



Trustees' Annual Report for the period

		Period start date			Period end date		
From	18	12	2018	To	31	12	2019

Section A Reference and administration details

Charity name Bardet-Biedl Syndrome UK (BBS UK)

Other names charity is known by

Registered charity number (if any) 1181244

Charity's principal address 43 Balton Way
 Harwich
 Postcode **CO12 4UP**

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Richard Zimble		18/12/2018 - 27/04/2019	
2	Stefan Crocker			
3	Laura Dowswell			
4	Emma Oates			
5	Dianne Hand			
6	Christian Bolton-Edenborough			
7	Rachael Foley			
8	Abbie Geeson			

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
Bank	Barclays Bank PLC	Barclays, 8-10 Calverley Road, Tunbridge Wells, Kent TN1 2TB
Independent Examiner	Fryza Bannister Financials Ltd	The Stables, Goblands Farm Business Centre, Cemetery Lane, Hadlow, Kent TN11 0LT

Name of chief executive or names of senior staff members (Optional information)

Section B Structure, governance and management

Description of the charity’s trusts

Type of governing document (eg. trust deed, constitution)	Constitution adopted 18/12/2019
How the charity is constituted (eg. trust, association, company)	Charitable Incorporated Organisation
Trustee selection methods (eg. appointed by, elected by)	Trustees are appointed or reappointed annually at the Annual General Meeting.

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity’s organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees’ consideration of major risks and the system and procedures to manage them.

The Charitable Incorporated Organisation (CIO) formed under this constitution formally represents the incorporation of the unincorporated charity, Bardet-Biedl Syndrome UK (1027384), formerly known as Laurence-Moon-Bardet-Biedl Society and LMBBS. The CIO is the successor body to the original Charity. The CIO will request from the Charity Commission to be entered into the register of mergers to formally link the unincorporated and incorporated charities.

BBS UK has the following policies in place: Business Continuity Plan, Child Protection, Code of Conduct, Complaints, Confidentiality, Conflict of Interest, Dignity at Work, Disciplinary, Equal Opportunities, Finance, Grievance, Health and Safety, Handling of DBS Certificate Information, Lone Worker, Management Structure, Pay Review, Reserves, Safeguarding Vulnerable Adults, Social Media Moderation, Volunteer and Whistleblowing.

BBS UK has the following Information Governance policies in place: Collection and Recording of Service User Data, Data Protection, Email Use, Home Working, Information Governance, Information Sharing, Information Security Reporting and Auditing.

BBS UK has the following handbooks in place: Health & Safety handbook, Information Governance handbook and a Staff handbook.

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.

Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

The objects of the CIO are:
(a) to preserve and protect the health and promote the welfare of persons diagnosed with Bardet-Biedl Syndrome and their families;
(b) 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.

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

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 main activities the charity undertakes in pursuance of its objectives are:

- Annual Family Weekend Conference
- Activity breaks and trips for young people, adults and their families
- Young People's Group and the Adult Focus Group
- Support services to help with transitions through health diagnosis and progression of BBS.
- Production of twice-yearly newsletters and an annual conference report

Section D Achievements and performance

Summary of the main achievements of the charity during the year

Since the incorporation of Bardet-Biedl Syndrome UK (BBS UK) in December 2018 the Board of Trustees have worked throughout 2019 on the conversion of the charity structure and have continued setting up the new finance facilities, HMRC Gift Aid registration and the renewal of the membership of the new organisation and have established a new membership database.

Section E Financial review

Brief statement of the charity’s policy on reserves

The charity funds as at 31 December 2019 were £0.00

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 risk to the charity is loss of funding from reduced donations.

Trustees of the charity have approved the reserves policy and decided that free reserves should be sufficient to cover six months ongoing costs in the event of a loss of income and to meet any unforeseen expenditure that may occur.

Details of any funds materially in deficit

Not Applicable

Bardet-Biedl Syndrome UK (BBS UK)

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2019

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

In February 2020 the transfer of assets less any outstanding liabilities will be transferred from the unincorporated charity, Bardet-Biedl Syndrome UK (1027384) to the CIO.

Section F Other optional information

Postponement of the BBS UK Annual General Meeting (AGM)

The 2020 BBS UK Annual Family Conference had to be cancelled because of the COVID-19 pandemic. We were due to hold our AGM on 18th April 2020, but owing to the cancellation, this could not take place.

On current government advice we are unable to hold face to face meetings but the new Corporate Insolvency and Governance Act, permits CIOs like ourselves to hold our AGM via electronic means. After consultation with the Charity Commission and the Board of Trustees, we feel it is in the charity's best interests to hold the AGM virtually at this time, rather than to delay it further. We are therefore making arrangements to hold our AGM on Monday, September 28th at 10.30am via a video Zoom Meeting.

Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)	<i>Stefan Crocker</i>	
Full name(s)	Mr Stefan Crocker	
Position (eg Secretary, Chair, etc)	Chairman	
Date	24/02/20	

Bardet-Biedl Syndrome UK (BBS UK)

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2019



CHARITY COMMISSION
FOR ENGLAND AND WALES

BARDET-BIEDL SYNDROME UK (BBS UK)

1181244

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Receipts and payments accounts

For the period from	18-Dec-18	To	31-Dec-19
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Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	-	-	-	-	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	-	-	-	-	-
A3 Payments					
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	-	-	-	-	-
Net of receipts/(payments)	-	-	-	-	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	-	-	-	-	-

Bardet-Biedl Syndrome UK (BBS UK)

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2019

Section B Statement of assets and liabilities at the end of the period				
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds		-	-	-
		-	-	-
		-	-	-
	Total cash funds	-	-	-
	(agree balances with receipts and	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
	<i>Abbie Geeson</i>	Abbie Geeson	13/03/2020	