

BBS UK Annual General Meeting Minutes

Zoom Video meeting

13th July 2021, 1pm – 2pm

Prior to the welcome, BBS UK Service Manager Tonia Hymers confirmed there were 27 members present, the AGM was quorate and could proceed.

1. Welcome

The BBS UK Chair, Stefan Crocker, introduced himself and welcomed participants to the 2021 Annual General Meeting (AGM) for Bardet-Biedl Syndrome UK (BBS UK). The Trustees and members of staff present were invited to introduce themselves, they were:

1. Laura Dowswell – Vice Chair
2. Abbie Geeson - Treasurer
3. Dianne Hand - Secretary
4. Rachael Foley - Trustee
5. Judith Aylott - Trustee
6. Dr. Shehla Mohammed - Trustee
7. Liam Wilkie - Trustee
8. Christine Saxon – Fundraising Co-ordinator
9. Tonia Hymers – Service Manager

2. Apologies

Apologies were received from members, Michael and Drina Parker and Aneeba Ahmed and Trustee, Emma Oates.

3. Conflicts of Interest

Stefan Crocker confirmed there were no conflicts of interest to record.

4. Minutes of the 2020 AGM and Matters arising

The Minutes of the last AGM of BBS UK, held on 28th September 2020, had previously been circulated and were confirmed to be a true record of proceedings. The approval of the minutes was proposed by the Chair, Stefan Crocker and seconded by Vice-Chair, Laura Dowswell. It was confirmed there were no matters arising.

5. Reports and Accounts

Chair's Report:

The Chair's report was read out by Dianne Hand on behalf of the Chair, Stefan Crocker.

This year has presented the Charity with many challenges due to the Covid-19 pandemic. The Board of Trustees and staff team have worked hard to meet these challenges and through regular Zoom meetings we have managed to find new ways of supporting our members and families; this has included the recruitment of Rebecca Perfect in the capacity of Advice Officer.

I would like to thank our hardworking clinics team who have been supporting the telemedicine clinics. This has allowed new and existing patients to continue to access the clinics service. The team have done a fantastic job keeping in touch with patients and reminding them that despite the difficult circumstances there is still support available.

The Charity has ensured members have been kept up-to-date with relevant developments during the pandemic via webinars led by Professor Phil Beales, which were both informative and reassuring, offering advice from shielding through to the vaccine roll out. I would like to thank all those involved in delivering these webinars.

There have been a number of administrative projects undertaken. BBS UK has produced new leaflets and reviewed/rebranded others and distributed these to members in multiple formats. A membership survey has commenced to assess how BBS affects those diagnosed and their quality of life. It also aims to better understand how well those affected have been supported by the Charity, where the gaps are and what they would like from BBS UK in the future.

Despite there being limited opportunities to fundraise, our members have found innovative ways to help raise funds for the Charity. For this we are extremely grateful. I would like to thank our Fundraising Officer, Christine Saxon, for her hard work in seeking new ways to raise funds.

BBS UK is acutely aware that social interaction and peer support is pivotal in helping to protect the mental health of our membership. In recognition of this, the Charity has been trialling a monthly online social group which we will continue to develop over the coming months. We are optimistic about the future and are looking forward to when we will be able to resume face to face events. In the meantime, there is significant work being done to 'keep-in-touch' with our members and the virtual BBS UK conference held in May 2021 was a huge success.

Treasurer's Report: Abbie Geeson

The Unincorporated Charity, Bardet-Biedl Syndrome UK (1027384) and the Charitable Incorporated Organisation (1181244) was entered into the Charity Commission register of mergers on the 23/12/2020, therefore the 2020 annual accounts and the finance review represents both charities and are consolidated accounts. During the reporting period BBS UK, CIO (1181244) received the remaining assets of BBS UK (1027384).

Income during 2020 was £53,704 compared to £101,078 in 2019, a decrease of 47%. This decrease is attributed to the Covid-19 pandemic and the reduction of event contributions, general donations and donations received from fundraising events.

Expenditure during 2020 which included restricted expenditure from funds previously carried forward, was £55,174 compared to £104,976 in 2019, a decrease of 47%. This decrease is attributed to the Covid-19 pandemic and the cancellation of BBS UK events held throughout the year.

The unrestricted fund had a surplus of £1,216 at year end. As of the 31st December 2020 unrestricted funds were £104,637 and restricted funds were £6,742.

During the reporting period there were:

- No particulars of any guarantee given by the CIO, where potential liability under the guarantee is outstanding at the date of the statement.
- No particulars of any debt outstanding at the date of the statement which is owed by the CIO and which is secured by an express charge on any assets of the CIO.

Management of risk:

BBS UK relies on income from donations and fundraising events undertaken by its membership and through the Friends of BBS UK donation scheme. The main financial risks to the charity are:

- Failing to secure sufficient funds
- Loss of income from reduced donations
- The loss of key personnel
- The Covid-19 pandemic

Throughout 2020 the budget and reserve levels were monitored on a monthly basis and reported to trustees at the quarterly board of trustee meetings. This was established practice but due to the pandemic, the principal risks to the charity and the unstable financial situation did have an impact of income during the reporting period and measures were taken to minimise the risks and the impact to our beneficiaries and services.

BBS UK Policy on Reserves:

Trustees regularly review the level of reserves and have agreed unrestricted reserves should be sufficient to cover six months expenditure to manage income shortfalls and to meet any unforeseen expenditure which may occur.

The Charity funds as of the 31st December 2020 were £111,380. These are represented by restricted funds of £6,742 and designated funds of £20,955. This leaves general funds of £83,683 which is free reserves.

The purpose of the designated funds are as follows:

- The Chris Humphreys Memorial Fund: £955 – This subsidy fund was set up in 2020 to support newly diagnosed individuals and their families to access our events.
- The Annual Family Weekend and Conference: £20,000 is committed future expenditure. The weekend brings together over 200 diagnosed individuals and their families.

The free reserves represent 8.5 months of expenditure. The excess reserves held is due to the review of previously designated funds set aside which will now be allocated to meet the shortfall of income forecasted in early 2021. This will bring reserves into line with the minimum reserves required of 6 months expenditure by May 2021.

Going Concern:

Going concern has been reviewed in light of the uncertainty relating to COVID-19. There are no material uncertainties about the Charity's ability to continue. The financial position is reviewed on a month-by-month basis, and should this situation change then the Trustees would take the appropriate steps.

Fundraising Report: Christine Saxon

We should like to start the report with a huge “Thank-you” to all the members, staff, and Trustees for making such a huge effort this year in what has been unprecedented conditions for fundraising.

Donations and general fundraising in 2020 were unsurprisingly down on last year, due to lockdowns, shielding and travel restrictions cancelling most community events in the year. This has temporarily halted the rise in income over the last five years. We hope to get back on track in 2021 using a five-year plan for growth and development.

Grants and Trust income has been understandably quick to cover the frontline emergency Covid response and therefore income from this source has been hard to access for BBS UK, however we are extremely grateful to several Trusts who have supported BBS UK this year who prefer to remain unnamed.

Looking at the income in more detail, Just Giving proved to be the greatest source of fundraising with contributions from many individuals completing the 2.6 Challenge in April, and a host of ‘virtual’ events through the year bringing in over £16,000. £15,000 came in general donations bolstered by an incredible Lady Golf Captains adoption, for which we are very grateful.

Virgin Money brought us over £4,000 through the efforts of Tom Horn, our Marathon Runner, who endured interrupted training routines, finally running a solo event in the Autumn.

Gift Aid raised over £4,000 so it is always worth helping to increase your donations, if eligible, by signing a declaration in our favour. We cannot forget the rainiest August ever when the inaugural 'BBS Big Barbeque' was supported by a few hardy souls and their families, but we shall give it another try in 2021. More successful was the Christmas card initiative, which raised over £800, thanks to your support. This is also to be repeated in 2021 as a new stream of income.

However, it does not have to be large amounts: individuals making regular donations through our Friends of BBS UK have helped us to raise over £7,000 this year and increasingly regular monthly giving is seen to provide the Charity with regular sustainable funds that we can plan our services on. 2020 has shown how general income can rise and fall dependant on external forces, so £10 per month regularly pledged would provide BBS UK with £120 per year, and with Gift Aid this would become a donation of £150. We are needing this financial security now, to minimise the risk to our charity. Please join as a Friend this year.

Last year's trend of our families raising more by working together, using their contacts, speaking to friends and work colleagues and through networking has continued and it is encouraging that newly diagnosed patients and their families have shown an interest in raising funds in this way. In our fundraising plans we are looking at developing regional support groups, a logical step forward to engage more with local and regional sources of funding.

In conclusion, we are looking forward with renewed vigour as 2021 unlocks and our thanks go to everyone who has kept us posted about their networking and fundraising activities. We love sharing your events and achievements through our social media outlets, newsletters, and website, because you inspire and encourage others to follow your lead

[Approval of the 2020 Report and Accounts](#)

The vote to approve the 2020 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

Dianne Hand stated that Virginia Cashin had retired from the Board of Trustees in March 2021 and thanked her for her involvement. Emma Oates is retiring from the Board at this AGM and was thanked for her many years of passionate support of the Charity.

Members were asked to vote in favour of electing Stefan Crocker as Trustee for a further term of 3 years. A show of hands confirmed a majority were in favour and no one was against; Stefan Crocker was duly elected to the Board.

Dr. Shehla Mohammed and Liam Wilkie were co-opted by trustees in February 2021 and were also standing for election.

Members were asked to vote in favour of electing Dr. Shehla Mohammed as Trustee for her first term of 3 years. A show of hands confirmed a majority were in favour and no one was against; Dr Shehla Mohammed was duly elected to the Board.

Members were then asked to vote in favour of electing Liam Wilkie as Trustee for his first term of 3 years. A show of hands confirmed a majority were in favour and no one was against; Liam Wilkie was duly elected to the Board.

8. Election of BBS UK Honorary Officers

Of the current Officers:

Laura Dowswell was nominated and eligible for election to the position of Chair; no further nominations had been received for this position. Members were asked to vote in favour of electing Laura Dowswell as Chair of BBS UK. A show of hands confirmed a majority were in favour and no one was against; Laura Dowswell was duly elected as Chair.

Abbie Geeson was eligible for re-election to the position of Treasurer; no further nominations had been received for this position. Members were asked to vote in favour of electing Abbie Geeson as Treasurer of BBS UK. A show of hands confirmed a majority were in favour and no one was against; Abbie Geeson was duly elected as Treasurer.

Dianne Hand was eligible for re-election to the position of Secretary; no further nominations had been received for this position. Members were asked to vote in favour of

electing Dianne Hand as Secretary of BBS UK. A show of hands confirmed a majority were in favour and no one was against; Dianne Hand was duly elected as Secretary.

9. Any Other Business

Abbie Geeson informed members that BBS UK will be reviewing its financial accounting period. Currently this runs from the 1st January to the 31st December each year and we will possibly be changing this to the 1st April to the 31st March instead. Therefore, the next set of accounts and annual report for 2021 might be extended by 3 months in order for this to occur and will most likely cover all activities from the 1st January 2021 to the 31st March 2022. There will be further updates for members in the newsletters.

10. Close of AGM

Laura Dowswell introduced herself as the new Chair before closing the AGM. Members were thanked for their attendance.

11. Update from the Charity Team

The Charity Update was rescheduled for Autumn 2021.