

DRAFT BBS UK Annual General Meeting Minutes

Hilton Hotel, Northampton

24th September 2023, 10:35 – 11:00am

Prior to the welcome, BBS UK Chair Laura Dowswell confirmed the AGM was quorate and could proceed.

1. Welcome

The BBS UK Chair, Laura Dowswell, introduced herself and welcomed everyone to the 2023 Annual General Meeting (AGM) for Bardet-Biedl Syndrome UK (BBS UK). The Trustees were invited to introduce themselves, they were:

1. Laura Dowswell – Chair
2. Abbie Geeson - Treasurer
3. Stefan Crocker - Trustee
4. Rachael Foley – Trustee
5. Azrat Mirza - Trustee
6. Chetan Meshram – Trustee (co-opted November 2022)
7. Gareth Owens – Trustee (co-opted February 2023)
8. Tazeem Abbas – Trustee (co-opted March 2023)

2. Apologies

Apologies were received from trustees, Dianne Hand, Dr Shehla Mohammed and Liam Wilkie.

3. Conflicts of Interest

Laura Dowswell confirmed there were no conflicts of interest to record.

4. Minutes of the 2022 AGM and Matters arising

The Minutes of the last AGM of BBS UK, held on 11th September 2022, had previously been circulated and were confirmed to be a true record of proceedings. The approval of the minutes was proposed by Abbie Geeson and seconded by Rachael Foley. It was confirmed there were no matters arising.

5. Reports and Accounts

Chair's Report: Laura Dowswell

Like many smaller charities, BBS UK has faced numerous challenges over the last two or three years, not only with the pandemic but also 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 which include not only to maintain the delivery of the Charity's vital services, and to ensure that the Charity continues to be sustainable, but to develop our services to meet the increased needs of our community.

We have seen some positive changes and are delighted to welcome Natalie Braunton to the staff team in the role of Operations Assistant.

We've also recruited four new Trustees to the Board and welcome Azrat Mirza, Chetan Meshram, Gareth Owens and Tazeem Abbas who bring with them professional skills as well as lived experience of BBS.

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 Team have continued to provide excellent support to the service and to patients attending the face to face and telemedicine clinics.

There have been a number of team projects undertaken during the last year, including the IT Equipment Fund, our partnership with Slimming World, the Maypole Counselling Pilot Project and our newly formed Regional Group in Ireland. I was delighted to be invited to their first ever Information Day held in Belfast in May 2023. It was lovely meeting so many new families and seeing the support they were able to offer each other.

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

BBS UK's financial period runs from the 1st April 2022 – 31st March 2023. The financial accounts are prepared on the accrual basis. It should be noted in the previous financial

year BBS UK extended its financial year to incorporate 1st January 2021 – 31st March 22 and the financial statements reflected a 15-month period and were prepared on a receipts and payments basis.

On the 1st of April 2022 BBS UK took over the NHS Specialised Commissioned Services, third sector contract to provide the BBS Clinic Support Service, which was previously held by its now, dormant subsidiary company BBS UK Clinics Ltd, this meant an increase to income during the financial year. During the year the charity experienced the loss of two core key personnel. This impacted on both income generation of key grant funding and on project delivery. In January 2023 two new core employees were recruited and as such we expect to meet our budget outcomes next financial year.

The total Charity funds as of the 31st of March 2023 was £165,046 (21-22 £172,406). The General fund had a surplus of £30,465, transfers of £22,068 were made to other funds and the General fund stands at £129,600 (21-22 £121,203).

The Trustees made transfers from the General fund to the following designated funds:

- Annual Family Weekend and Conference £20,923
- Fixed Assets £1,145
- The Trustees also repurposed part of the designated IT Equipment Fund transferring £3,000 to the Chris Humphreys Memorial Fund.

The Trustees provided support of £955 from the Chris Humphreys Memorial Fund and £947 from the IT Equipment Fund. Further designated expenditure was £19,968 for the 2022 Annual Family Weekend and Conference and £5,955 for the Advice Service. The designated fund stands at £32,368 (21-22 £38,125).

The restricted fund stands at £3,078 (21-22 £13,078).

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:

- The Chris Humphreys Memorial Fund £3,000 – This subsidy fund is to support newly diagnosed individuals and their families to access our events based on assessment of need.
- The Annual Family Weekend and Conference £25,000 is committed future expenditure. The weekend brings together over 200 diagnosed individuals and their families.
- The IT Equipment Fund £3,223 - This fund was set up 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 Fund £1,445 which cannot be used to fund expenditure without being sold.

The remaining reserves of £129,600 are held in the General fund as free reserves and represent six 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
- The Covid-19 Pandemic

Approval of the 2022-2023 Report and Accounts

The vote to approve the 2022-2023 reports and accounts was undertaken, a majority were in favour and no one opposed.

6. Appointment of the Independent Examiner

Abbie Geeson 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 the Independent Examiner appointment.

7. Election of BBS UK Trustees to the Board

Laura Dowswell stated that Abbie Geeson has resigned from the Board of Trustees as Treasurer and Trustee. In her 7 years on the Board, Abbie also held the role of Secretary and Laura on behalf of BBS UK thanked her for the invaluable contribution that she has made and stated that she will be greatly missed as a member of our team.

A third of trustees are required to retire at each AGM but are eligible for re-election. Stefan Crocker, Rachael Foley and Liam Wilkie are the trustees longest in office since the last election and therefore will retire but are eligible for re-election.

Members were asked to vote in favour of re-electing Stefan Crocker to the Board of Trustees for the 3rd year of his 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 re-electing Rachael Foley to the Board of Trustees for the 3rd year of her 2nd term. 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 Liam Wilkie to the Board of Trustees for the 3rd year of his 1st term. A show of hands confirmed a majority were in favour and no one was against.

Chetan Meshram was co-opted to the Board of Trustees in November 2022 and was eligible to be elected to the Board of Trustees for his 1st term of 3 years. A show of hands confirmed a majority were in favour and no-one was against.

Gareth Owens was co-opted to the Board of Trustees in February 2023 and was eligible to be elected to the Board of Trustees for his 1st term of 3 years. A show of hands confirmed a majority were in favour and no-one was against.

Tazeem Abbas was co-opted to the Board of Trustees in March 2023 and was eligible to be elected to the Board of Trustees for her 1st term of 3 years. A show of hands confirmed a majority were in favour and no-one was against.

8. Election of BBS UK Honorary Officers

Of the current Officers:

Laura Dowswell was eligible for re-election to the position of Chair.

Chetan Meshram is eligible for election to the position of Vice Chair.

Tazeem Abbas was eligible for 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.

9. Any Other Business – None

10. Close of AGM – Laura Dowswell thanked everyone for giving up their time to attend and reiterated that the BBS UK team is always there to support everyone going forward.

Meeting closed.