

BBS UK Annual General Meeting (AGM) minutes

8th November 2025, 10:00am – 11:00am via Zoom

Prior to the meeting starting, BBS UK Operations Manager Tonia Hymers confirmed that the meeting was quorate.

1. Welcome and Introductions

The BBS UK Chair, Emma Hughes, introduced herself and welcomed everyone to the 2025 Annual General Meeting (AGM) for Bardet-Biedl Syndrome UK (BBS UK). The Trustees were invited to introduce themselves; they were:

- Emma Hughes - Chair
- Chetan Meshram – Vice-Chair
- Tazeem Abbas - Treasurer
- Dianne Hand - Secretary
- Gareth Owens – Trustee
- Bilaal Ali - Trustee

2. Apologies

Apologies were received from trustees Dr Shehla Mohammed, Liam Wilkie and Rachael Zimbler.

3. Conflict of Interest

No conflicts of interest were declared.

4. Matters Arising and Minutes of the 2025 AGM

The Minutes of the last AGM of BBS UK, held on 9th November 2024, had previously been circulated and were confirmed to be a true record of proceedings. The approval of the minutes was proposed by Tazeem Abbas and seconded by Gareth Owens. It was confirmed there were no matters arising.

5. Reports and Accounts

Report from the 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.

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.

Treasurer's Report: Tazeem Abbass

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 the 1st April 2024 – 31st March 2025.

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.

Approval of 2024/25 Annual Reports and Accounts

Emma Hughes then held a vote to approve the the 2024/25 Annual Report and Accounts. A majority were in favour, and no one opposed.

6. Independent Examiners

Appointment of the Independent Examiner

Tazeem Abbas proposed Westcotts to act as the Independent Examiner for the Charity for the coming financial year. A vote was undertaken, a majority were in favour, and no one opposed.

7. Election of Committee

Tazeem Abbas is retiring as Trustee and Treasurer and Chair, having served two years on the committee. Tazeem has given two years of dedicated and valued service to BBS UK, providing excellent financial oversight and guidance. On behalf of the Board and the membership, we thank her sincerely for her commitment and contribution.

We're very grateful that Tazeem has kindly offered to remain in an advisory capacity for a short period to support a smooth handover while the Board recruits a new Treasurer.

The Board will continue to ensure strong financial governance throughout this transition, and will keep members informed as the recruitment process progresses.

Once again, our warmest thanks and best wishes to Tazeem for her dedication and support over the past two years.

A third of the trustees are required to retire at each AGM but are eligible for re-election.

- Gareth Owens is retiring by rotation and is eligible and willing to serve for a further year to complete his first term.

Members were asked to vote in favour of re-electing **Gareth Owens** as Trustee for another year to complete his first term. A show of hands confirmed a majority were in favour and no one was against.

Dianne Hand is retiring as Trustee. In line with Clause 16 of the Constitution, trustees who have served more than two terms may be reappointed with the approval of the members in exceptional circumstances.

The Board believes this is one such occasion - Dianne's extensive experience and historic knowledge of BBS UK are invaluable, especially while we are without a Treasurer and during the transition to appoint a new one.

The Trustees therefore recommend Dianne's reappointment as Trustee and Secretary for one further year to ensure continuity and governance stability.

Members were asked to vote in favour of re-electing **Dianne Hand** as Trustee for another year. A show of hands confirmed a majority were in favour and no one was against.

8. Election of Honorary Officer

Emma Hughes was eligible for re-election to the position of Chair.

Chetan Meshram was eligible for re-election to the position of Vice-Chair.

Dianne Hand was eligible for re-election to the position of Secretary.

No further nominations had been received for these honorary positions and could therefore be elected unopposed.

Members were asked to vote in favour of the appointment of the Honorary Officers of BBS UK. A show of hands confirmed a majority were in favour and no one was against.

9. Any Other Business

No other business.

10. Close of AGM

Emma Hughes thanked everyone for giving up their time to attend this AGM and reiterated that the BBS UK team is always there to support everyone going forward.

Meeting closed.