



# TRUSTEES' REPORT AND ACCOUNTS

FOR THE YEAR ENDED 31<sup>st</sup> MARCH 2024



## **Bardet-Biedl Syndrome UK**

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

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## **Bardet-Biedl Syndrome UK**

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

### **Administration Details**

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

**Web:** [www.bbsuk.org.uk](http://www.bbsuk.org.uk)

**Email:** [admin@bbsuk.org.uk](mailto: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**

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### **Bardet-Biedl Syndrome**

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

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

### **Vision, Mission, Values**

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

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

#### **Values:**

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

### **Structure, Governance and Management**

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

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

### **Trustees**

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

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

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

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

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

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

### **BBS Clinics NHS Contract**

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

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

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

## **Additional Governance**

### **Policies and Procedures**

BBS UK has the following policies in place:

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

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BBS UK has the following Information Security policies in place:

- Bring Your Own Device
- Confidentiality
- Data Protection
- Data Quality
- Data 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.

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### **How we look after and safeguard information**

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

BBS UK processes and stores information in accordance with:

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

BBS UK maintains compliance via:

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

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

## **Objectives and Activities**

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

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

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



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

- BBS Clinic Support Team providing support, facilitation and advocacy services to NHS multi-disciplinary clinics.
- Advice Service supporting members with accessing local support across the areas of health, education, social care and benefits.
- Information booklets available in multiple formats, including:
  - Medical Information Booklet
  - Introducing Bardet-Biedl Syndrome
  - Booklet for Schools and Colleges
  - My Life, My Future (Transition Handbook)
  - Who We Are and How We Can Help
- Annual family conference weekend bringing beneficiaries together with interested professionals and experts, to provide access to the latest research and to participate in tailored workshops.
- BBS UK website: [www.bbsuk.org.uk](http://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

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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

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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

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### **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**

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**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.

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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 "

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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.

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### **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

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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

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### **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:

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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
<b>Total</b>	<b>£315,786.71</b>

## 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.



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### 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

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

The financial accounts are prepared on the accrual basis.

Total Charity funds as of the 31<sup>st</sup> 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.

## **Bardet-Biedl Syndrome UK**

Report of the Trustees and Statement of Financial Activities for the year ended 31<sup>st</sup> 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: 17<sup>th</sup> October 2024

## Bardet-Biedl Syndrome UK

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

### Accounts for year ended 31<sup>st</sup> 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 £
<b>Incoming resources (Note 3)</b>					
<b>Income and endowments from:</b>					
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
<b>Total</b>	<b>315,787</b>	<b>-</b>	<b>-</b>	<b>315,787</b>	<b>242,781</b>
<b>Resources expended (Note 5)</b>					
<b>Expenditure on:</b>					
Raising funds	1,094	-	-	1,094	3,470
Charitable activities	277,783	288	-	278,071	246,671
<b>Total</b>	<b>278,878</b>	<b>288</b>	<b>-</b>	<b>279,165</b>	<b>250,141</b>
<b>Net income/(expenditure) before investment gains/(losses)</b>	<b>36,909</b>	<b>-</b>	<b>-</b>	<b>36,621</b>	<b>-</b>
Net gains/(losses) on investments	-	-	-	-	-
<b>Net income/(expenditure)</b>	<b>36,909</b>	<b>288</b>	<b>-</b>	<b>36,621</b>	<b>7,360</b>
<b>Net movement in funds</b>	<b>36,909</b>	<b>-</b>	<b>-</b>	<b>36,621</b>	<b>7,360</b>

## Bardet-Biedl Syndrome UK

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

### Reconciliation of funds:

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


## Section B Balance sheet

	Unrestricted funds £	Restricted income funds £	Endowment funds £	Total this year £	Total last year £
<b>Fixed assets</b>					
Tangible assets (Note 10)	3,241	-	-	3,241	1,145
<b>Total fixed assets</b>	<b>3,241</b>	<b>-</b>	<b>-</b>	<b>3,241</b>	<b>1,145</b>
<b>Current assets</b>					
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
<b>Total current assets</b>	<b>211,014</b>	<b>3,078</b>	<b>-</b>	<b>214,092</b>	<b>173,939</b>
Creditors: amounts falling due within one year (Note 13)	15,666	-	-	15,666	10,038
<b>Net current assets/(liabilities)</b>	<b>195,348</b>	<b>3,078</b>	<b>-</b>	<b>198,426</b>	<b>163,901</b>
<b>Total assets less current liabilities</b>	<b>198,589</b>	<b>3,078</b>	<b>-</b>	<b>201,667</b>	<b>165,046</b>
<b>Total net assets or liabilities</b>	<b>198,589</b>	<b>3,078</b>	<b>-</b>	<b>201,667</b>	<b>165,046</b>
<b>Funds of the Charity</b>					
Restricted income funds (Note 14)	2,790			2,790	3,078
Unrestricted funds (Note 15)		198,877	-	198,877	161,968
<b>Total funds</b>	<b>2,790</b>	<b>198,877</b>	<b>-</b>	<b>201,667</b>	<b>165,046</b>

**Bardet-Biedl Syndrome UK**

Report of the Trustees and Statement of Financial Activities for the year ended 31<sup>st</sup> 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 31<sup>st</sup> 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*	✓	* -Tick as appropriate
No*		

**Please disclose:**

<b><i>(i) the nature of the change in accounting policy;</i></b>	<b>Not applicable</b>
<b><i>(ii) the reasons why applying the new accounting policy provides more reliable and more relevant information; and</i></b>	<b>Not applicable</b>
<b><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></b>	<b>Not applicable</b>

### 1.4 Changes to accounting estimates

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

Yes*	✓	* -Tick as appropriate
No*		

**Please disclose:**

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

### 1.5 Material prior year errors

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

Yes*	✓	* -Tick as appropriate
No*		

**Please disclose:**

<b><i>(i) the nature of the prior period error;</i></b>	<b>Not applicable</b>
---	-----------------------

## Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31<sup>st</sup> 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>	<b>Not applicable</b>
<i>(iii) the amount of the correction at the beginning of the earliest prior period presented in the accounts.</i>	<b>Not applicable</b>

### 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.*

<b>Recognition of income</b>	<p>These are included in the Statement of Financial Activities (SoFA) when:</p> <ul style="list-style-type: none"> <li>the charity becomes entitled to the resources;</li> <li>it is more likely than not that the trustees will receive the resources; and</li> <li>the monetary value can be measured with sufficient reliability.</li> </ul>	<table border="1"> <thead> <tr> <th>Yes</th> <th>No</th> <th>N/a</th> </tr> </thead> <tbody> <tr> <td style="text-align: center;">✓</td> <td></td> <td></td> </tr> </tbody> </table>	Yes	No	N/a	✓		
Yes	No	N/a						
✓								
<b>Offsetting</b>	<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"> <thead> <tr> <th>Yes</th> <th>No</th> <th>N/a</th> </tr> </thead> <tbody> <tr> <td style="text-align: center;">✓</td> <td></td> <td></td> </tr> </tbody> </table>	Yes	No	N/a	✓		
Yes	No	N/a						
✓								
<b>Grants and donations</b>	<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"> <thead> <tr> <th>Yes</th> <th>No</th> <th>N/a</th> </tr> </thead> <tbody> <tr> <td style="text-align: center;">✓</td> <td></td> <td></td> </tr> </tbody> </table>	Yes	No	N/a	✓		
Yes	No	N/a						
✓								
<b>Legacies</b>	<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"> <thead> <tr> <th>Yes</th> <th>No</th> <th>N/a</th> </tr> </thead> <tbody> <tr> <td style="text-align: center;">✓</td> <td></td> <td></td> </tr> </tbody> </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 31<sup>st</sup> March 2024.

<b>Government grants</b>	The charity has received government grants in the reporting period	Yes	No	N/a
			✓	
<b>Tax reclaims on donations and gifts</b>	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
		✓		
<b>Contractual income and performance related grants</b>	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
		✓		
<b>Donated services and facilities</b>	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
		✓		
<b>Support costs</b>	The charity has incurred expenditure on support costs.	Yes	No	N/a
		✓		
<b>Volunteer help</b>	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
		✓		
<b>Income from interest, royalties and dividends</b>	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
		✓		
<b>Settlement of insurance claims</b>	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
		✓		
<b>2.3 EXPENDITURE AND LIABILITIES</b>				
<b>Governance and support costs</b>	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
		✓		
<b>Deferred income</b>	No material item of deferred income has been included in the accounts.	Yes	No	N/a
		✓		
<b>Creditors</b>	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 31<sup>st</sup> March 2024.

<b>Basic financial instruments</b>	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 £
<b>Donations and legacies:</b>	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	-
	<b>Total</b>	130,082	-	-	130,082	56,265
<b>Charitable activities:</b>	Event Funding	10,000	-	-	10,000	7,000
	NHS - Commissioned Services	171,107	-	-	171,107	162,357
	<b>Total</b>	181,107	-	-	181,107	169,357

## Bardet-Biedl Syndrome UK

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

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

<b>Income from investments:</b>	Interest income	664	-	-	664	123
	Dividend income		-	-	-	13,376
	<b>Total</b>	664	-	-	664	13,499

<b>Other:</b>	Other	1,400	-	-	1,400	349
	<b>Total</b>	1,400	-	-	1,400	349

<b>TOTAL INCOME</b>	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		-
	<b>Total</b>	-

	Description	Last year £
Government grant 1		
Other		-
	<b>Total</b>	-

## Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31<sup>st</sup> 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
<b>Expenditure on raising funds:</b>				£				£
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
<b>Total expenditure on raising funds</b>	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
<b>Total expenditure on charitable activities</b>	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 31<sup>st</sup> March 2024.

### Other

		-	-	-	-	-	-	-
	-	-	-	-	-	-	-	-
<b>Total other expenditure</b>	-	-	-	-	-	-	-	-
<b>TOTAL EXPENDITURE</b>	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
<b>Total</b>	<b>230,707</b>	<b>-</b>	<b>47,364</b>	<b>278,071</b>	<b>201,039</b>	<b>-</b>	<b>45,632</b>	<b>246,671</b>

## Bardet-Biedl Syndrome UK

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

### Note 6: Support Costs

	<b>Support Costs</b>	<b>Grand total 2024</b>	<b>Total 2023</b>
<b>Support cost</b>	<b>£</b>	<b>£</b>	<b>£</b>
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	-	-	-
<b>Total</b>	<b>47,364</b>	<b>47,364</b>	<b>45,632</b>

### 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

	<b>This year £</b>	<b>Last year £</b>
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 31<sup>st</sup> 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	-	-
<b>Total staff costs</b>	<b>190,099</b>	<b>176,010</b>

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	-	-
<b>Total</b>	<b>9</b>	<b>10</b>

## Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31<sup>st</sup> 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**

<b>This year</b>	<b>Last year</b>
<b>£</b>	<b>£</b>
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

<b>Fixtures, fittings and equipment</b>	<b>Total</b>
<b>£</b>	<b>£</b>
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

<b>SL</b>	<b>SL</b>
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 31<sup>st</sup> 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 31<sup>st</sup> 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
<b>Other funds</b>	-	-	-	-	-	-
<b>Total Funds</b>	<b>3,078</b>	<b>-</b>	<b>288</b>	<b>-</b>	<b>-</b>	<b>2,790</b>

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
<b>Other funds</b>	-	-	-	-	-	-
<b>Total Funds</b>	<b>13,078</b>	<b>-</b>	<b>-10,000</b>	<b>-</b>	<b>-</b>	<b>3,078</b>

##### 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 31<sup>st</sup> 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
<b>Other funds</b>	-	-	-	-	-	-
<b>Total Funds</b>	<b>161,968</b>	<b>315,787</b>	<b>- 278,878</b>	<b>-</b>	<b>-</b>	<b>198,877</b>

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
<b>Total Funds</b>	<b>159,328</b>	<b>242,781</b>	<b>-240,141</b>	<b>-</b>	<b>-</b>	<b>161,968</b>

##### 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 31<sup>st</sup> 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.*

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## Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31<sup>st</sup> 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	-	-
<b>TOTAL</b>	438	-

**Bardet-Biedl Syndrome UK**

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

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

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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.*

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**Bardet-Biedl Syndrome UK**

Report of the Trustees and Statement of Financial Activities for the year ended 31<sup>st</sup> 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 31<sup>st</sup> 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.