



TRUSTEES' REPORT AND ACCOUNTS

FOR THE YEAR ENDED 31st DECEMBER 2019

FOR

BARDET-BIEDL SYNDROME UK

Registered Charity No's: 1027384 and SCO41839



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Bardet-Biedl Syndrome UK

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

Administration Details

Main Address:

Bardet-Biedl Syndrome UK
1 Blackthorn Avenue
Southborough
Tunbridge Wells
Kent
TN4 9YA

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Web Page: www.bbsuk.org.uk

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Bardet-Biedl Syndrome UK is a Registered Charity in England and Wales (1027384)

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:

Richard Zimble, (Retired April 2019)
Stefan Crocker, Chair
Laura Dowswell, Vice-Chair
Abbie Geeson, Treasurer
Rachael Foley, Secretary
Emma Oates, Trustee
Dianne Hand, Trustee
Christian Bolton-Edenborough, Trustee
Judith Aylott, Trustee (Elected April 2019)

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 an estimated 550 diagnosed individuals known to us in the UK) can mean a delayed diagnosis and lack of adequate local health care.

Structure, Governance and Management

Bardet-Biedl Syndrome UK (formally known as LMBBS) was established in 1993 and is the only registered charity supporting people with Bardet-Biedl Syndrome, their families and carers in the UK. The aims of the Charity are to preserve and protect the health and promote the welfare of persons who have BBS, and to advance the education of the medical and educational professionals and the general public on the subject of BBS. The governing document of the Charity is a constitution, which was adopted on 1st August 1993.

The Board of Trustees is responsible for the governance of the Charity. The Charity now consists of approximately 670 patients/family members and 37 professionals. 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. Each family has two votes; single members without a family have one vote. Associate membership is open to those interested in furthering the work of the Charity.

Conversion to the Charitable Incorporated Organisation (CIO)

The Board of Trustees have continued to work throughout 2019 to set up the new CIO. The Charitable Incorporated Organisation (CIO) 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.

Trustees

Trustees are elected during the Annual General Meeting of the Charity. The Honorary Officers of the Charity hold office for one year, but are eligible for re-election annually. They must be ex officio members of the Charity, the Executive Committee or of any other Committee. The Executive Committee hold office for two years. All Trustees give their time freely and receive no remuneration or other benefits; however, any incurred expenses are refunded as appropriate.

Additional Governance

BBS UK/BBS UK Clinics Ltd 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/BBS UK Clinics Ltd 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/BBSUK Clinics Ltd 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.

Bardet-Biedl Syndrome UK has been entered in the Scottish Charity Register with Charity number SC041839 under the Charities and Trustee Investment (Scotland) Act 2005. Since 2012, BBS UK is a member of the Fundraising Standards Board.

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 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

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

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:

- To preserve and protect the health and promote the welfare of persons affected by Bardet-Biedl Syndrome and their families
- 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

The main activities the charity undertakes in pursuance of its objectives for the public benefit are:

- 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.
- 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.
- 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.
- Our support services help with transitions through health diagnosis and progression of BBS. 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.
- The BBS UK website enables us to share information about Bardet-Biedl Syndrome and our projects and services. Our new website is currently under development and will be up and running in 2019. Our Facebook page facilitates the development of an online community that self supports with members helping each other through the challenges often faced.
- 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 endeavors. We also produce information such as the BBS UK Medical Booklet and 'Who are we and how can we help' leaflets. All our publications are made available in large print, CD and audio recordings via our website and through our YouTube channel. In addition, the 'Who are we and how can we help' leaflet is available in Urdu and Turkish.
- Attendance at relevant seminars and conferences, which gives us the opportunity to learn from experts, share best practices, network and raise awareness of Bardet-Biedl Syndrome.

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 and Abbie Geeson. The Directors are in charge of 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.

To achieve the above, we provide information and support to the patients and their families/carers before, during and after clinics. We organise accommodation for patients when needed and assist with travel arrangements. Our involvement pre-clinic ensures patients and their families are well informed about the syndrome and feel well supported to attend. We have 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 we provide ongoing support and liaise between patient and hospital where required and generally provide an ongoing point of contact.

In addition we provide information and assistance to clinicians where appropriate. This may take the form of liaising with patients on their behalf, supporting research projects or assisting with awareness and development programmes. In addition to providing direct clinic services, we organise an annual family conference, bringing together interested professionals and those with BBS, their families and carers, for a formal conference programme and social weekend. We provide information leaflets, which are currently under review and produce two Newsletters and a Conference Report annually. All publications are committed to the health promotion and lifestyle management issues of those with BBS and their families/carers and are distributed to our members in accessible formats, as well as being available on the BBS UK website. We manage the website and keep it updated with clinic news and the latest research and medical information and maintain a database of BBS patients. We report annually to the Commissioning team as is required.

Chairman's Report

Stefan Crocker, Chairman

During my first year as Chairman it has been a great honour to follow the great work of Phil Humphries, Steve Burge and most recently Richard Zimble. I have been out and about representing the charity on many occasions and meeting with fellow BBS adults through my volunteering at the BBS clinic at St Thomas' hospital. I have enjoyed participating in board meetings and decision making, this most importantly included the completion of the CIO conversion. I would like to thank all our trustees and volunteers for their time and the fantastic work on behalf of BBS UK. I would like to highlight a few specific individuals for praise. Firstly, Judith Aylott on completing her first year as a trustee and she has thoroughly involved herself. Finally, the board has reshuffled the honorary office holders. Abbie has done a great job as Treasurer and performed sterling work on the CIO conversion. Laura has been great and very supportive of me in her role as vice-chairman. Lastly, I would like to thank Rachael as she has done an excellent job in the role of Secretary.

2019 was a busy year for the charity. Three major events were held beginning with a highly successful conference in April. This was followed by a brilliant and highly popular Young Person's weekend, held at Whitemoor Lakes, and the amazing and oversubscribed Adult Social Weekend in Birmingham. We are looking at repeating the Adult Social Weekend in 2020 but we are considering a southern based venue. After a couple of years of hard work, the CIO conversion was completed. This conversion reduces the financial liability of the charity's board members. It does mean that the membership has to be completed again, if you have not completed a current membership form please do so asap. We have also entered into a rebranding exercise this year and have a shiny new logo. In the coming months the rebranding should stretch to our documents, handbooks and merchandise. The charity also took on two new members of staff. We recruited Rebecca Perfect as an Administration and Development Officer in January 2019. At the same time, we were blessed to encounter Christine Saxon and we recruited her as Fundraising Officer also in January 2019.

Fundraising exploits have been good in 2019. The main highlight was a comedy night in London, it featured many top name comedians and was organised by Liddy Vincent's brother Andre. Liddy was heavily involved in promoting the event and making sure tickets were sold out. A group of BBS adults and parents undertook runs during the Great South Run. This involved participation in both the 5km and 10-mile runs. There were many other fundraising events which Christine will cover. The charity highly values everyone who decides to fundraise for us, as a small charity you are the lifeblood of BBS UK. The charity always encourages new fundraisers, if you are keen or unsure how to please talk to Christine and she can advise how to and the suitability of your fundraising endeavours.

Achievements and Performance

BBS UK Family Support Team

Tonia Hymers, Service Manager

Angela Scudder, Support Officer: London

Amy Clapp, Support Officer: Birmingham

We have had another busy and rewarding year with new referrals continuing to flow in; we currently have approximately 559 patients on our database, an increase in 50 from the previous year. To address the increasing numbers and waiting times, a new telemedicine service has been rolled out across the four centres. This is an incredibly innovative service and there have inevitably been teething problems here and there. With the support and feedback from patients, we continue to support the development of this new aspect of the service ensuring it remains patient centred and comparable across the four centres.

Maintaining good communication with patients and hospitals enables us to ensure the best possible patient experience and feedback continues to be overwhelmingly positive. Patients and their families tell us how highly they value the service, the BBS UK Support Team, clinicians and support staff across the four centres.

In addition to clinic facilitation services, our team provides family and patient support and liaison services, we produce leaflets and newsletters and organise events aimed at improving knowledge and awareness of BBS and reducing isolation. We continue to be busy supporting families with Education, Health and Care Plan applications, benefits applications/appeals and local authority referrals; the ways in which we can support our families are many and the results are rewarding.

In April 2019, we welcomed a new member of staff, Liddy Vincent to the team. Liddy provides clinic support at three of our four centres and has quickly become invaluable in that respect, ensuring the day runs smoothly and providing support to patients and clinics team members as needed.

The family support team worked hard alongside the Board of Trustees to ensure another excellent conference in 2019 and Conference 2020 is set to be one of our most successful yet, with an increase in attendees and an increase in first time delegates. We are incredibly grateful to the BBS Clinicians and other professionals who continue to support this event year on year, giving up their weekend to ensure our families have the most up to date information about the syndrome, relevant benefits and support.

In July we had another fantastic weekend at Whitemoor Lakes Outdoor Activity Centre in beautiful Staffordshire. During the weekend, our families enjoyed archery, hi-ropes, abseiling, canoeing, raft-building and sailing. In the evenings we had a sing-song and games around a bonfire followed by a movie and popcorn!

Bardet-Biedl Syndrome UK

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

This very special weekend provides the opportunity for families to enjoy activities together, alongside other families who fully understand what it means to live with Bardet-Biedl Syndrome and it is fantastic to see everyone coming together and supporting each other.

In October we held another Adults Social Weekend at the Holiday Inn in Birmingham City Centre. We enjoyed a lovely meal on the Friday night, catching up with old friends and meeting new; everyone really valued the opportunity to spend time with other adults living with the syndrome in a relaxed and inclusive environment. On the Saturday we had a BBC Studios Tour, followed by afternoon tea and Blood Brothers at the Birmingham Hippodrome.

A new BBS UK Transition Handbook, 'My Life, My Future!' has been published and distributed and has been very well received, our grateful thanks to Genetic Disorders UK and their Jeans for Genes programme for funding this project. This invaluable resource was produced in collaboration with young people who have BBS and is the only publication specifically written for young people with the syndrome. The charity is undergoing a re-brand and once completed will see the publication and distribution of a booklet for schools, a basic leaflet about BBS and an updated medical information booklet; the text for these are complete and ready for design and layout.

The coming year will no doubt bring new challenges and we look forward to supporting the charity and clinics services in meeting those challenges. The most enjoyable and rewarding aspect of our work is attending clinics and events and we look forward to meeting and supporting many more families and individuals over the coming year.

Fundraising Review

Christine Saxon, Fundraising Officer

My first report since joining and I should like to thank all the members, staff and Trustees for making me feel so welcome. Special recognition should go to Dianne Hand, Trustee, who continues to support the fundraising function with gusto. She has sent over 50 thank you cards and letters this year, and we have also introduced the Certificate of Thanks to give to those who have helped BBS UK in any way.

One of the joys of writing a report for the AGM is that it gives us the opportunity to look back and appreciate all that has been accomplished in 2019.

Your fundraising effort for BBS UK has grown a pace in the last five years. In total you have worked hard through raffles, coffee mornings, summer fairs, sponsored walks, swimathons, runs and extreme challenges to both raise our profile and money; £192,546 in total.

Donations and General fundraising in 2019 has been brilliant, rising from just under £18k in 2015 to over £51k this year. In any business this would be gargantuan growth but, in a charity, this is exceptional, and enables us to develop our support and services.

Bardet-Biedl Syndrome UK

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

The main difference that I can see is increased families working together, using their contacts, speaking to friends and work colleagues and as a collective raising more by spreading the word. Last year we had a great presentation by the Wilkies, who illustrated how they had made a difference. This heightened profile continues to bring in gifts from Scotland: The Tractor event at Perth, the Kilt Walk and a couple of corporate donations have been received.

The Hobbs family in Leicestershire have replicated this approach. Organising a team of over 40 to enter the Tough Mudder event, they raised over £10k whilst spin offs continue from Coffee Lounges, corporate support and evening live music events.

Another family event saw the combined efforts of Liddy Vincent and her brothers who organised a star-studded evening for BBS UK at the Comedy Store in London's West End. This raised around £5000. We need to be attracting these larger events as they have knock on awareness for BBS UK and widen our supporter base.

Fundraising started in this year will continue to bring in income next year too. Thomas Billam attracted media attention before Christmas as he is running the Edinburgh Half Marathon in May 2020 blindfolded. Just Giving continues to be a key source of funds with over 59 pages opened in the period, though Thomas is a student, his Just Giving page has already reached over £2,000. Press coverage helps.

HOWEVER, it doesn't have to be large amounts: whatever the event, whatever the income we are so grateful for all your hard work and donations raised.

Grants and Trusts continue to support us, we have made over 25 applications this year and identified another 70 to approach. A parent with connections to the Lotus Charitable Trust made an approach and they gifted us £5000. This is their second gift in two years, we are extremely grateful for their support.

Jeans 4Genes week has given BBS UK the opportunity for some great PR: full article in Woman magazine, two radio broadcasts, three local paper articles and several companies agreeing to support, alongside a few schools and existing supporters.

In conclusion thank you to everyone who has kept us posted about their 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.

Treasurer's Report

Abbie Geeson, Treasurer

Income during 2019 was £101,078 compared to £96,327 in 2018, which included restricted grants of £13,885. There was a reduction in unrestricted fundraising and donation income

Bardet-Biedl Syndrome UK

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

from the previous year but the momentum of fundraising events undertaken by the charity's membership during the year continued.

Expenditure during 2019 was £104,976 compared to £61,860 in 2018. The increase in expenditure was due to several reasons; the review of the Admin Officer role, the employment of a Fundraising Officer, the purchase of new IT equipment, a new contract for service for a freelance Bookkeeper and the designated spend of the Research fund.

At the end of 2019 the Charity had total funds of £112,850. Of this £9,429 is restricted and relates to specific grants which will be spent in 2020.

A realistic and prudent budget has been set for 2020 which will enable the core activities and objectives of the Charity to be carried out. Expenditure remains well controlled although the costs of activities will naturally rise each year.

As ever Trustees are mindful of the uncertainty of securing income from other sources which is needed to support its long- term sustainability of services and projects. BBS UK relies solely on the committed and ongoing support of its members and we are continually working to diversify the charity's income stream.

The Trustees would like to take this opportunity to offer huge thanks and extend our appreciation to all our regular donors and those that freely give up their time to fundraise for the Charity.

The new Charitable Incorporated Organisation (1181244) will formally represent the incorporation of the Unincorporated Charity, Bardet-Biedl Syndrome UK (1027384) and the CIO is the successor body to the original Charity. During 2020 the assets and liabilities of the Unincorporated Charity will be transferred to the Incorporated Charity.

BBS UK Reserves and Designated Funds

The Charity funds as at 31 December 2019 were £112,850.

These are represented by restricted funds of £9,429 and designated funds of £56,540 for committed expenditure. This leaves general funds of £46,881 which is free reserves.

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 which is why the Charity will be designating future project/core costs.

Trustees of the charity have approved the reserves policy and decided 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.

Bardet-Biedl Syndrome UKReport of the Trustees and Statement of Financial Activities for the year ended 31st December 2019

The unrestricted expenditure for 2020 is budgeted at £83,790. The free reserves at the end of 2019 would therefore represent 6 months' expenditure and trustees consider the current level of reserves to be adequate for the charity to operate with sufficient reserves to avoid financial difficulties.

	£
Total funds held at 31 December 2019	112,850
Less:	
Restricted fund	(9,429)
Designated fund: 2021 Family weekend	(16,000)
Designated fund: 2021 Adult activity weekend	(9,400)
Designated: 2021 Staff costs	(31,140)
 Free reserves at 31 December 2019	 <u>46,881</u>

Declaration

The Trustees declare that they have approved the 2019 Annual Report

Signed on behalf of the Board of Trustees

Stefan Crocker


Position: Chair

Date: 10/03/2020

The 2019 annual report and accounts represent the last active year of the Unincorporated Charity. As this was the final annual report it was due to be presented to its members on the 18th April 2020, however, this meeting was postponed due to the COVID-19 Pandemic. We are therefore making alternative meeting arrangements in order for our members to consider the 2019 annual report and accounts.

Bardet-Biedl Syndrome 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		1027384 SC041839		CC16a
		Receipts and payments accounts				
		For the period from	01-Jan-19	To	31-Dec-19	
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						
Donations and Fundraising		60,117	13,885		74,002	72,875
Childrens Family Weekend		1,971			1,971	2,152
Adult Social Weekend Contributions		5,076			5,076	5,269
Friends Account		7,146			7,146	7,012
Annual Family Weekend Contributions		2,105			2,105	2,145
Sales of Promotional Goods/Xmas Cards		964			964	1,329
Gift Aid		7,679			7,679	4,870
Interest		92			92	67
Weather Lottery					-	51
Raffle/Tombola		2,043			2,043	406
Refunds (FRSB)					-	151
	<i>Sub total (Gross income for AR)</i>	87,193	13,885	-	101,078	96,327
A2 Asset and investment sales, (see table).						
		-	-	-	-	-
		-	-	-	-	-
	<i>Sub total</i>	-	-	-	-	-
	Total receipts	87,193	13,885	-	101,078	96,327
A3 Payments						
J4G Project Costs			2,760		2,760	1,513
BDB			177		177	3,052
Travel-Trustees		1,881			1,881	1,267
Accommodation		663			663	1,081
Childrens Family Weekend		4,795			4,795	4,428
Annual Family Weekend		13,665			13,665	13,785
Adult Social Weekend		9,491			9,491	9,990
Fundraising Costs						
Marathon		906			906	396
Santa Run					-	100
Raising Funds		142			142	-
AFVS		144			144	-
Salaries		7,944			7,944	5,540
Awards for All - Admin officer			8,985		8,985	-
Equipment		1,871			1,871	713
Recruitment Advertising		299			299	670
Contractor: Bookkeeper		2,135			2,135	-
Printing/Tapes, Publications		1,901			1,901	6,137
Telephone, Postage, Stationery		1,516			1,516	2,263
Franking Machine Lease only		186			186	186
Purchase of Promotional Goods		1,330			1,330	985
IT Consumables		61			61	120
Courses		151			151	-
Insurance/Data Protection		300			300	443
Subscriptions		567			567	545
Refunds		114			114	1,272
Exhibitions		625			625	194
CRB Forms		96			96	84
GDPR/Staff					-	286
Website					-	5,000
CIO Conversion		1,222			1,222	855
Freelance Fundraiser		225			225	775
Grant Payment		40,824			40,824	-
	<i>Sub total</i>	93,054	11,922	-	104,976	61,680

Bardet-Biedl Syndrome UK

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

A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	93,054	11,922	-	104,976	61,680
Net of receipts/(payments)	- 5,861	1,963	-	- 3,898	34,647
A5 Transfers between funds			-	-	-
A6 Cash funds last year end	109,282	7,466	-	116,748	82,101
Cash funds this year end	103,421	9,429	-	112,850	116,748

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	Cash at Bank	103,421	9,429	-
		-	-	-
		-	-	-
	Total cash funds (agree balances with receipts and payments account(s))	103,421	9,429	-
		OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		Fund to which asset belongs	Cost (optional)	Current value (optional)
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 liability relates	Amount due (optional)	When due (optional)
B5 Liabilities	Details		-	
			-	
Signed by one or two trustees on behalf of all the trustees		Signature	Print Name	Date of approval
		<i>Abbie Geeson</i>	Abbie Geeson	11/03/2020



**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**

Charity Name
BARDET-BIEDL SYNDROME UK

**On accounts for the year
ended**

31 DECEMBER 2019	Charity no (if any)	1027384 SC041839
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Set out on pages

15 TO 16 OF THE TRUSTEES' 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").

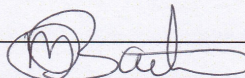
I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**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: 12/3/2020

Name: MICHAEL BANNISTER

**Relevant professional
qualification(s) or body
(if any):**

ACCA.

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).