core service and a primary funding focus for BBS UK.

The Clinics Team have continued to provide excellent support to the service and to patients attending the face to face and telemedicine clinics and, even during the pandemic, we have been able to access vital clinical services.

There have been a number of team projects undertaken during the last year, including the IT Equipment Fund, our partnership with Slimming World and our newly formed Regional Group in Ireland.

Last year we were unable to come together due to the pandemic and although this brought disappointment, it also brought positivity and excitement as we embraced the technology and developed a two-day online conference via the Zoom platform. The social aspect that is so enjoyed at our events was undoubtedly missing, but everyone relished the opportunity to come together. Furthermore, having the event online enabled us to reach a wider audience, including overseas delegates, local care teams, extended family members and those who would find attending the event too difficult. Conference 2022 will be held in person but we will also live-stream the event to ensure we maintain this momentum.

I hope that like my family and I, you are very much looking forward to connecting with others at this year's conference. It will be a wonderful opportunity for us to come together as a community and meet friends, both old and new.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

On behalf of the Board and also personally, I would like to offer sincere thanks, firstly to the staff team who have faced unprecedented challenges due to the pandemic but have shown resilience and commitment throughout, 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 come through the pandemic and how we will continue to grow 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, Service Manager

Introduction

Following an incredibly difficult year, 2021 proved to be equally challenging with further restrictions and 'lock-downs' increasing the anxiety and isolation of the BBS community. It became apparent that many had fragile support systems in place which did not stand up to the impact of Covid and, in this respect, the pandemic has exposed/highlighted areas of risk and safeguarding that have previously gone unnoticed. In addition to responding to the immediate needs of our community, this reporting year has been about listening to our members and understanding what will be needed going forward. We have been reviewing the work that has been undertaken to date, determining our core services and considering new and innovative ways of delivering exceptional support. During a year when many charities have cut services, we are incredibly proud to report a year of growth and development, which is in no small part thanks to having such a dedicated and committed team of trustees, staff and volunteers.

Staff Team

The impact of Covid at the beginning of 2021 was increasingly felt among the staff team, as many of them juggled their work responsibilities with home-schooling their children and caring responsibilities, as well as the many other effects of Covid. We supported our team throughout this difficult period by making use of flexible working, furlough and flexi-furlough where needed. Our approach has been rewarded with exceptional commitment and dedication from the team to the organisation and its service users. Midway through the year, we were fortunate to be able to grow our support team with the addition of Laura and Shirin. Later in the year, Léonie joined the team, working on admin, engagement and events. They have all very quickly become invaluable team members, committed to our membership and charity and we are excited to see what we can achieve together into the future.

BBS UK Advice Service

At the beginning of the reporting year we realised that our community, already struggling to access local support services, was going to need additional support because services were

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

under increasing funding pressure while facing rising demands. In response, we developed the BBS UK Advice Service to provide high quality support with accessing local services across housing, social care, benefits and education and this has quickly established itself as an essential core service and a primary funding need for BBS UK. Our Advice Service and Clinics Support Team work closely together, to ensure the best possible provision for those who need it.

BBS Specialised Clinics

The pandemic has inevitably impacted upon the NHS-funded BBS clinics service, with follow-up appointment times stretching to two years and beyond. However, the teams have adopted a hybrid approach, offering a mix of face to face and telemedicine appointments at each centre, to reduce the waiting times and improve access and attendance. Those who are still anxious about returning to a face-to-face clinic, or who find travelling to clinic too difficult, are well supported via the telemedicine service; it has also proven useful for those who are isolating or who have tested positive for Covid but are otherwise well. The BBS UK team continue to ensure high levels of attendance and provide excellent support to patients to be certain that they get the most out of each clinic appointment.

The impact of the past two years is going to be felt for some time, with local healthcare services struggling to catch up, leaving many of our community finding it difficult to access the local support they need. The BBS clinics teams have been supportive throughout, providing a much-needed point of contact and care co-ordination provision, where appropriate. Our heartfelt thanks go to the BBS teams at all four centres, for their continued dedication and commitment to our community.

Events

It was clear very early on in the year that we would be unable to resume our face to face events for the foreseeable future; however we organised a very successful two-day online conference. Day one was aimed at professionals involved in the care, support and education of those with BBS, and day two was aimed at those living with the syndrome, their families and carers. We were well supported by a wide range of professionals and experts in BBS and the programme across the two days was packed with relevant, interesting and exciting presentations that provided a sense of hope and community for us all. Feedback was overwhelmingly positive and, although we missed being able to spend time together in person, everyone enjoyed the interaction and feeling of community that was generated. Having the event online increased accessibility and enabled us to deliver to a wider audience and future events will be live-streamed. Planning for Conference 2022 is underway and will return to the Hilton, Northampton.

Publications

We reviewed and updated our 'My Life, My Future' transition handbook for young people which informs the basis of our transition work, to be developed over the coming year. We also produced a Newsletter and Conference Report, both of which are sent out in accessible formats including audio CD and email.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

Additional Projects:

The Maypole Project: Having secured an unrestricted grant at the beginning of the year, we embarked on a collaboration with The Maypole Project, developing a pilot scheme to provide counselling and support to those who are isolated and experiencing social anxiety. The programme offers six one-to-one counselling sessions, followed by group therapeutic sessions to enable participants to develop their confidence and social/communication skills, within a supportive setting. Going forward, BBS UK will work with the participants to maximise the impact of this project, ensuring that they have the local support needed to access their local communities and to make the most of their developing skills and confidence.

IT Equipment Scheme: This scheme is for those who need a computing device to support them with accessing social and educational opportunities and medical care. Our team will first assist with accessing external funding and, where this is exhausted, will go on to fund a device which may be a desk-top, lap-top or tablet.

Slimming World on Referral: BBS UK are working in collaboration with 'Slimming World on Referral' to offer 12 weeks of free membership to those diagnosed with BBS who are wishing to lose weight. Results are mixed; however many participants have lost considerable amounts of weight and are reporting improved wellbeing.

Regional Groups: BBS UK is committed to developing Regional Groups to improve local support and communication. This has commenced with the development of BBS UK: Ireland. This important work will continue during the coming year and will expand to include BBS UK: Scotland.

Collaborative Working / Raising Awareness

BBS UK are connected to many other charities and umbrella organisations, both formally and informally. Our organisation benefits from attending conferences, seminars, networking and training events, all of which enable us to raise awareness and identify opportunities for learning and collaboration. Many of these events remained online during the reporting year and we continued to make good use of them.

During the year, we have presented to the UK Cilia Network and to Genomics Masters students within their learning module. We are also represented on the Ciliopathy Alliance and BBS International boards. We benefit considerably from working with these organisations and, in particular, we have enjoyed working with our counterparts across the world in the development of BBS International; 2021 saw the very first BBS Global Day.

Research

We have supported research projects, from providing letters of support to disseminating research information and questionnaires. In support of our growing engagement in research, we attended a NICE Induction, which provided an overview of patient and public involvement in medicine appraisals at NICE. When technologies are put to NICE, all stakeholders are asked to provide a submission of evidence to enable a holistic appraisal to

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

take place. This is an area in which BBS UK, and our membership, can work together to ensure that the wider BBS voice and experience is heard and understood.

Three Year Strategy

We have reviewed our services and organisational development and finalised our three-year strategy, formalising our vision, mission and values. A key aspect informing this work is the BBS UK Membership Audit, which asked about the impact of the Syndrome and sought to understand what BBS UK can do to better support our community. The aims and objectives for the coming three years are therefore to:

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

Feedback received:

- “I am very grateful for the support I have from the liaison officer. I can call her any time and talk to her.”
- “Without the support of BBS UK, life would be more difficult.”
- “BBS UK is my second family. Thank you so, so much for all your support.”
- “From the moment we contacted the society 19 years ago, the service and support we have received has been fantastic and a lifesaver.”
- “When my son had a diagnosis of BBS it was so reassuring to have an organisation to turn to for further information, support and to meet other families who had been/were going through the same as us.”
- “BBS UK has had a positive impact on how we adjusted to my son’s diagnosis.”

Fundraising Review

Christine Saxon, Fundraising Officer

I would like to thank all of our supporters for their incredible resilience, imagination and hard work in fundraising for BBS UK over the past 15 months. Our fundraising effort has expanded so much in the past seven years, which has allowed our services and support to develop. The figures this year must be read with a cautionary note as they cover 15 months of income, due to the charity year end being extended from December to March. In addition, this year’s figures are against a diminished annual income last year following the Covid-19 pandemic and the allied restrictions on socialising. Total income this year is £154,564.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

This year we have increased our Friends of BBS UK numbers. Furthermore, several of our existing Friends have increased their donations, to bring in just under £10,000. This is regular known income, which helps BBS UK to plan for service delivery, and is vital to our overall income.

For the first time, we have attracted gifts from a variety of foundations, trusts and grants; these donations, which are a considerable addition to our other activities, have amounted to over £45,000. We are appreciative of their impact on the charitable sector throughout the pandemic, and also for the future.

Several larger fundraising events this year have collectively raised over £13,000, including a BBS UK BBQ in Northern Ireland and an equestrian event in the West Midlands. We are pleased that these larger events are now being organised and we encourage all members to share their ideas because, with help available, the more elaborate events may well be possible.

Runs, walks, garden parties, quiz nights and challenge events have all had their place in fundraising in the community for the past 15 months; two newer ideas of having a face painting stall and a nail day at a beauty salon, proved popular. Thank you to you all for your ideas, time, efforts, and commitment to raising over £38,632.

Just Giving, Paypal and Charitable Aid Foundation continue to provide a relatively easy way of allowing supporters to sponsor your ventures, as well as adding Gift Aid to the donations. Sadly, Virgin Giving, another payment platform you have used mainly for Marathon fundraising, has ceased this year, but we thank them for the way in which they have helped us to raise income in the past.

Gift Aid remains a critical part of our income, as all eligible gifts with Gift Aid bring in an extra 25p for every £1 given. On a £10 gift that is £2.50, on a £100 gift that is £25 and it costs nothing to the individual. This year, compared with the last financial year, our Gift Aid has dropped from £4,730 in a 12 month period to £2,096 in a 15 month period. Wherever possible, please continue to tick the box that says you would like us to claim Gift Aid on your gift...a tick in the box if you are eligible, what could be easier?

On a very positive note, this year we have had more donations coming in from companies. This includes employers who will match-fund the money you raise for BBS UK, employers who have a nominated Charity of the Year, and employers who will make donations through matching their employees' wages, via Payroll Giving. Keep up the excellent work by asking if your company, workplace or corporate organisation will do this; it will encourage more income, as well as spreading the word further about BBS UK.

We have recently developed a Fundraising Sub-Committee, bringing together staff and Trustees to share ideas, look at income and develop best practice within the fundraising function. I am grateful to them for their hard work and enthusiasm.

This has been a great year, where families, friends and new supporters have all combined to move BBS UK out of the pandemic into an exciting future. I have been moved by the support we have received during this particularly challenging time and look forward to writing the next report in 2023.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

Treasurer's Report

Abbie Geeson, Treasurer

BBS UK extended its financial year to incorporate 1st January 2021 – 31st March 22. Therefore, the financial accounts reflect a 15-month period.

As previously described, BBS UK Clinics Ltd, a wholly owned subsidiary of BBS UK, will become dormant and all assets will be transferred to the charity. In March 2022, BBS UK received a dividend payment from the Company from its retained capital and reserves as of the 31st March 2021 and this is reflected within the income report below and the financial accounts.

Income during this financial year was £154,564 (2020 £53,704). This includes:

- £80,468 unrestricted grants, donations and member fundraising events.
- £3,684 other income from shared costs and the HMRC Job Retention Scheme.
- £20,000 restricted grants.
- £50,412 dividend received from BBS UK Clinics Ltd.

Expenditure during this financial year was £93,539 (2020 £55,174). This includes:

- £79,874 unrestricted expenditure
- £13,664 restricted expenditure from funds previously carried forward and newly received grant spend.

The unrestricted fund had a surplus of £54,690. As of the 31st March 2022, unrestricted funds were £159,328 (2020 £104,638)

During the reporting period:

- There were no guarantees given by the CIO. (This is where a potential liability under a guarantee is outstanding at the date of the statement).
- There were no debts outstanding by the CIO. (This is money owed which would be secured by an express charge on any assets of the CIO).

Reserves Policy

Trustees regularly review the budget and the level of reserves, which are monitored on a monthly basis and reported at the quarterly board of trustee meetings.

Trustees have agreed unrestricted reserves should be sufficient to cover six months expenditure, to manage income shortfalls and to meet any unforeseen expenditure which may occur.

The total Charity funds as of the 31st March 2022 were £172,405. These are represented by restricted funds of £13,078 and designated funds of £38,125. This leaves general funds of £121,202 which is free reserves. The free reserves represent six months of expenditure.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

The purpose of the designated funds are as follows:

- The Chris Humphreys Memorial Fund £955 – This subsidy fund was set up in 2020 to support newly diagnosed individuals and their families to access our events.
- The Annual Family Weekend and Conference £24,045 is committed future expenditure. The weekend brings together over 200 diagnosed individuals and their families.
- The IT Equipment Fund £7,170 - 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.
- The Advice Service £5,955 – To support the development and growth of this new integral BBS service.

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

BBS UK relies on income from donations and fundraising events undertaken by its membership and through the Friends of BBS UK donation scheme.

The main financial risks to the charity are:

- The NHS England contract
- Failing to secure sufficient funds
- 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 Dowsell

Laura Dowsell


Position: Chair

Date: 10th June 2022

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

Accounts for year ended 31st March 2022

 CHARITY COMMISSION FOR ENGLAND AND WALES	BARDET-BIEDL SYNDROME UK (BBS UK)		1181244		CC16a
	Receipts and payments accounts				
	For the period from	1-Jan-21	To	31-Mar-22	
	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Grants	10,000	20,000		30,000	
Donations and Fundraising	58,038	-	-	58,038	39,452
Childrens Family Weekend		-	-	-	-
Adult Social Weekend Contributions		-	-	-	-
Friends Account	9,877	-	-	9,877	7,049
Annual Family Weekend Contributions	-	-	-	-	1,600
Sales of Promotional Goods/Xmas Cards	448	-	-	448	829
Gift Aid	2,096	-	-	2,096	4,730
Interest	8	-	-	8	44
Raffle/Tombola	-	-	-	-	-
Shared Costs Co.	2,080			2,080	
HMRC JRS	1,604			1,604	
BBS UK CL Dividend	50,412			50,412	
Sub total (Gross income for AR)	134,564	20,000	-	154,564	53,704
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	134,564	20,000	-	154,564	53,704
A3 Payments					
J4G Project Costs	-	1,422		1,422	2,687
BDB	-	1,514		1,514	-
Advice Services	11,870	10,438		22,308	-
Travel-Trustees	-			-	578
Accommodation	-			-	-
Childrens Family Weekend	-			-	-
Annual Family Weekend	1,381			1,381	1,314
Adult Social Weekend	-			-	-
Designated: Well Being Support Service	10,000			10,000	
IT Equipment Fund	2,830			2,830	
Publications:				-	
Newsletter 20	2,220			2,220	
Conference Report 21	3,140			3,140	
Newsletter 21	2,416			2,416	
Re-prints	-			-	
Development/Training	307			307	
AGM/Membership	360			360	
Fundraising Costs				-	
Marathon	-			-	-
Raising Funds	1,102			1,102	878
AFVS	-			-	-
Salaries	31,388			31,388	24,747
Welfare	459			459	
Clinical Supervision	300			300	
Awards for All - Admin officer	-			-	-
Equipment	816			816	2,607
Recruitment Advertising	395			395	-
Contractor: Bookkeeper	3,740			3,740	2,960
Training	111			111	

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

Printing/Tapes, Publications				-	2,110
Telephone, Postage, Stationery	1,392			1,392	1,835
Franking Machine Lease only	89			89	161
Purchase of Promotional Goods	117			117	1,843
IT Consumables				-	64
Courses				-	95
Insurance/Data Protection	709			709	772
Subscriptions	2,816			2,816	1,651
Website	863			863	
Refunds				-	-
Miscellaneous	(291)	291		-	176
Exhibitions				-	-
CRB Forms	37			37	12
Accountancy fees	1,002			1,002	2,148
Professional Fees	306			306	
Slimming World Vouchers				-	2,970
Rebrand				-	4,068
Website				-	1,498
CIO Conversion				-	-
Freelance Fundraiser				-	-
Grant Payment				-	-
Sub total	79,874	13,664	-	93,539	55,174
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	79,874	13,664	-	93,539	55,174
Net of receipts/(payments)	54,690	6,336	-	61,025	(1,470)
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	104,638	6,742	-	111,380	112,850
Cash funds this year end	159,328	13,078	-	172,405	111,380
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £	
B1 Cash funds	Cash at Bank	159,328	13,078	-	
		-	-	-	
		-	-	-	
	Total cash funds	159,328	13,078	-	
	(agree balances with receipts and payments account(s))	OK	OK	OK	

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st March 2022.

		Unrestricted funds	Restricted funds	Endowment funds
	Details	to nearest £	to nearest £	to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
		Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
		Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name		Date of approval
	<i>A Geeson</i>	Abbie Geeson		19/05/2022

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	15 Months ended 31 MARCH 2022	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 31/03/2022.

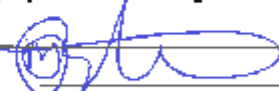
Responsibilities and basis of report As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

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:** 29/7/22

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 2022.

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

A large empty rectangular box with a thin black border, intended for providing details of items that the examiner wishes to disclose. The box is currently blank.

BARDET-BIEDL SYNDROME UK (BBS UK)

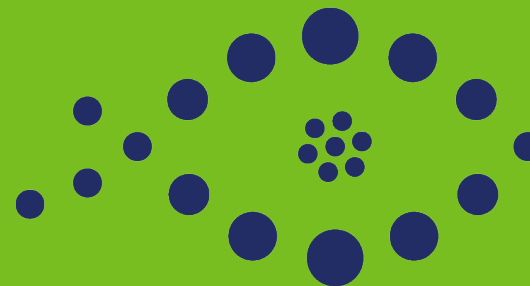
England & Wales - Charity number 1181244

Accounts



TRUSTEES' REPORT AND ACCOUNTS

FOR THE YEAR ENDED 31st DECEMBER 2020



Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

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Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

1. Administration Details

Main Address:

Bardet-Biedl Syndrome UK
43 Balton Way
Harwich
Essex
C012 4UP

Tel: 07421 312 731

Web Page: www.bbsuk.org.uk

Email: admin@bbsuk.org.uk

Bardet-Biedl Syndrome UK is a Registered Charity in England and Wales (1181244)

President: Professor Philip Beales BSc LMSSA MD FRCP

Patrons: Baroness Helena Kennedy Of the Shaws Q.C.
Ryan Jones BSc (Hons)

Bankers: Barclays Bank PLC

Independent Accounts Examiner: M. Bannister of Fryza Bannister Financials Ltd

Board of Trustees:

Chair: Stefan Crocker
Vice-Chair: Laura Dowswell
Secretary: Dianne Hand
Treasurer: Abbie Geeson
Trustee: Emma Oates
Trustee: Rachael Foley
Trustee: Judith Aylott (Co-opted: 11/03/2020)
Trustee: Virginia Cashin (Elected: 28/09/2020)
Trustee: Christian Bolton-Edenborough (Retired: 16/02/2020)

2. 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 560 diagnosed individuals known to us in the UK) can mean a delayed diagnosis and lack of adequate local health care.

3. 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 550 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.

3.1 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 the Charity 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.

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.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

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 focussed on developing governance skills, such as Safeguarding, GDPR and recruitment. 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.

4. Additional Governance Update

BBS UK/BBS UK Clinics Ltd has the following policies in place:

- Business Continuity
- Bring your own device
- Child Protection
- Code of Conduct
- Complaints
- Conflict of Interest
- Dignity at Work
- Disciplinary
- Driving Whilst on Business
- Equal Opportunities
- Finance
- Grievance
- Handling of DBS Certificate Information
- Health and Safety
- Lone Worker
- Management Structure
- Pay Review
- Reserves
- Safeguarding Vulnerable Adults
- Social Media Moderation
- Trustee Recruitment
- Volunteer
- Whistleblowing

BBS UK/BBS UK Clinics Ltd has the following Information Security policies in place:

- Collection and Recording of Service User Data
- Confidentiality / Code of Conduct
- Data Impact Assessment Procedure
- Data Protection
- Data Retention and Disposal
- Email Use
- Home Working - Handling
- Information Governance
- Information Sharing
- Information Security Reporting and Auditing
- Privacy Notice
- Subject Access Request.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

BBS UK/BBSUK Clinics Ltd has the following handbooks in place:

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

BBS UK Clinics Ltd 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 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.

4.1 How we look after and safeguard information

BBS UK and BBS UK Clinics Ltd. aim 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 and BBS UK Clinics Ltd process and store 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 and BBS UK Clinics Ltd maintain 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.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

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

5. 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.

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

1. Our Annual Family Weekend Conference which brings beneficiaries together with interested professionals and experts to provide access to the latest research and for members to participate in tailored workshops. Throughout the weekend there is the vital opportunity to connect with others and receive advice and support from the Charity, each other and external organisations.
2. Our activity breaks and trips give young people, adults and their families the chance to get away from the day-to-day challenges they face and build friendships with others in the same situation and be active.
3. Our Young People's Group and the Adult Focus Group enable and facilitate those with BBS to share their experiences in a safe environment and to have a voice that can impact change and understanding around social, emotional and health problems and the difficulties experienced day to day and within schools and work.
4. Our Adult Social group, held virtually, aims to create a friendly and inclusive environment, bringing people together, helping with social isolation and giving the opportunity for people to share experiences and form connections.
5. Our support services help with transitions through health diagnosis and progression of BBS and supporting members with accessing local support across areas of health,

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Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

education, social care and benefits etc. We encourage steps towards independence with an emphasis on empowering our young people, adults and families in ensuring they feel in control during times of rapid change.

6. The BBS UK website, www.bbsuk.org.uk, enables us to share information about Bardet-Biedl syndrome and our projects and services. Our Facebook page, Twitter and YouTube facilitate the development of an online community that self supports with members helping each other through the challenges often faced.
7. The production of twice-yearly newsletters and an annual conference report provide up to date research, information, guidance, personal perspectives and details of our projects and fundraising endeavours. We also produce a wide range of information booklets which are made available in accessible formats and different languages via our website.
8. Attendance at relevant seminars and conferences, which gives us the opportunity to learn from experts, share best practice, network and raise awareness of Bardet-Biedl syndrome.

6. BBS UK Clinics Ltd

BBS UK Clinics Ltd (company number 07257216) is a private company limited by shares and is incorporated in England and Wales. It is a wholly owned subsidiary of Bardet-Biedl Syndrome UK and is a separate legal entity, managed by its Board of Directors who are Tonia Hymers, Kevin Sales, Laura Dowswell, Abbie Geeson and Alf Pare. The Directors are responsible for the Company's day-to-day management, and all aspects of its financial accounting, employment and contracts. BBS UK Clinics Ltd reports regularly to BBS UK on its financial position and service activities.

Bardet-Biedl Syndrome UK Clinics Ltd 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:

- 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.

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Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

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 ensure they are aware of all relevant benefits and social support services. Post clinic, ongoing support and liaison services are available.

7. Chair's Report

Stefan Crocker, Chair

This year has presented the Charity with many challenges due to the Covid-19 pandemic. The Board of Trustees and staff team have worked hard to meet these challenges and through regular Zoom meetings we have managed to find new ways of supporting our members and families; this has included the recruitment of Rebecca Perfect in the capacity of Advice Officer.

I would like to thank our hardworking clinics team who have been supporting the telemedicine clinics. This has allowed new and existing patients to continue to access the clinics service. The team have done a fantastic job keeping in touch with patients and reminding them that despite the difficult circumstances there is still support available.

The Charity has ensured members have been kept up-to-date with relevant developments during the pandemic via webinars led by Professor Phil Beales, which were both informative and reassuring, offering advice from shielding through to the vaccine roll out. I would like to thank all those involved in delivering these webinars.

There have been a number of administrative projects undertaken. BBS UK has produced new leaflets and reviewed/rebranded others and distributed these to members in multiple formats. A membership survey has commenced to assess how BBS affects those diagnosed and their quality of life. It also aims to better understand how well those affected have been supported by the Charity, where the gaps are and what they would like from BBS UK in the future.

Despite there being limited opportunities to fundraise, our members have found innovative ways to help raise funds for the Charity. For this we are extremely grateful. I would like to thank our Fundraising Officer, Christine Saxon, for her hard work in seeking new ways to raise funds.

BBS UK is acutely aware that social interaction and peer support is pivotal in helping to protect the mental health of our membership. In recognition of this, the Charity has been trialling a monthly online social group which we will continue to develop over the coming months. We are optimistic about the future and are looking forward to when we will be able to resume face to face events. In the meantime, there is significant work being done to 'keep-in-touch' with our members and the virtual BBS UK conference looks set to be a success with already over 100 people confirmed to join.

8. Achievements and Performance

Tonia Hymers, Service Manager

Our support team has had a very different year responding and adapting to the Covid-19 pandemic. The first lockdown in March 2020 saw the cancellation of all planned activities including our much valued and anticipated weekend family conference and social/activity weekends which provide information, support and social contact for approximately 300 beneficiaries throughout the year. Our community, already isolated, has felt the loss of these events and has struggled enormously with the impact of Covid-19 and the shielding requirements.

The specialised BBS clinics were paused, however were quickly able to resume as a telemedicine service. Our team provided advocacy and support services to approximately 200 individuals attending approximately 30 specialised BBS clinics, either face to face or via telemedicine. The BBS clinics team at St Thomas' Rare Disease Centre said BBS UK played a 'pivotal role' in supporting the service during the lockdown period. Local healthcare services became extremely difficult to reach during the first lockdown and the BBS service provided a lifeline for those in our community who needed it, to access specialised medical support and information.

Keen to ensure the needs of our group are met, we have been proactive in engaging with patients, parents, the commissioning team and clinicians to seek out best practice for the telemedicine service. This has involved attending review meetings, organising focus groups and collecting evaluation data and this is ongoing.

8.1 Covid-19 Impact and Response

A key problem identified early on was that the information being released by the government was not easily accessible or understood by our beneficiaries who are visually impaired and many with learning difficulties. We realised that some patients were not fully aware of the restrictions and shielding guidelines and were continuing to put themselves at risk. We were also concerned that many were lacking sufficient local support.

We responded to these issues very quickly with a two-fold approach:

1. We telephoned all beneficiaries who we knew to be potentially vulnerable and/or living alone or living with older parents to support them with accessing local support services.
2. We provided our membership with easy-to-understand information, via social media, email and our website including, Covid-19 symptoms, 'What to do if you think you have Covid-19', Clinically Vulnerable and Clinically Extremely Vulnerable categories and Shielding.

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In support of this, BBS UK developed a Covid-19 Information Hub on our website to provide a focal point for all our resources. Also included in the hub were resources supporting an active lifestyle during lockdown and tips to maintain positive mental health and wellbeing.

We held several webinars to provide information about Covid-19, shielding, mental health and vaccinations. Panel members included key clinicians from the specialised BBS clinics service. Our Covid-19 webinars provided opportunities for beneficiaries to ask questions of their clinics team and also to share their own experiences of lockdown and resources/organisations that they had found useful.

During the second and third lockdowns, we continued providing relevant and timely information and support to our families. In addition, we worked with the specialised BBS clinics service to ensure our community had early access to the Covid-19 vaccination, reflecting the increased vulnerability that comes with obesity, visual impairment and learning difficulties.

With the BBS UK staff team largely working from home, the initial impact of Covid-19 was minimal. Clinics moved to telemedicine and visits to hospitals were few. Risk assessments, information and PPE were provided to all staff as needed. During the 2nd wave, the biggest impact on our team was the need for parents to provide home-schooling for their children in addition to their work. We have continued supporting our team throughout this difficult period making use of flexible working, furlough and flexi-furlough where needed.

8.2 Information Provision

BBS UK finalised its transition to a Charitable Incorporated Organisation which saw the adoption of a new logo for the first time since the Charity was established. We took the opportunity to review all of our information resources which resulted in several new publications and a redeveloped website. The following booklets are now available in print, Word and PDF:

- BBS UK Medical Information Booklet (also available in audio)
- Introducing Bardet-Biedl Syndrome (also available in audio, EasyRead, Turkish, Urdu)
- Booklet for Schools and Colleges
- My Life, My Future (Transition Handbook for Young People)
- Friends of BBS UK
- Who We Are and What We Do.

We held a webinar launching the BBS UK Booklet for Schools and Colleges, in which we outlined how the booklet and accompanying 'Student Passport' should be used and introduced our newly developed SEND/EHCP information resource. The webinar was recorded and is available on the BBS UK website.

We produced two newsletters, which included useful articles and personal perspectives focused on supporting the health and wellbeing of our beneficiaries.

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A key difficulty we have had is managing communications with our community as we have transitioned to a CIO and commenced using the CharityLog database system; for a period of time we have had to work from two different databases. This process is almost complete and will facilitate improved care and communication moving forward.

8.3 Raising Awareness and Collaboration

BBS UK are connected to many other charities and umbrella organisations, formally and informally and our organisation benefits from attending conferences, seminars, networking and training events raising awareness and seeking opportunities for learning and collaboration. The loss of these events over the past year has therefore had an impact however we have made good use of our current contacts and online platforms with the following outcomes:

- BBS UK became a founding member of Bardet-Biedl Syndrome International
- We were invited to present at a Findacure workshop
- We had an article published in SEN Magazine
- We attended virtual conferences, webinars and workshops.

8.4 Strategy Planning/Membership Audit

We have used this reporting period to review our services and organisational development and formulated a five-year strategy plan. A key aspect of this is the BBS UK Membership Audit, which asks about the impact of the Syndrome and seeks to understand what BBS UK can do to better support our community. Preliminary data will be presented at the BBS UK Conference in May 2021.

As previously described, Covid-19 has had a significant impact and we expect this to be felt across the coming five-year period. Key areas of focus will include improving communication with and easing isolation of our community; enhancing our information, advice and support provision, and empowering our membership to self-advocate.

8.5 Future Services, Events and Activities

Projects and services under development and identified as being a priority for our beneficiaries in line with the strategy, aims and objectives of the Charity include an Advice Service, Counselling/Wellbeing Support, IT Equipment Fund and Slimming World BBS UK.

The BBS UK Conference 2021 is being held via the Zoom platform across two days. Day one is aimed at professionals involved in the care, support and education of those with BBS, and day two is aimed at those living with the syndrome, their families and carers. We will all miss the invaluable social aspect that is so important to all who attend and are very much looking forward to the return of a face-to-face conference, hopefully in 2022 (providing restrictions are lifted).

We are hoping to hold a social weekend for adults living with the Syndrome and an activity weekend for families later on in the year, with a decision to be made in early summer.

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Comments Received:

“BBS UK is an excellent organisation with excellent staff and volunteers. They have given us tremendous support since diagnosis. I don't know what we would have done without BBS UK. When my son had a diagnosis of BBS it was so reassuring to have an organisation to turn to for further information, support and to meet other families who had been/were going through the same as us.”

“Had a positive impact on how we adjusted to my son's diagnosis.”

“BBS UK have been, as always very supportive, especially during lockdowns”.

“The support I have received since being diagnosed with BBS has been brilliant.”

“Superb liaison and made us feel prepared for our stay (at clinic).”

“Brilliant support. Fabulous team of people...”.

9. Fundraising Review

Christine Saxon, Fundraising Officer

We should like to start the report with a huge “Thank-you” to all the members, staff, and Trustees for making such a huge effort this year in what has been unprecedented conditions for fundraising.

Donations and general fundraising in 2020 were unsurprisingly down on last year, due to lockdowns, shielding and travel restrictions cancelling most community events in the year. This has temporarily halted the rise in income over the last five years. We hope to get back on track in 2021 using a five-year plan for growth and development.

Grants and Trust income has been understandably quick to cover the frontline emergency Covid response and therefore income from this source has been hard to access for BBS UK, however we are extremely grateful to several Trusts who have supported BBS UK this year who prefer to remain unnamed.

Looking at the income in more detail, Just Giving proved to be the greatest source of fundraising with contributions from many individuals completing the 2.6 Challenge in April, and a host of ‘virtual’ events through the year bringing in over £16,000. £15,000 came in general donations bolstered by an incredible Lady Golf Captains adoption, for which we are very grateful.

Virgin Money brought us over £4,000 through the efforts of Tom Horn, our Marathon Runner, who endured interrupted training routines, finally running a solo event in the Autumn.

Gift Aid raised over £4,000 so it is always worth helping to increase your donations, if eligible, by signing a declaration in our favour. We cannot forget the rainiest August ever when the inaugural ‘BBS Big Barbeque’ was supported by a few hardy souls and their

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families, but we shall give it another try in 2021. More successful was the Christmas card initiative, which raised over £800, thanks to your support. This is also to be repeated in 2021 as a new stream of income.

However, it does not have to be large amounts: individuals making regular donations through our Friends of BBS UK have helped us to raise over £7,000 this year and increasingly regular monthly giving is seen to provide the Charity with regular sustainable funds that we can plan our services on. 2020 has shown how general income can rise and fall dependant on external forces, so £10 per month regularly pledged would provide BBS UK with £120 per year, and with Gift Aid this would become a donation of £150. We are needing this financial security now, to minimise the risk to our charity. Please join as a Friend this year.

Last year's trend of our families raising more by working together, using their contacts, speaking to friends and work colleagues and through networking has continued and it is encouraging that newly diagnosed patients and their families have shown an interest in raising funds in this way. In our fundraising plans we are looking at developing regional support groups, a logical step forward to engage more with local and regional sources of funding.

In conclusion, we are looking forward with renewed vigour as 2021 unlocks and our thanks go to everyone who has kept us posted about their networking and fundraising activities. We love sharing your events and achievements through our social media outlets, newsletters, and website, because you inspire and encourage others to follow your lead.

10. Treasurer's Report

Abbie Geeson, Treasurer

The Unincorporated Charity, Bardet-Biedl Syndrome UK (1027384) and the Charitable Incorporated Organisation (1181244) was entered into the Charity Commission register of mergers on the 23/12/2020, therefore the 2020 annual accounts and the finance review represents both charities and are consolidated accounts. During the reporting period BBS UK, CIO (1181244) received the remaining assets of BBS UK (1027384).

Income during 2020 was £53,704 compared to £101,078 in 2019, a decrease of 47%. This decrease is attributed to the Covid-19 pandemic and the reduction of event contributions, general donations and donations received from fundraising events.

Expenditure during 2020 which included restricted expenditure from funds previously carried forward, was £55,174 compared to £104,976 in 2019, a decrease of 47%. This decrease is attributed to the Covid-19 pandemic and the cancellation of BBS UK events held throughout the year.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

The unrestricted fund had a surplus of £1,216 at year end. As of the 31st December 2020 unrestricted funds were £104,637 and restricted funds were £6,742.

During the reporting period there were:

- No particulars of any guarantee given by the CIO, where potential liability under the guarantee is outstanding at the date of the statement.
- No particulars of any debt outstanding at the date of the statement which is owed by the CIO and which is secured by an express charge on any assets of the CIO.

10.1 Management of risk

BBS UK relies on income from donations and fundraising events undertaken by its membership and through the Friends of BBS UK donation scheme. The main financial risks to the charity are:

- Failing to secure sufficient funds
- Loss of income from reduced donations
- The loss of key personnel
- The Covid-19 pandemic

Throughout 2020 the budget and reserve levels were monitored on a monthly basis and reported to trustees at the quarterly board of trustee meetings. This was established practice but due to the pandemic, the principal risks to the charity and the unstable financial situation did have an impact of income during the reporting period and measures were taken to minimise the risks and the impact to our beneficiaries and services.

10.2 BBS UK Policy on Reserves

Trustees regularly review the level of reserves and have agreed unrestricted reserves should be sufficient to cover six months expenditure to manage income shortfalls and to meet any unforeseen expenditure which may occur.

The Charity funds as of the 31st December 2020 were £111,380. These are represented by restricted funds of £6,742 and designated funds of £20,955. This leaves general funds of £83,683 which is free reserves.

The purpose of the designated funds are as follows:

- The Chris Humphreys Memorial Fund: £955 – This subsidy fund was set up in 2020 to support newly diagnosed individuals and their families to access our events.
- The Annual Family Weekend and Conference: £20,000 is committed future expenditure. The weekend brings together over 200 diagnosed individuals and their families.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

The free reserves represent 8.5 months of expenditure. The excess reserves held is due to the review of previously designated funds set aside which will now be allocated to meet the shortfall of income forecasted in early 2021. This will bring reserves into line with the minimum reserves required of 6 months expenditure by May 2021.

10.3 Going Concern

Going concern has been reviewed in light of the uncertainty relating to COVID-19. There are no material uncertainties about the Charity's ability to continue. The financial position is reviewed on a month-by-month basis, and should this situation change then the Trustees would take the appropriate steps.

11. Declaration

The Trustees declare that they have approved the 2020 Annual Report

Signed on behalf of the Board of Trustees

Stefan Crocker


Position: Chair

Date: 23/04/21

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

12. Accounts for year ended 31st December 2020.

 CHARITY COMMISSION FOR ENGLAND AND WALES		BARDET-BIEDL SYNDROME UK (BBS UK)		1181244		CC16a
		Receipts and payments accounts				
For the period from		01-Jan-20	To	31-Dec-20		
A1 Receipts						
Donations and Fundraising	39,452	-	-	39,452	74,002	
Childrens Family Weekend	-	-	-	-	1,971	
Adult Social Weekend Contributions	-	-	-	-	5,076	
Friends Account	7,049	-	-	7,049	7,146	
Annual Family Weekend Contributions	1,600	-	-	1,600	2,105	
Sales of Promotional Goods/Xmas Cards	829	-	-	829	964	
Gift Aid	4,730	-	-	4,730	7,679	
Interest	44	-	-	44	92	
Raffle/Tombola	-	-	-	-	2,043	
Sub total (Gross income for AR)	53,704	-	-	53,704	101,078	
A2 Asset and investment sales, (see table).						
	-	-	-	-	-	
Sub total	-	-	-	-	-	
Total receipts	53,704	-	-	53,704	101,078	
A3 Payments						
J4G Project Costs	-	2,687	-	2,687	2,760	
BDB	-	-	-	-	177	
Travel-Trustees	578	-	-	578	1,881	
Accommodation	-	-	-	-	663	
Childrens Family Weekend	-	-	-	-	4,795	
Annual Family Weekend	1,314	-	-	1,314	13,665	
Adult Social Weekend	-	-	-	-	9,491	
Fundraising Costs	-	-	-	-	906	
Marathon	-	-	-	-	142	
Raising Funds	878	-	-	878	144	
AFVS	-	-	-	-	144	
Salaries	24,747	-	-	24,747	7,944	
Awards for All - Admin officer	-	-	-	-	8,985	
Equipment	2,607	-	-	2,607	1,871	
Recruitment Advertising	-	-	-	-	299	
Contractor: Bookkeeper	2,960	-	-	2,960	2,135	
Printing/Tapes, Publications	2,110	-	-	2,110	1,901	
Telephone, Postage, Stationery	1,835	-	-	1,835	1,516	
Franking Machine Lease only	161	-	-	161	186	
Purchase of Promotional Goods	1,843	-	-	1,843	1,330	
IT Consumables	64	-	-	64	61	
Courses	95	-	-	95	151	
Insurance/Data Protection	772	-	-	772	300	
Subscriptions	1,651	-	-	1,651	567	
Refunds	-	-	-	-	114	
Miscellaneous	176	-	-	176	-	
Exhibitions	-	-	-	-	625	
CRB Forms	12	-	-	12	96	
Accountancy fees	2,148	-	-	2,148	-	
Slimming World Vouchers	2,970	-	-	2,970	-	
Rebrand	4,068	-	-	4,068	-	
Website	1,498	-	-	1,498	-	
CIO Conversion	-	-	-	-	1,222	
Freelance Fundraiser	-	-	-	-	225	
Grant Payment	-	-	-	-	40,824	
Sub total	52,487	2,687	-	55,174	104,976	
A4 Asset and investment purchases, (see table)						
	-	-	-	-	-	
Sub total	-	-	-	-	-	
Total payments	52,487	2,687	-	55,174	104,976	
Net of receipts/(payments)	1,217	(2,687)	-	(1,470)	(3,898)	
A5 Transfers between funds	-	-	-	-	-	
A6 Cash funds last year end	103,421	9,429	-	112,850	116,748	
Cash funds this year end	104,638	6,742	-	111,380	112,850	

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Cash at Bank	104,638	6,742	-
		-	-	-
		-	-	-
	Total cash funds	104,638	6,742	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
	<i>A J Geeson</i>	A J Geeson	20/05/2021	

13. Independent Examiner's 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 year
ended** 31 DECEMBER 2020 **Charity no
(if any)** 1181244

Set out on pages 9 TO 15 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 year ended 31/12/2019.

**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:** 7/6/2021

Name: MICHAEL BANNUSTER

**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 December 2020.

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