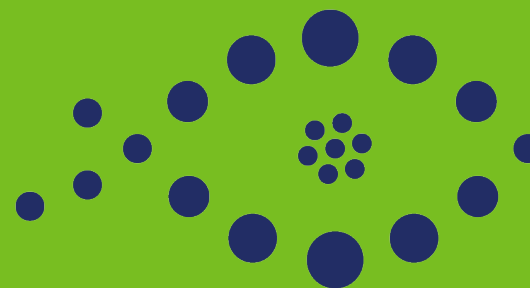




TRUSTEES' REPORT AND ACCOUNTS

FOR THE YEAR ENDED 31st DECEMBER 2020



Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

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Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

1. Administration Details

Main Address:

Bardet-Biedl Syndrome UK
43 Balton Way
Harwich
Essex
C012 4UP

Tel: 07421 312 731

Web Page: www.bbsuk.org.uk

Email: admin@bbsuk.org.uk

Bardet-Biedl Syndrome UK is a Registered Charity in England and Wales (1181244)

President: Professor Philip Beales BSc LMSSA MD FRCP

Patrons: Baroness Helena Kennedy Of the Shaws Q.C.
Ryan Jones BSc (Hons)

Bankers: Barclays Bank PLC

Independent Accounts Examiner: M. Bannister of Fryza Bannister Financials Ltd

Board of Trustees:

Chair: Stefan Crocker

Vice-Chair: Laura Dowswell

Secretary: Dianne Hand

Treasurer: Abbie Geeson

Trustee: Emma Oates

Trustee: Rachael Foley

Trustee: Judith Aylott (Co-opted: 11/03/2020)

Trustee: Virginia Cashin (Elected: 28/09/2020)

Trustee: Christian Bolton-Edenborough (Retired: 16/02/2020)

2. 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 560 diagnosed individuals known to us in the UK) can mean a delayed diagnosis and lack of adequate local health care.

3. Structure, Governance and Management

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 and 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 around 550 individuals living with BBS, their families and carers, and also 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 his/her family and any family with one or more affected children, including their grandparents and carers.

3.1 Trustees

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 the Charity 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.

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.

Bardet-Biedl Syndrome UK

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The Board seeks to be representative of the people with whom the Charity works and 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 focussed on developing governance skills, such as Safeguarding, GDPR and recruitment. 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.

4. Additional Governance Update

BBS UK/BBS UK Clinics Ltd has the following policies in place:

- Business Continuity
- Bring your own device
- Child Protection
- Code of Conduct
- Complaints
- Conflict of Interest
- Dignity at Work
- Disciplinary
- Driving Whilst on Business
- Equal Opportunities
- Finance
- Grievance
- Handling of DBS Certificate Information
- Health and Safety
- Lone Worker
- Management Structure
- Pay Review
- Reserves
- Safeguarding Vulnerable Adults
- Social Media Moderation
- Trustee Recruitment
- Volunteer
- Whistleblowing

BBS UK/BBS UK Clinics Ltd has the following Information Security policies in place:

- Collection and Recording of Service User Data
- Confidentiality / Code of Conduct
- Data Impact Assessment Procedure
- Data Protection
- Data Retention and Disposal
- Email Use
- Home Working - Handling
- Information Governance
- Information Sharing
- Information Security Reporting and Auditing
- Privacy Notice
- Subject Access Request.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

BBS UK/BBSUK Clinics Ltd has the following handbooks in place:

- Health & Safety Handbook
- Information Governance Handbook
- Staff Handbook

BBS UK Clinics Ltd has **Cyber Essentials Certification** which is an official UK wide government-backed scheme that provides protection against the most common cyber threats and demonstrates our commitment to cyber security.

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.

Disclosure and Barring Service checks (DBS) are carried out prior to commencement of employment, trusteeship and volunteering duties. DBS checks are carried out regularly 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 their governing board.

4.1 How we look after and safeguard information

BBS UK and BBS UK Clinics Ltd. aim 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 and BBS UK Clinics Ltd process and store 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 and BBS UK Clinics Ltd maintain compliance via:

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

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

For this reporting period, BBS UK and BBS UK Clinics Ltd reported no breaches in security and no 'near misses'.

5. 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 on the subject of 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:

1. Our Annual Family Weekend Conference which brings beneficiaries together with interested professionals and experts to provide access to the latest research and for members to participate in tailored workshops. Throughout the weekend there is the vital opportunity to connect with others and receive advice and support from the Charity, each other and external organisations.
2. Our activity breaks and trips give young people, adults and their families the chance to get away from the day-to-day challenges they face and build friendships with others in the same situation and be active.
3. Our Young People's Group and the Adult Focus Group enable and facilitate those with BBS to share their experiences in a safe environment and to have a voice that can impact change and understanding around social, emotional and health problems and the difficulties experienced day to day and within schools and work.
4. Our Adult Social group, held virtually, aims to create a friendly and inclusive environment, bringing people together, helping with social isolation and giving the opportunity for people to share experiences and form connections.
5. Our support services help with transitions through health diagnosis and progression of BBS and supporting members with accessing local support across areas of health,

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

education, social care and benefits etc. We encourage steps towards independence with an emphasis on empowering our young people, adults and families in ensuring they feel in control during times of rapid change.

6. The BBS UK website, www.bbsuk.org.uk, enables us to share information about Bardet-Biedl syndrome and our projects and services. Our Facebook page, Twitter and YouTube facilitate the development of an online community that self supports with members helping each other through the challenges often faced.
7. The production of twice-yearly newsletters and an annual conference report provide up to date research, information, guidance, personal perspectives and details of our projects and fundraising endeavours. We also produce a wide range of information booklets which are made available in accessible formats and different languages via our website.
8. Attendance at relevant seminars and conferences, which gives us the opportunity to learn from experts, share best practice, network and raise awareness of Bardet-Biedl syndrome.

6. BBS UK Clinics Ltd

BBS UK Clinics Ltd (company number 07257216) is a private company limited by shares and is incorporated in England and Wales. It is a wholly owned subsidiary of Bardet-Biedl Syndrome UK and is a separate legal entity, managed by its Board of Directors who are Tonia Hymers, Kevin Sales, Laura Dowswell, Abbie Geeson and Alf Pare. The Directors are responsible for the Company's day-to-day management, and all aspects of its financial accounting, employment and contracts. BBS UK Clinics Ltd reports regularly to BBS UK on its financial position and service activities.

Bardet-Biedl Syndrome UK Clinics Ltd has a contract with NHS England to facilitate the specialist multi-disciplinary clinics, which take place in Great Ormond Street Hospital and St Thomas' Hospital, London and Birmingham Children's Hospital and Queen Elizabeth Hospital, Birmingham. The requirements of the contract with the National Specialised Commissioning Team include:

- To maximise access to NHS provided services for patients with Bardet-Biedl Syndrome (BBS).
- To provide emotional and practical support and advocacy services for patients affected by BBS and their families.
- To provide information relating to services provided for patients with BBS, including relevant health promotion and lifestyle information, to maximise the health and life chances of people living with BBS.

Bardet-Biedl Syndrome UK

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To achieve the above, information and support is provided to the patients and their families/carers before, during and after clinics. Accommodation is organised for patients when needed and assistance is given with travel arrangements. This service provision ensures patients and their families are well informed about the syndrome and feel well supported to attend their clinic appointment. BBS UK has a presence at each clinic, offering emotional and practical support to patients and their families and ensure they are aware of all relevant benefits and social support services. Post clinic, ongoing support and liaison services are available.

7. Chair's Report

Stefan Crocker, Chair

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 looks set to be a success with already over 100 people confirmed to join.

8. Achievements and Performance

Tonia Hymers, Service Manager

Our support team has had a very different year responding and adapting to the Covid-19 pandemic. The first lockdown in March 2020 saw the cancellation of all planned activities including our much valued and anticipated weekend family conference and social/activity weekends which provide information, support and social contact for approximately 300 beneficiaries throughout the year. Our community, already isolated, has felt the loss of these events and has struggled enormously with the impact of Covid-19 and the shielding requirements.

The specialised BBS clinics were paused, however were quickly able to resume as a telemedicine service. Our team provided advocacy and support services to approximately 200 individuals attending approximately 30 specialised BBS clinics, either face to face or via telemedicine. The BBS clinics team at St Thomas' Rare Disease Centre said BBS UK played a 'pivotal role' in supporting the service during the lockdown period. Local healthcare services became extremely difficult to reach during the first lockdown and the BBS service provided a lifeline for those in our community who needed it, to access specialised medical support and information.

Keen to ensure the needs of our group are met, we have been proactive in engaging with patients, parents, the commissioning team and clinicians to seek out best practice for the telemedicine service. This has involved attending review meetings, organising focus groups and collecting evaluation data and this is ongoing.

8.1 Covid-19 Impact and Response

A key problem identified early on was that the information being released by the government was not easily accessible or understood by our beneficiaries who are visually impaired and many with learning difficulties. We realised that some patients were not fully aware of the restrictions and shielding guidelines and were continuing to put themselves at risk. We were also concerned that many were lacking sufficient local support.

We responded to these issues very quickly with a two-fold approach:

1. We telephoned all beneficiaries who we knew to be potentially vulnerable and/or living alone or living with older parents to support them with accessing local support services.
2. We provided our membership with easy-to-understand information, via social media, email and our website including, Covid-19 symptoms, 'What to do if you think you have Covid-19', Clinically Vulnerable and Clinically Extremely Vulnerable categories and Shielding.

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In support of this, BBS UK developed a Covid-19 Information Hub on our website to provide a focal point for all our resources. Also included in the hub were resources supporting an active lifestyle during lockdown and tips to maintain positive mental health and wellbeing.

We held several webinars to provide information about Covid-19, shielding, mental health and vaccinations. Panel members included key clinicians from the specialised BBS clinics service. Our Covid-19 webinars provided opportunities for beneficiaries to ask questions of their clinics team and also to share their own experiences of lockdown and resources/organisations that they had found useful.

During the second and third lockdowns, we continued providing relevant and timely information and support to our families. In addition, we worked with the specialised BBS clinics service to ensure our community had early access to the Covid-19 vaccination, reflecting the increased vulnerability that comes with obesity, visual impairment and learning difficulties.

With the BBS UK staff team largely working from home, the initial impact of Covid-19 was minimal. Clinics moved to telemedicine and visits to hospitals were few. Risk assessments, information and PPE were provided to all staff as needed. During the 2nd wave, the biggest impact on our team was the need for parents to provide home-schooling for their children in addition to their work. We have continued supporting our team throughout this difficult period making use of flexible working, furlough and flexi-furlough where needed.

8.2 Information Provision

BBS UK finalised its transition to a Charitable Incorporated Organisation which saw the adoption of a new logo for the first time since the Charity was established. We took the opportunity to review all of our information resources which resulted in several new publications and a redeveloped website. The following booklets are now available in print, Word and PDF:

- BBS UK Medical Information Booklet (also available in audio)
- Introducing Bardet-Biedl Syndrome (also available in audio, EasyRead, Turkish, Urdu)
- Booklet for Schools and Colleges
- My Life, My Future (Transition Handbook for Young People)
- Friends of BBS UK
- Who We Are and What We Do.

We held a webinar launching the BBS UK Booklet for Schools and Colleges, in which we outlined how the booklet and accompanying 'Student Passport' should be used and introduced our newly developed SEND/EHCP information resource. The webinar was recorded and is available on the BBS UK website.

We produced two newsletters, which included useful articles and personal perspectives focused on supporting the health and wellbeing of our beneficiaries.

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A key difficulty we have had is managing communications with our community as we have transitioned to a CIO and commenced using the CharityLog database system; for a period of time we have had to work from two different databases. This process is almost complete and will facilitate improved care and communication moving forward.

8.3 Raising Awareness and Collaboration

BBS UK are connected to many other charities and umbrella organisations, formally and informally and our organisation benefits from attending conferences, seminars, networking and training events raising awareness and seeking opportunities for learning and collaboration. The loss of these events over the past year has therefore had an impact however we have made good use of our current contacts and online platforms with the following outcomes:

- BBS UK became a founding member of Bardet-Biedl Syndrome International
- We were invited to present at a Findacure workshop
- We had an article published in SEN Magazine
- We attended virtual conferences, webinars and workshops.

8.4 Strategy Planning/Membership Audit

We have used this reporting period to review our services and organisational development and formulated a five-year strategy plan. A key aspect of this is the BBS UK Membership Audit, which asks about the impact of the Syndrome and seeks to understand what BBS UK can do to better support our community. Preliminary data will be presented at the BBS UK Conference in May 2021.

As previously described, Covid-19 has had a significant impact and we expect this to be felt across the coming five-year period. Key areas of focus will include improving communication with and easing isolation of our community; enhancing our information, advice and support provision, and empowering our membership to self-advocate.

8.5 Future Services, Events and Activities

Projects and services under development and identified as being a priority for our beneficiaries in line with the strategy, aims and objectives of the Charity include an Advice Service, Counselling/Wellbeing Support, IT Equipment Fund and Slimming World BBS UK.

The BBS UK Conference 2021 is being held via the Zoom platform across two days. Day one is aimed at professionals involved in the care, support and education of those with BBS, and day two is aimed at those living with the syndrome, their families and carers. We will all miss the invaluable social aspect that is so important to all who attend and are very much looking forward to the return of a face-to-face conference, hopefully in 2022 (providing restrictions are lifted).

We are hoping to hold a social weekend for adults living with the Syndrome and an activity weekend for families later on in the year, with a decision to be made in early summer.

Bardet-Biedl Syndrome UK

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Comments Received:

“BBS UK is an excellent organisation with excellent staff and volunteers. They have given us tremendous support since diagnosis. I don't know what we would have done without BBS UK. When my son had a diagnosis of BBS it was so reassuring to have an organisation to turn to for further information, support and to meet other families who had been/were going through the same as us.”

“Had a positive impact on how we adjusted to my son's diagnosis.”

“BBS UK have been, as always very supportive, especially during lockdowns”.

“The support I have received since being diagnosed with BBS has been brilliant.”

“Superb liaison and made us feel prepared for our stay (at clinic).”

“Brilliant support. Fabulous team of people...”.

9. Fundraising Review

Christine Saxon, Fundraising Officer

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

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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.

10. Treasurer's Report

Abbie Geeson, Treasurer

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.

Bardet-Biedl Syndrome UK

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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.

10.1 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.

10.2 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.

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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.

10.3 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.

11. Declaration

The Trustees declare that they have approved the 2020 Annual Report

Signed on behalf of the Board of Trustees

Stefan Crocker


Position: Chair

Date: 23/04/21

Bardet-Biedl Syndrome UK

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12. Accounts for year ended 31st December 2020.

 CHARITY COMMISSION FOR ENGLAND AND WALES		BARDET-BIEDL SYNDROME UK (BBS UK)		1181244		CC16a
		Receipts and payments accounts				
For the period from		01-Jan-20	To	31-Dec-20		
A1 Receipts						
Donations and Fundraising	39,452	-	-	39,452	74,002	
Childrens Family Weekend	-	-	-	-	1,971	
Adult Social Weekend Contributions	-	-	-	-	5,076	
Friends Account	7,049	-	-	7,049	7,146	
Annual Family Weekend Contributions	1,600	-	-	1,600	2,105	
Sales of Promotional Goods/Xmas Cards	829	-	-	829	964	
Gift Aid	4,730	-	-	4,730	7,679	
Interest	44	-	-	44	92	
Raffle/Tombola	-	-	-	-	2,043	
Sub total (Gross income for AR)	53,704	-	-	53,704	101,078	
A2 Asset and investment sales, (see table).						
	-	-	-	-	-	
Sub total	-	-	-	-	-	
Total receipts	53,704	-	-	53,704	101,078	
A3 Payments						
J4G Project Costs	-	2,687	-	2,687	2,760	
BDB	-	-	-	-	177	
Travel-Trustees	578	-	-	578	1,881	
Accommodation	-	-	-	-	663	
Childrens Family Weekend	-	-	-	-	4,795	
Annual Family Weekend	1,314	-	-	1,314	13,665	
Adult Social Weekend	-	-	-	-	9,491	
Fundraising Costs	-	-	-	-	906	
Marathon	-	-	-	-	142	
Raising Funds	878	-	-	878	144	
AFVS	-	-	-	-	144	
Salaries	24,747	-	-	24,747	7,944	
Awards for All - Admin officer	-	-	-	-	8,985	
Equipment	2,607	-	-	2,607	1,871	
Recruitment Advertising	-	-	-	-	299	
Contractor: Bookkeeper	2,960	-	-	2,960	2,135	
Printing/Tapes, Publications	2,110	-	-	2,110	1,901	
Telephone, Postage, Stationery	1,835	-	-	1,835	1,516	
Franking Machine Lease only	161	-	-	161	186	
Purchase of Promotional Goods	1,843	-	-	1,843	1,330	
IT Consumables	64	-	-	64	61	
Courses	95	-	-	95	151	
Insurance/Data Protection	772	-	-	772	300	
Subscriptions	1,651	-	-	1,651	567	
Refunds	-	-	-	-	114	
Miscellaneous	176	-	-	176	-	
Exhibitions	-	-	-	-	625	
CRB Forms	12	-	-	12	96	
Accountancy fees	2,148	-	-	2,148	-	
Slimming World Vouchers	2,970	-	-	2,970	-	
Rebrand	4,068	-	-	4,068	-	
Website	1,498	-	-	1,498	-	
CIO Conversion	-	-	-	-	1,222	
Freelance Fundraiser	-	-	-	-	225	
Grant Payment	-	-	-	-	40,824	
Sub total	52,487	2,687	-	55,174	104,976	
A4 Asset and investment purchases, (see table)						
	-	-	-	-	-	
Sub total	-	-	-	-	-	
Total payments	52,487	2,687	-	55,174	104,976	
Net of receipts/(payments)	1,217	(2,687)	-	(1,470)	(3,898)	
A5 Transfers between funds	-	-	-	-	-	
A6 Cash funds last year end	103,421	9,429	-	112,850	116,748	
Cash funds this year end	104,638	6,742	-	111,380	112,850	

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Cash at Bank	104,638	6,742	-
		-	-	-
		-	-	-
	Total cash funds	104,638	6,742	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name		Date of approval
	<i>A J Geeson</i>	A J Geeson		20/05/2021

13. Independent Examiner's Report



**CHARITY COMMISSION
FOR ENGLAND AND WALES**

**Independent examiner's
report on the accounts**

Section A Independent Examiner's Report

**Report to the trustees/
members of** BARDET-BIEDL SYNDROME UK (BBS UK)

**On accounts for the year
ended** 31 DECEMBER 2020 **Charity no
(if any)** 1181244

Set out on pages 9 TO 15 OF THE CHAIR'S REPORT AND ACCOUNTS

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/12/2019.

**Responsibilities and
basis of report** As the charity trustees of the Trust, 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 Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**Independent
examiner's statement** I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Signed:  **Date:** 7/6/2021

Name: MICHAEL BANNUSTER

**Relevant professional
qualification(s) or body
(if any):** DIRECTOR, AMICUS ACCOUNTANCY LTD.
CHARTERED CERTIFIED ACCOUNTANTS.

Address: THE STABLES, GOBLANDS FARM BUSINESS CENTRE,
CEMETERY LANE, HADLOW,
KENT, TN11 0LT

Section B Disclosure

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2020.

Give here brief details of any items that the examiner wishes to disclose.