

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  
Chelmsford 2  
Leicester  
LE87 2BB

# **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](http://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:

<b>Facebook Page Followers:</b>	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
<b>Total Income</b>	<b>£ 185,454</b>

## **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.

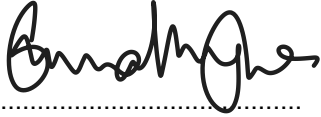
The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008, 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 .....<sup>23/9/25</sup> 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: 3<sup>rd</sup> 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 £
<b>Income and Endowments from:</b>					
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>
<b>Expenditure on:</b>					
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
<b>Reconciliation of funds</b>					
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 £
<b>Fixed assets</b>			
Tangible assets	15	5,137	3,241
<b>Current assets</b>			
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
<b>Creditors: Amounts falling due within one year</b>	18	<u>(20,778)</u>	<u>(15,666)</u>
<b>Net current assets</b>		<u>297,602</u>	<u>198,426</u>
<b>Net assets</b>		<u>302,739</u>	<u>201,667</u>
<b>Funds of the Charity:</b>			
<b>Restricted income funds</b>			
Restricted funds		25,668	2,790
<b>Unrestricted income funds</b>			
Unrestricted funds		<u>277,071</u>	<u>198,877</u>
<b>Total funds</b>	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 on ....23/9/25..... 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:

<b>Asset class</b>	<b>Depreciation method and rate</b>
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

	<b>Unrestricted funds General £</b>	<b>Restricted funds £</b>	<b>Total 2025 £</b>
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>

	<b>Unrestricted funds General £</b>	<b>Total 2024 £</b>
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

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

	<b>Unrestricted funds General £</b>	<b>Total 2024 £</b>
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

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

#### 5 Investment income

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

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

#### 6 Other income

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

	<b>Unrestricted funds General £</b>	<b>Total 2024 £</b>
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

	<b>Unrestricted funds General £</b>	<b>Total 2025 £</b>
Donations expenses	<u>433</u>	<u>433</u>

	<b>Unrestricted funds General £</b>	<b>Total 2024 £</b>
Donations expenses	<u>289</u>	<u>289</u>

##### b) Costs of trading activities

	<b>Unrestricted funds General £</b>	<b>Total 2025 £</b>
Other trading activities	<u>1,486</u>	<u>1,486</u>

	<b>Unrestricted funds General £</b>	<b>Total 2024 £</b>
Other trading activities	<u>805</u>	<u>805</u>

## Bardet-Biedl Syndrome UK

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

#### 8 Expenditure on charitable activities

	<b>Note</b>	<b>Unrestricted funds General £</b>	<b>Restricted funds £</b>	<b>Total 2025 £</b>
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>

	<b>Note</b>	<b>Unrestricted funds General £</b>	<b>Restricted funds £</b>	<b>Total 2024 £</b>
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:

	<b>2025</b>
	<b>£</b>
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:

	<b>2025</b>	<b>2024</b>
	<b>£</b>	<b>£</b>
<b>Staff costs during the year were:</b>		
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:

	<b>2025</b>	<b>2024</b>
	<b>No</b>	<b>No</b>
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

	<b>2025</b>	<b>2024</b>
	<b>£</b>	<b>£</b>
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 £
<b>Cost</b>		
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>
<b>Depreciation</b>		
Charge for the year	2,562	2,562
At 31 March 2025	<u>2,562</u>	<u>2,562</u>
<b>Net book value</b>		
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 £
<b>Unrestricted funds</b>					
<b>General</b>					
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>
<b>Restricted funds</b>					
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 £
<b>Total funds</b>	<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 £
<b>Unrestricted funds</b>					
<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	<u>1,145</u>	<u>-</u>	<u>-</u>	<u>2,096</u>	<u>3,241</u>
	161,968	315,787	(278,878)	-	198,877
<b>Restricted funds</b>					
Jeans 4 Genes	<u>3,078</u>	<u>-</u>	<u>(288)</u>	<u>-</u>	<u>2,790</u>
<b>Total funds</b>	<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**

	<b>Unrestricted funds General £</b>	<b>Restricted funds £</b>	<b>Total funds at 31 March 2025 £</b>
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 General £	Restricted funds £	Total funds at 31 March 2024 £
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.