

Charity registration number: 1181244



Bardet-Biedl Syndrome UK

Annual Report and Financial Statements

for the Year Ended 31 March 2026



Bardet-Biedl Syndrome UK

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Bardet-Biedl Syndrome UK

Reference and Administrative Details

Trustees:

Emma Hughes, Chair
Chetan Meshram, Vice Chair
Dianne Hand, Secretary
Tazeem Abbas, Treasurer (resigned 8 November 2025)
Liam Wilkie
Rachael Zimbler
Dr Shehla Mohammed
Gareth Owens
Bilal Ali
Natasha Murray (appointed 13 November 2025)

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 2026.

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 BBS 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 BBS.

Values:

- **Committed and Passionate:** We are committed and passionate about supporting and empowering those affected by BBS to achieve the best possible outcomes.
- **Inclusive and Community Minded:** We value diversity and ensure our services are inclusive and accessible to everyone in the BBS community.
- **Experienced and Understanding:** The voice of our community is at the heart of our work. We use our deep experience and understanding of BBS and its impact to inform our services.
- **Positive and Forward Looking:** We maintain a positive attitude towards challenges, and stride forwards with optimism and open to opportunity.
- **Collaborative:** We actively seek opportunities to connect, engage and partner with others, nationally and internationally, sharing best practices to enhance our work and strengthen our impact.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

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.

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 Chief Executive Officer, with their onboarding supported by an induction process.

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 charity's service users, and ensures that 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.

Day-to-day operations are delegated to staff. The charity has appointed a Data Protection Officer (DPO) to support compliance with data protection legislation and information governance.

NHS Contract

Bardet-Biedl Syndrome UK holds a contract with NHS England to support the delivery of specialist multi-disciplinary clinics at Great Ormond Street Hospital and St Thomas' Hospital in London, and Birmingham Children's Hospital and Queen Elizabeth Hospital in Birmingham.

Through this contract, the charity works to:

- Maximise access to NHS services for patients with Bardet-Biedl syndrome (BBS)
- Provide emotional and practical support, including advocacy, to patients and their families

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

- Deliver information and guidance to support health, wellbeing and quality of life

Support is provided before, during and after clinic appointments, including assistance with travel and accommodation where needed. BBS UK has a presence at each clinic, offering practical and emotional support, and helping patients and families to access relevant benefits and wider support services. Ongoing support and liaison are also available following clinic appointments.

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). We have produced our first Carbon Reduction Plan, establishing a baseline footprint, covering homeworking and essential travel by our remote team.

From this we will develop 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

The charity maintains appropriate policies and procedures to support its operations and ensure good governance. These include:

- Safeguarding
- Data Protection / GDPR
- Health & Safety
- Equality, Diversity and Inclusion
- Financial Controls / Finance Policy
- Information Governance / Confidentiality
- Complaints Policy

Additional quality assurances

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.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Key staff have undertaken **Safer Recruitment** training, and 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 governing board.

How we look after and safeguard information

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

BBS UK processes and stores information in accordance with:

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

BBS UK maintains compliance via:

- Established and routinely maintained policies and procedures for the effective and secure management of information assets and resources
- Regular 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.

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.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

- 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

Report from the Chair of BBS UK

Emma Hughes,

It is my privilege to present this year's Chair's Report for BBS UK.

As a small, user-led charity, we continue to provide vital support to individuals and families affected by Bardet-Biedl syndrome across the UK. This year has been one of significant progress. Alongside delivering the high-quality support our community relies upon every day, we have invested in strengthening the charity for the future through service development, improved governance, a new organisational strategy and a renewed focus on long-term sustainability.

Demand for our services remains high, reflecting both the complexity of Bardet-Biedl syndrome and the increasing need for specialist advice, advocacy and emotional support. I am incredibly proud of the professionalism, compassion and commitment shown by our staff team, who continue to deliver outstanding support while responding to growing demand and increasingly complex needs.

During the year we have strengthened our service offer, including expanding our Advice Service, developing our specialist counselling provision with Rareminds, and continuing to enhance our Clinics Support Service. These services remain at the heart of our work, ensuring that individuals and families feel informed, supported and empowered before, during and after their NHS appointments.

We have also continued to invest in bringing our community together through online groups, educational events and our annual conference. Opportunities to connect with others who understand the realities of living with BBS remain one of the most valued aspects of our work and play an important role in reducing isolation and improving wellbeing.

This year also marked the launch of our new 2025–2030 Strategy, providing a clear and ambitious roadmap for the future. The strategy builds on our strengths while setting out how we will improve awareness of BBS, strengthen our services, support mental health and wellbeing, amplify the voices of those affected by the condition, and ensure BBS UK remains a resilient and sustainable organisation for years to come.

Alongside our strategic development, we have continued to strengthen our governance and organisational resilience. We have invested in our people, policies and systems, enhanced our quality assurance processes, and maintained a strong focus on financial sustainability to ensure the charity is well placed to meet future opportunities and challenges.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Fundraising has been a particular highlight of the year. Our supporters have once again demonstrated extraordinary generosity, enthusiasm and commitment by taking on a wide range of fundraising challenges and events, raising vital funds while also increasing awareness of Bardet-Biedl syndrome. We are sincerely grateful to everyone who has donated, fundraised or supported our work. During the year we also introduced our 2025–2028 Fundraising Strategy, providing a clear framework for developing sustainable and diverse income streams that will help reduce reliance on any single source of funding and ensure we can continue delivering our strategic ambitions for the BBS community.

We are equally proud of the partnerships we continue to build with NHS services, researchers, funders and the wider rare disease community. By working collaboratively, we are helping to improve understanding of Bardet-Biedl syndrome, influence service development and ensure that the experiences of people living with BBS help shape future care, research and policy.

On behalf of the Board of Trustees, I would like to thank our staff team for their professionalism, expertise and unwavering commitment throughout the year. I would also like to thank my fellow trustees for the time, experience and guidance they freely give in support of the charity.

Finally, to our members, families, volunteers, fundraisers, supporters, partners and everyone who places their trust in BBS UK—thank you. Your support, encouragement and generosity make everything we achieve possible.

Although there is still much to do, I am confident that BBS UK is in a strong position to meet the opportunities and challenges ahead. Together, we will continue working towards a future where everyone affected by Bardet-Biedl syndrome is supported, connected, informed and empowered to achieve the best possible outcomes.

Achievements and Performance

During the year, BBS UK has continued to deliver its core services while also laying the foundations for the delivery of its new 2025–2030 strategy. This strategy sets out a clear direction for the organisation, focused on strengthening support, improving reach, and ensuring the needs and voices of those affected by Bardet-Biedl syndrome remain central to our work.

Progress during the year is summarised below, in line with our strategic priorities:

1. Improve service reach and awareness

We have continued to develop our communication channels to ensure that individuals and families affected by BBS can access timely and relevant information. Our website, newsletters and digital platforms remain key tools for engagement, alongside ongoing work to improve the quality and accessibility of our data and communications.

We have established connection with a specialised eye centre to support the distribution of our Medical Information Booklets and have developed a new leaflet, *'Know Your Services'*. This will be further supported by a 'Know Your Services' campaign in the coming year.

2. Sustain and strengthen support services

Demand for our services remains high, and we have continued to deliver advice, advocacy and clinic support to individuals and families navigating complex health, education and social care systems. Work has also been undertaken to strengthen capacity within our services to ensure we can respond effectively to increasing and more complex need, with two new Advice Workers and a new Patient Liaison Officer joining our team.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Our focus for the coming year is to secure multi-year funding for our Advice Service and to improve our outcome reporting.

3. Enhance mental health and emotional wellbeing

We recognise the significant emotional impact of living with a rare condition. During the year, we have further established our Rareminds Counselling Service, a highly specialised provision for those living with Bardet-Biedl syndrome.

We aim to further develop our information resources and signposting to facilitate access to appropriate mental health support for our wider community.

4. Reduce isolation through inclusive connection

Reducing isolation remains a key priority. We have established two online social groups and delivered informative and supportive online workshops, and in-person conference meetings in Northampton and Dublin, helping to bring together individuals and families who may otherwise feel isolated due to the rarity of the condition.

Going forward, we aim to further develop social groups and strengthen our connections with other charities, enabling us to signpost additional opportunities for social connection and activities through trusted partners.

5. Empower and amplify patient experience

We are committed to ensuring that the lived experience of those affected by BBS informs our work. We actively involve service users in shaping services through our Service User Advisory Board, as well as through questionnaires and evaluation surveys.

We aim to further strengthen the patient voice by supporting BBS UK members to contribute to external steering groups, public consultations and policy panels.

6. Strengthen governance

The charity has continued to review and develop its governance arrangements to ensure they remain effective and proportionate. This includes regular board skills audits, trustee training, succession planning, and the strengthening of policies, processes and oversight to support the long-term sustainability of the organisation.

We will continue to build on this work to ensure the charity remains well-governed, resilient and fit for future growth.

7. Strengthen collaborations and support research

We have continued to work in partnership with NHS services, researchers and the wider rare disease community. Through these collaborations, we support improved understanding of BBS and contribute to the development and dissemination of research that benefits our community.

We will continue to prioritise these partnerships and our support of research, helping to drive improvements in care and outcomes.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Summary

Overall, the year has been one of continued delivery and steady progress. We have a committed, skilled and experienced team of staff, trustees, and volunteers, and we are well positioned to deliver on our new strategy and continue supporting the BBS community through high-quality, sustainable services that meet evolving needs.

Fundraising Review

Overview

The fundraising environment remains competitive, with charities continuing to adapt to changing economic conditions and donor behaviours. Despite this, BBS UK has maintained a stable and developing fundraising position, supported by a combination of statutory funding, grants, and community-led fundraising activity.

Total income from fundraising this year was **£83,768**.

Fundraising Approach

During the year, we established the principles set out in our 2025–2028 Fundraising Strategy, with a focus on building sustainable and diversified income streams. This includes strengthening donor relationships, improving stewardship, and prioritising approaches that align with our values and capacity.

Our approach is rooted in developing meaningful relationships with our community, ensuring that fundraising is built on trust, transparency and engagement.

Income Streams

Grants and Trusts

Grants and trust income, *received into our account*, totalled **£42,368**, representing **94%** of our target; our sincere thanks go to:

- BBC Children in Need
- The Powell Family Foundation
- Anton Jurgens Charitable Trust

Our strategic focus remains on submitting high-quality applications to well-researched funders, with an emphasis on building longer-term funding relationships.

Community Fundraising and Events

Community-led fundraising has been exceptional, raising **£31,196**, representing **156%** of our target.

Fundraising events included ultra-marathons, full marathons, 10k runs, a skydive, bungee jump, Tough Mudder, Valentine's Quiz, Afternoon Tea and a workplace lunch – our community have fundraised in many different and heroic ways, but above all, they have had FUN!

In line with our strategy, we are focusing on providing exceptional support to our fundraisers, rather than developing multiple centrally driven campaigns, recognising the strength and commitment of our supporter network. Our heartfelt thanks to all our fundraisers for their tireless commitment to our charity.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Individual and Regular Giving

We continue to receive support through individual donations and our regular giving programme.

- Individual giving: **£1,904**
- Regular giving: **£12,361**
- Gift Aid: **£4,435**

Our 'Friends of BBS UK' programme remains an important part of building predictable and sustainable income, and we will continue to develop this in the coming months and years.

Corporate Partnerships

We received **£10,114** into our Corporate Giving income stream, which included **£10,000** from Rhythm Pharmaceuticals through an unrestricted educational grant for the BBS UK Ireland Information Day. 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.

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 for their generous support. We will continue to develop ethical and appropriate partnerships that align with our values and support our long-term sustainability.

Legacy Giving

Legacy giving includes donations made in memory of loved ones, often in lieu of flowers at funerals, as well as gifts left to the charity in wills.

We are deeply humbled to have been remembered by families and friends at such a difficult time. These gifts are incredibly meaningful and are treated with the utmost respect and gratitude.

- Total income: **£4,301**

We are increasingly recognising the importance of legacy giving as a long-term income stream and have begun to develop our approach to legacy promotion, ensuring this is done with care, sensitivity and respect.

Looking Forward

BBS UK enters the next period with a stable foundation but a clear need to continue diversifying income streams and reducing reliance on statutory funding.

Our priorities for the coming year include:

- Increasing grant income through targeted, high-quality applications
- Growing regular giving and donor retention
- Expanding community-led fundraising activity
- Developing corporate partnerships
- Raising awareness of legacy giving opportunities

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

We will continue to monitor progress against our fundraising strategy, ensuring that our approach remains realistic, sustainable, and aligned with the needs of the organisation and the community we support.

Financial Review

On behalf of the Board of Trustees

As we have heard, this has been a year of continued financial stability and operational progress for BBS UK.

BBS UK's financial period runs from 1st April 2025 to 31st March 2026, with accounts prepared on an accrual basis.

- Total income for the year was **£311,987** (2025: £395,748).
- Total expenditure was **£312,442** (2025: £294,676)
- Resulting in a deficit of **£455** (2025: Surplus £101,072)

At 31st March 2026, total funds stood at **£302,284** (2025: £302,739).

During the year, a transfer of **£2,263** was made from restricted funds into general funds, comprising residual balances from restricted grants, **£2,218** relating to a Jeans for Genes grant, where the funded project had concluded several years previously, and the original grant-making arrangements were no longer in operation; and **£45** remaining from a grant from the Eveson Trust.

During the year there was also a transfer of **£117,558** from general funds to designated funds:

- **£14,998** to the Annual Family Weekend and Conference
- **£2,574** to the Chris Humphreys Memorial Fund
- A net **£0** to the IT Equipment Fund comprising £3,697 transferred to the designated fund, and £3,697 returned to the General fund, following receipt of a restricted grant.
- A net **£5,000** to the Rareminds Counselling Project comprising £12,000 transferred to the designated fund and £7,000 returned to the General fund following a budget review.
- **£94,000** to fund the Advice Service over three years (2025-28)
- **£986** to Fixed Assets, reflecting capitalised expenditure

General Funds decreased to **£197,094** (2025: £267,203) with a deficit for the year of **£70,109**.

Designated Funds stood at **£87,355** (2025: £9,868)

Restricted Funds stood at **£17,835** (2025: £25,668).

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

- Chris Humphreys Memorial Fund: **£885** (2025: £2,167)
- Annual Family Weekend and Conference: **£100** (2025: £9,498)
- IT Equipment Fund: **£1,303** (2025: £1,197)
- Rareminds Counselling Project: **£3,745** (2025: £750)
- Advice Service: **£32,000**

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

Income

The charity's income continues to be derived from a combination of statutory funding, grants, and voluntary income.

Key sources of income during the year included:

- NHS England contract: **£216,154**
- Grants and trusts: **£28,000**
- Donations and fundraising: **£55,768**
- Event funding: **£10,900**
- Merchandise: **£339**
- Bank Interest: **£826**

The Trustees recognise the importance of maintaining a diversified income base and continue to work towards reducing reliance on any single funding source.

Expenditure

Total expenditure for the year was **£312,442** with the majority of costs relating to the delivery of charitable activities.

Expenditure included:

- Charitable activities: **£271,869**
- Raising funds: **£2,096**
- Support and Governance costs: **£38,477**

The Trustees continue to ensure that resources are used efficiently and in line with the charity's objectives.

Reserves Policy and Going Concern

The charity aims to maintain unrestricted reserves sufficient to cover approximately six months of core expenditure.

Following the year end, trustees reviewed the charity's designated reserves as part of the 2026/27 budgeting process. Existing designated balances carried forward were incorporated into updated reserve allocations for the forthcoming year:

- £5,000 - Chris Humphreys Memorial Fund, to support newly diagnosed individuals and their families to access our events based on assessment of need.
- £24,000 - Conference fund, to support delivery of the annual BBS UK Conference Weekend.
- £2,600 - IT Equipment Fund, to improve digital access to services.
- £5,000 - Rareminds Counselling Fund, providing specialist counselling for people affected by Bardet-Biedl syndrome.
- £62,000 - Advice Service Reserve, designated to support continuity and sustainability of the Advice Service over the 2026-2028 period.

At the year end, free reserves were **£197,094** representing approximately **6.4** months of expenditure.

Bardet-Biedl Syndrome UK

Trustees' Report (continued)

The Trustees have assessed the financial position of the charity and consider that it has adequate resources to continue in operational existence for the foreseeable future. The financial statements have therefore been prepared on a going concern basis.

Risk and Financial Management

The Trustees regularly review financial performance, budgets and forecasts to ensure the charity remains financially sustainable.

Key financial risks include:

- Dependence on key income streams
- Securing sufficient voluntary income
- Managing increasing demand for services

Appropriate controls and monitoring processes are in place to mitigate these risks.

Conclusion

The charity remains in a stable financial position, supported by a combination of secured funding and ongoing fundraising activity. The Trustees will continue to focus on strengthening financial sustainability to support the delivery of the charity's strategic objectives.

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.

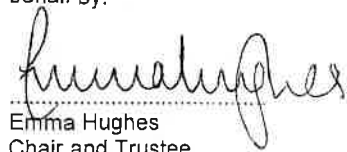
The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008, 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 charity'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 08.10.26 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 2026.

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: 15th October 2026

Bardet-Biedl Syndrome UK

Statement of Financial Activities for the Year Ended 31 March 2026

	Note	Unrestricted funds £	Restricted funds £	Total 2026 £	Total 2025 £
Income and Endowments from:					
Donations and legacies	2	58,768	25,000	83,768	170,454
Charitable activities	3	227,393	-	227,393	223,444
Investment income	4	826	-	826	850
Other income	5	-	-	-	1,000
Total income		<u>286,987</u>	<u>25,000</u>	<u>311,987</u>	<u>395,748</u>
Expenditure on:					
Raising funds	6	(2,096)	-	(2,096)	(1,919)
Charitable activities	7	<u>(279,776)</u>	<u>(30,570)</u>	<u>(310,346)</u>	<u>(292,757)</u>
Total expenditure		<u>(281,872)</u>	<u>(30,570)</u>	<u>(312,442)</u>	<u>(294,676)</u>
Net income/(expenditure)		5,115	(5,570)	(455)	101,072
Gross transfers between funds		<u>2,263</u>	<u>(2,263)</u>	<u>-</u>	<u>-</u>
Net movement in funds		7,378	(7,833)	(455)	101,072
Reconciliation of funds					
Total funds brought forward		<u>277,071</u>	<u>25,668</u>	<u>302,739</u>	<u>201,667</u>
Total funds carried forward	19	<u>284,449</u>	<u>17,835</u>	<u>302,284</u>	<u>302,739</u>

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

The funds breakdown for 2025 is shown in note 19.

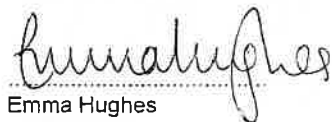
Bardet-Biedl Syndrome UK

(Registration number: 1181244)

Balance Sheet as at 31 March 2026

	Note	2026 £	2025 £
Fixed assets			
Tangible assets	14	4,085	5,137
Current assets			
Debtors	15	80,968	91,502
Cash at bank and in hand	16	<u>248,861</u>	<u>226,878</u>
		329,829	318,380
Creditors: Amounts falling due within one year	17	<u>(31,630)</u>	<u>(20,778)</u>
Net current assets		<u>298,199</u>	<u>297,602</u>
Net assets		<u>302,284</u>	<u>302,739</u>
Funds of the Charity:			
Restricted income funds			
Restricted funds		17,835	25,668
Unrestricted income funds			
Unrestricted funds		<u>284,449</u>	<u>277,071</u>
Total funds	19	<u>302,284</u>	<u>302,739</u>

The financial statements on pages 16 to 30 were approved by the Trustees, and authorised for issue on 08.10.26 and signed on their behalf by:



Emma Hughes
Trustee

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2026

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 2026 (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 charity for UK corporation tax purposes. Accordingly, the Charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Tangible fixed assets

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

Depreciation and amortisation

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

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

Cash and cash equivalents

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

Fund structure

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

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

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2026 (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 2026 (continued)

2 Income from donations and legacies

	Unrestricted funds General £	Restricted funds £	Total 2026 £
Donations and Gifts	34,671	-	34,671
Legacies	4,301	-	4,301
Gift aid	4,435	-	4,435
Grants Received	3,000	25,000	28,000
Regular Giving	12,361	-	12,361
	<u>58,768</u>	<u>25,000</u>	<u>83,768</u>

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

3 Income from charitable activities

	Unrestricted funds General £	Total 2026 £
Event Funding	10,900	10,900
NHS - Commissioned Services	216,154	216,154
Merchandise	339	339
	<u>227,393</u>	<u>227,393</u>

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

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2026 (continued)

4 Investment income

	Unrestricted funds General £	Total 2026 £
Interest receivable on bank deposits	826	826

	Unrestricted funds General £	Total 2025 £
Interest receivable on bank deposits	850	850

5 Other income

	Unrestricted funds General £	Total 2025 £
Other income	1,000	1,000

6 Expenditure on raising funds

a) Costs of generating donations and legacies

	Unrestricted funds General £	Total 2026 £
Donations expenses	2,096	2,096

	Unrestricted funds General £	Total 2025 £
Donations expenses	433	433

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2026 (continued)

b) Costs of trading activities

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

7 Expenditure on charitable activities

	Note	Unrestricted funds General £	Restricted funds £	Total 2026 £
Charitable activities		241,678	30,191	271,869
Allocated support costs	8	38,098	379	38,477
		<u>279,776</u>	<u>30,570</u>	<u>310,346</u>

	Note	Unrestricted funds General £	Restricted funds £	Total 2025 £
Charitable activities		242,080	7,140	249,220
Allocated support costs	8	43,537	-	43,537
		<u>285,617</u>	<u>7,140</u>	<u>292,757</u>

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2026 (continued)

8 Analysis of support costs

Support costs allocated to charitable activities

	Support costs £	Total 2026 £	Total 2025 £
Office expenses	3,483	3,483	6,434
Travelling	7,586	7,586	6,648
Insurance	2,297	2,297	1,994
Telephone and fax	1,540	1,540	1,480
IT security and support	5,963	5,963	4,678
Database	203	203	675
Website	1,443	1,443	733
Printing, postage and stationery	401	401	552
Exhibition Fees	218	218	1,123
Sundry expenses	648	648	623
Accountancy fees	1,182	1,182	4,774
Partial Exemption VAT disallowed	341	341	-
Data Protection Consultancy	1,440	1,440	-
Staff costs	5,728	5,728	5,238
Trade subscriptions	1,793	1,793	929
Independent Examiner's fee	2,173	2,173	5,094
Depreciation	2,038	2,038	2,562
	<u>38,477</u>	<u>38,477</u>	<u>43,537</u>

9 Net incoming/outgoing resources

Net (outgoing)/incoming resources for the year include:

	2026 £	2025 £
Depreciation of fixed assets	<u>2,038</u>	<u>2,562</u>

10 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 £888 (2025: £830) in respect of travel costs.

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2026 (continued)

11 Staff costs

The aggregate payroll costs were as follows:

	2026	2025
	£	£
Staff costs during the year were:		
Wages and salaries	220,759	186,050
Social security costs	1,296	17,060
Pension costs	5,008	10,022
	<u>227,063</u>	<u>213,132</u>

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

	2026	2025
	No	No
Charitable activities	<u>8</u>	<u>8</u>

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

12 Independent examiner's remuneration

	2026	2025
	£	£
Examination of the financial statements	<u>2,173</u>	<u>5,094</u>

13 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 2026 (continued)

14 Tangible fixed assets

	Furniture and equipment £	Total £
Cost		
At 1 April 2025	7,699	7,699
Additions	986	986
At 31 March 2026	8,685	8,685
Depreciation		
At 1 April 2025	2,562	2,562
Charge for the year	2,038	2,038
At 31 March 2026	4,600	4,600
Net book value		
At 31 March 2026	4,085	4,085
At 31 March 2025	5,137	5,137

15 Debtors

	2026 £	2025 £
Trade debtors	76,455	88,193
Prepayments	4,513	2,996
Other debtors	-	313
	80,968	91,502

16 Cash and cash equivalents

	2026 £	2025 £
Cash at bank	248,861	226,878

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2026 (continued)

17 Creditors: amounts falling due within one year

	2026 £	2025 £
Trade creditors	6,040	375
Taxation and social security	21,792	15,801
Other creditors	1,215	2,142
Accruals	2,583	2,460
	<u>31,630</u>	<u>20,778</u>

18 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 £5,008 (2025 - £10,022).

19 Funds

	Balance at 1 April 2025 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 March 2026 £
Unrestricted funds					
General					
General Funds	267,203	286,987	(241,801)	(115,295)	197,094
Chris Humphreys Memorial Fund	426	-	(885)	2,574	2,115
Conference Weekend	3,002	-	(100)	14,998	17,900
IT Equipment Fund	1,303	-	(1,303)	-	-
Fixed Assets	5,137	-	(2,038)	986	4,085
Rare minds Counselling	-	-	(3,745)	5,000	1,255
Advice Service	-	-	(32,000)	94,000	62,000
	<u>277,071</u>	<u>286,987</u>	<u>(281,872)</u>	<u>2,263</u>	<u>284,449</u>

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2026 (continued)

	Balance at 1 April 2025 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 March 2026 £
Restricted funds					
Jeans 4 Genes	2,790	-	(572)	(2,218)	-
The National Lottery (Rareminds Counselling Project)	8,465	-	(8,465)	-	-
The Eveson Trust (Transition Project)	45	-	-	(45)	-
BBC Children in Need	14,368	-	(10,776)	-	3,592
The Powell Family Foundation	-	25,000	(10,757)	-	14,243
	<u>25,668</u>	<u>25,000</u>	<u>(30,570)</u>	<u>(2,263)</u>	<u>17,835</u>
Total funds	<u>302,739</u>	<u>311,987</u>	<u>(312,442)</u>	<u>-</u>	<u>302,284</u>
	Balance at 1 April 2024 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 March 2025 £
Unrestricted funds					
General					
General Funds	190,949	365,730	(271,362)	(18,114)	267,203
Chris Humphreys Memorial Fund	2,593	-	(2,167)	-	426
Conference Weekend	1,049	-	(9,498)	11,451	3,002
IT Equipment Fund	1,045	-	(1,197)	1,455	1,303
Fixed Assets	3,241	-	(2,562)	4,458	5,137
Rareminds Counselling	-	-	(750)	750	-
	<u>198,877</u>	<u>365,730</u>	<u>(287,536)</u>	<u>-</u>	<u>277,071</u>
Restricted funds					
Jeans 4 Genes	2,790	-	-	-	2,790
The National Lottery (Rareminds Counselling Project)	-	13,650	(5,185)	-	8,465
The Eveson Trust (Transition Project)	-	2,000	(1,955)	-	45
BBC Children in Need	-	14,368	-	-	14,368
	<u>2,790</u>	<u>30,018</u>	<u>(7,140)</u>	<u>-</u>	<u>25,668</u>
Total funds	<u>201,667</u>	<u>395,748</u>	<u>(294,676)</u>	<u>-</u>	<u>302,739</u>

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2026 (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.

20 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total funds at 31 March 2026
	General		
	£	£	£
Tangible fixed assets	4,085	-	4,085
Current assets	311,994	17,835	329,829
Current liabilities	(31,630)	-	(31,630)
Total net assets	<u>284,449</u>	<u>17,835</u>	<u>302,284</u>

Bardet-Biedl Syndrome UK

Notes to the Financial Statements for the Year Ended 31 March 2026 (continued)

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

21 Related party transactions

There were no related party transactions in the year.