

BBS UK Annual General Meeting (AGM) minutes

9th November 2024, 10:00am – 12:00pm 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, Laura Dowswell, introduced herself and welcomed everyone to the 2024 Annual General Meeting (AGM) for Bardet-Biedl Syndrome UK (BBS UK). The Trustees were invited to introduce themselves; they were:

- Laura Dowswell - Chair
- Chetan Meshram – Vice-Chair
- Tazeem Abbas - Treasurer
- Dianne Hand - Secretary
- Stefan Crocker - Trustee
- Rachael Zimble - Trustee
- Liam Wilkie - Trustee
- Gareth Owens - Trustee

2. Apologies

Apologies were received from trustee Dr Shehla Mohammed.

3. Conflict of Interest

Rachael Zimble recorded a potential conflict of interest due to her role as Chair of Walthew House, a charity in Stockport that provides practical and emotional support to people who are blind, visually impaired, deaf, and or hard of hearing.

4. Matters Arising and Minutes of the 2023 AGM

The Minutes of the last AGM of BBS UK, held on 23rd September 2023, 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

Chair's Report: Laura Dowswell

Like many smaller charities, BBS UK has continued to face challenges in the tough economic times we now find ourselves facing. The Board of Trustees and staff team have worked incredibly hard to meet those challenges, not only to maintain the delivery of the Charity's vital services, and to ensure that the Charity continues to be sustainable, but to develop our services to meet the increased needs of our community.

We previously employed Samantha Serido as Fundraising and Communications Officer, who has since left for another position.

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

The BBS UK Advice Service continues to provide high quality support with accessing local services across housing, social care, benefits, and education; the work that is being undertaken and the outcomes that are being achieved, continue to show that this is an essential core service and a primary funding focus for BBS UK.

The Clinics Support Service Team have continued to provide excellent support to the NHS highly specialised multi-disciplinary service, and to patients attending the face to face and telemedicine clinics. Our NHS colleagues are very clear that the service could not run without the work undertaken by the BBS UK team, and we were delighted to secure a further four-year contract at the end of this reporting period.

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

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

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

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

Team BBS UK is made up of trustees, staff, volunteers, members, supportive professionals, fundraisers, donors, campaigners, supporting charities and organisations, and that is how we have managed to continue our growth and provide the support and information services that our community needs: by continuing to work together and by developing new ways of working, in order to improve the lives of all those living with Bardet-Biedl syndrome.

Treasurer's Report: Tazeem Abbass

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

The financial accounts are prepared on the accrual basis.

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

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

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

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

Reserves Policy and Going Concern

Trustees regularly review the budget and the level of reserves, which are monitored monthly and reported at the quarterly board of trustee meetings to ensure that the appropriate levels are maintained considering the main risks to the organisation and future developments. Trustees have agreed unrestricted free reserves should be sufficient to cover six months expenditure.

The following designated reserves are set aside at year-end as follows:

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

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

The trustees have reviewed the circumstances of the Charity and consider that adequate resources continue to be available to fund its activities for the foreseeable future. The trustees are of the view that the charity is a going concern.

Management of risk

The Trustees have identified that the main risks to the charity are:

- The NHS England clinic contract
- Failing to secure sufficient funds
- The loss of income from reduced donations
- The loss of key personnel

Approval of the 2023-2024 Report and Accounts

The vote to approve the 2023-2024 reports and accounts was undertaken, a majority were in favour, and no one opposed.

6. Independent Examiners

Appointment of the Independent Examiner

Tazeem Abbas proposed Amicus Accountancy 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.

Review of the independent examiner service and change of provider if appropriate

Tazeem Abbas proposed BBS UK undertake a review of the independent examiner service and change provider if appropriate at the beginning of the next financial year. A vote was undertaken, a majority were in favour, and no one opposed.

7. Amendment to Constitution

Laura Dowswell informed members that BBS UK have obtained advice from the Charities Commission and Trust Advice that confirms that, although within the terms of our constitution, we are able to hold our AGM online, it would be good practice to amend our constitution to explicitly state that.

A vote was therefore required on the following resolution:

To authorise the Trustees to make an addition to Clause 11 of the BBS UK Constitution to specify that the Charity may conduct its Annual General Meetings (AGMs) via electronic means, including but not limited to video conferencing, web conferencing, or other digital platforms, as deemed appropriate by the Board of Trustees.

A vote was undertaken to amend the constitution, a majority were in favour, and no one opposed.

8. Election of Committee

Chetan Meshram stated that two new trustees are eligible to be elected: Bilaal Ali and Emma Hughes. Bilaal Ali gave an introduction, followed by Emma Hughes.

Laura Dowswell is retiring as Trustee and Chair, having come to the end of her third term. In her 9 years on the Board.

Dianne Hand is retiring as Trustee and Secretary but is eligible for re-election due to exceptional circumstances. Dianne's historic and in-depth knowledge of the charity and its governance are vital during the transition period of appointment a new Chair. The trustees have agreed to invite Dianne to remain as Secretary for another year.

Stefan Crocker is retiring from the board, having reached the end of his third term as Trustee.

Rachael Zimblar has reached the end of her second term as Trustee and is eligible to serve for a further term of three years (3rd term) with member approval.

Emma Hughes is eligible for election for the position of Trustee for the 1st year of her 1st term.

Bilal Ali is eligible for election for the position of Trustee for the 1st year of his 1st term.

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.

Members were asked to vote in favour of re-electing **Rachael Zimbler** as Trustee for her 3rd term. A show of hands confirmed a majority were in favour and no one was against.

Members were asked to vote in favour of electing **Emma Hughes** as Trustee for her 1st term. A show of hands confirmed a majority were in favour and no one was against.

Members were asked to vote in favour of electing **Bilal Ali** as Trustee for his 1st term. A show of hands confirmed a majority were in favour and no one was against.

9. Election of Honorary Officer

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

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

Tazeem Abbas was eligible for re-election to the position of Treasurer.

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.

10. Any Other Business

Tonia Hymers, BBS UK Operations Manager thanked Laura Dowswell and Stefan Crocker for their time and dedication to the charity:

Stefan has been a highly valued member of the board for 9 years and has served as Vice-Chair and Chair during this time. Throughout his trusteeship, Stefan has been the biggest cheerleader for BBS UK and its services, getting behind all new ventures with enthusiasm and with the aim of improving awareness and access for all.

Stefan has also been an active volunteer at social events, information days and conferences, both at home and abroad, representing BBS UK in Germany and the United States. Tonia thanked Stefan for all that he has done for BBS UK and its membership over the years.

Laura has played a pivotal role in shaping BBS UK over the past nine years, serving first as Treasurer and then Vice-Chair, before taking up the post of Chair for the past three years.

When Laura initially joined the board, the charity was facing a number of governance and operational challenges. The charity was in need of experienced leadership, strong financial stewardship, and a can-do/will-do approach to take that forward.

As Treasurer, Laura's extensive experience in charitable finance ensured that we achieved the highest levels of financial transparency and accountability, which were crucial in strengthening our governance.

Laura's leadership has been equally transformative, providing invaluable support to her fellow trustees and staff team. In her role as Chair over the past three years, Laura has led the board and supported Tonia and the team to successfully deliver on our three-year strategy and has been instrumental in our current strategy review; under Laura's leadership, the charity has grown stronger, more resilient, and better prepared for the future.

On behalf of the board, staff team and membership, Tonia gave a heartfelt thank you for her years of service, for her leadership, and for the passion and commitment she has given to BBS UK.

The members and staff present showed their thanks and appreciation on screen through claps and Zoom reactions.

11. Close of AGM

Laura Dowswell 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.