



Bardet-Biedl Syndrome UK
Registered Charity No: 1027384 and SCO41839

TRUSTEES' REPORT AND ACCOUNTS

FOR THE YEAR ENDED 31st DECEMBER 2018

FOR

BARDET-BIEDL SYNDROME UK





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Administration Details

Main Address:

Bardet-Biedl Syndrome UK
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Email: info@bbsuk.org.uk

Bardet-Biedl Syndrome UK (formally known as LMBBS) is a Registered Charity in England and Wales (1027384) and in Scotland (SCO41839)

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, Chair
Stefan Crocker, Vice-Chair
Laura Dowswell, Treasurer
Abbie Geeson, Secretary
Emma Oates, Trustee
Dianne Hand, Trustee
Margarita Sweeney-Baird, Trustee (Retired April 2018)
Christian Bolton-Edenborough – Trustee (Elected April 2018)
Rachael Foley – Trustee (Elected April 2018)

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2018



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 worked throughout the year on converting the current charity structure and in December 2018 the Trustees were delighted to receive approval from the Charity Commission for the new CIO, Bardet-Biedl Syndrome UK (BBS UK) registered

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2018

charity (CIO) in England and Wales: No. 1181244. The CIO will become active in 2019 and the Trustees will continue to set up the finance facilities and renew the membership of the new organisation.

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

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

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2018

BBS UK strives to bring together through our projects and services, support to our members. The Charity has well developed projects some of which started back in 1993. The main activities the charity undertakes in pursuance of its objectives 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 and is a wholly owned subsidiary of Bardet-Biedl Syndrome UK. It is a separate legal entity and is 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

Richard Zimble, Chairman

The Charity has had another busy year planning, organising and supporting our various projects and events and in raising awareness of our syndrome. The Charity continues to develop and the Trustees are very proud of its progress in strengthening its governance, finance and fundraising activities.

I would like to thank all of the volunteers who gave up their time to give support at last year's Conference, the speakers for giving up their time to come and deliver some very interesting and valued talks to our members, the delegates who attended and made the 2018 Conference a very enjoyable time and experience for everyone and the staff at the Hilton Hotel who ensured that everyone was well supported, welcomed and looked after whilst staying at the hotel. The 2018 Conference was deemed a great success with new and old members attending with a wealth of information and advice available and good times had by all. To the new families who attended last year I hope that you enjoyed and got a lot out of your first Conference and I hope it was the first of many for your family.

I would like to thank the Staff, Honorary Officers, Trustees and Observers on the Committee for all their input, hard work and contribution to the Charity over the past year. At this year's AGM, Laura Dowswell is stepping down from her role as Treasurer and Abbie Geeson is stepping down as Secretary. I would like to thank them both for all of the hard work they have done whilst in these roles for BBS UK. I am stepping down as BBS UK Chairman and also as a BBS UK Trustee. I have been on the Board of Trustees for 10 years and feel it is time to leave and let someone else come onto the Board to help take our Charity further in the future.

The Charity had its third Social Weekend in 2018 and this was attended by 30 people which included guests and support staff. We are already planning our fourth Social Weekend for later this year. The Family Activity Weekend was also a great success and was attended by 25 people. Next year there will be another activity weekend and this will again be held at Whitemoor Lakes Activity Centre. I would like to take this opportunity to thank the volunteers for giving their support at our events and for their help throughout the year as without you it wouldn't be possible for these to be as accessible as they are to our members.

We continue to be active in raising awareness of Bardet-Biedl Syndrome and this has entailed attending various different events such as the Rare Disease Day in London and Birmingham and Sight Village in Leeds. The clinics are being well attended with numbers continuing to grow and networks between patients being formed. I would like to thank all of the clinics teams at all of the hospitals for the continued smooth running of the multi-disciplinary clinics. I would also like to thank Tonia, Angela and Amy for their hard work, dedication, support and smooth running of all of the clinics and support services and for all their dedicated support to the Board of Trustees and charity projects as well.

Our financial position continues to strengthen. We have made good progress with the CIO

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2018

conversion and the Board of Trustees have recently recruited a new Development and Administration Officer, Rebecca Perfect, who will support the Charity with its governance and development. The Board of Trustees have also recruited a Fundraising Officer, Christine Saxon, who will further develop our fundraising initiatives.

I would like to finish by thanking all the members, their families, friends and the public for making such a big effort with all of the fundraising throughout the year, and for the donations, as without your support many of the services that we provide wouldn't be possible.

BBS UK Family Support Team

Tonia Hymers, Service Manager
Angela Scudder, Support Officer: London
Amy Clapp, Support Officer: Birmingham

As a team we continually seek improvement and best practice and as such, our working practice is ever evolving. Having said that, 2018 was a year of consolidation following the change and restructure of previous years and the BBS UK Support Team is now firmly established and continues to provide excellent support and facilitation services across the Birmingham and London clinics service.

The BBS UK Annual Audit Meeting was held in November in Birmingham and was attended by Service Leads from all four centres, NHS England and BBS UK. The increasingly stretched service and possible solutions were discussed at length throughout the day, as was the introduction of tele-clinics which will be rolled out across the coming year. BBS UK's presentation reported on our activity across the previous year and included a summary of the completed evaluation forms from across the service and service user data. We spoke about our work with the Breaking Down Barriers project and our project outcomes to date before reporting on the successful opening of the two new Rare Disease Centres at St Thomas' Hospital, London and Birmingham Children's Hospital.

We also presented the results from a previously conducted Bowel Symptoms Audit which appears to implicate bowel disorders in BBS, in particular Irritable Bowel Syndrome. These results have been forwarded to key clinics team members in the hope that this will lead to further research.

Much of our work is done outside of clinics: providing family and patient support, liaising with families, clinicians and local authorities, facilitating clinics, producing newsletters and organising events. We continue to be busy supporting families with Education, Health and Care Plan applications, PIP and DLA applications and local authority referrals; the ways in which we can support our families are many and the results are rewarding. Fitting the specialist multi-disciplinary service within the NHS is always going to present challenges, however good communication with the 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 and the fantastic BBS UK Support Team, clinicians and support staff across the four centres.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2018

We currently have approximately 509 patients on our database, down from last year which reflects data processing changes following the introduction of GDPR in May. Patients who were on our database but did not want to attend clinics have now been removed. We continue to receive a high number of new referrals which continues to put a strain on the service with the gap between appointments for our patients stretching out to in excess of 20 months. We continue to support the clinics teams in continually looking at ways of managing the increasing demands on the service to ensure our patients, their families and carers receive the best possible support and care. Over the coming year we will see the introduction and integration of tele-clinics into the service which will enable the teams to provide more patient tailored care.

The BBS UK membership and patient group is ethnically diverse, with approximately 40% identifying themselves other than as 'White British', so at BBS UK we are keen to ensure that our support services are reaching all aspects of our membership. To that end, in May 2016 we applied to take part in a three-year project called 'Breaking Down Barriers', organised by Alstrom Syndrome UK and funded by the Sylvia Adams Charitable Trust. The three years have now come to an end however the project continues and we are delighted to have continued access to the excellent mentoring and workshops which have proven invaluable. The project aims to help patient organisations join together to support families from ethnically diverse backgrounds that have an increased risk of having children with genetic conditions and who have difficulty accessing mainstream services. The project has enabled BBS UK to develop a greater understanding of and provide greater support to ethnically diverse families and individuals and to facilitate greater access to the specialised BBS Clinics. Outcomes to date include increased attendance of delegates from ethnically diverse backgrounds at our Annual Family Conference and the translation of a leaflet about BBS and BBS UK into Turkish and Urdu. We have so enjoyed working with the BDB team across the three years and look forward to our continued involvement in this project.

The BBS UK Medical Information Booklet, launched at the BBS UK Family Conference in 2016 continues to be well received with requests from overseas to adopt and translate. Copies are available in hard copy, CD and PDF and can be found on the BBS UK website and the BBS UK YouTube channel. The booklet is currently undergoing a review by the BBS clinics teams and an updated, revised edition will be published this coming year.

The Bardet-Biedl Syndrome Information Booklet for Schools, a Transition Handbook (titles to be confirmed) and an Introducing BBS booklet are almost finished; the text is in place and work is now progressing on layout and design. The Information Booklet for Schools and Transition Handbook are being funded by Genetic Disorders UK, within their Jeans for Genes programme and we are incredibly grateful for their support. All BBS UK information booklets are produced in collaboration with patients, parents and professionals with relevant experience and expertise and are produced within the NHS England Information Standard framework.

The family support team worked hard alongside the Board of Trustees to ensure another excellent conference in 2018, and Conference 2019 looks set to be of an equally high standard. With a focus on health and wellbeing, we look forward to a weekend looking at ways of being and staying healthy. We are incredibly grateful to the BBS Clinicians and other professionals who continue to support this event year on year, giving up their

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2018

weekend to ensure our families have the most up to date information about the syndrome, relevant benefits and support. We are also grateful to the volunteer Events and Activities Support Team who enable our guests to enjoy a fun-filled day at Drayton Manor Theme Park; we are blessed to be so very well supported.

We have been working towards a 4th Family Activity Weekend to be held in July 2019 at Whitemoor Lakes Activity Centre. 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; we are all looking forward to what promises to be another fabulous weekend.

In September we held our 3rd Social Weekend at the Holiday Inn in Birmingham City Centre. We had great fun catching up with old friends and meeting new; everyone really valued the opportunity to spend time with others living with the syndrome in a relaxed and inclusive environment. On the Saturday we went to the theatre to see Saturday Night Fever and followed the performance with a gala dinner back at the hotel. We are currently planning our 4th Social Weekend for Autumn/Winter 2019.

We have no doubt that the coming year will prove as challenging and rewarding as the last, but we will work hard to ensure the BBS UK Family Support Service remains patient focused and continues to deliver the best possible care and support. The most enjoyable and rewarding aspect of our role is, of course, attending clinic days, conferences and activity events and we look forward to meeting and supporting many more individuals and families over the coming year.

Fundraising Review

Dianne Hand, Fundraising Team

On behalf of the Trustees of BBS UK I would like to say a huge heartfelt thank you to everyone who has supported our fundraising this year. The amount of money we have raised and the number of people who have supported BBS UK in some way has been truly magnificent. We have always said that the more we can raise, the more we can do and we are very excited about how we can continue to move the Charity forward and support our members. We are looking to supplement your wonderful generosity with grants and funding and we now have a Fundraising Officer, Christine Saxon, on board to help us do this.

Every penny counts and goes directly where it is needed, including family support, production of newsletters and information booklets and towards subsidising our Family Conference, our Social Weekend for adults and our Family Activity Weekend. Because of the astounding fundraising efforts of the Wilkie family and their supporters we are now in a position to be able to support research into Bardet-Biedl Syndrome. This is not something we have done before and so it is an incredible new journey for us and we look forward to working alongside Professor Beales and his team to find projects for us to become involved with.

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 have a go too. Every single donation

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2018

is appreciated, big and small, as we all try to make a difference to the lives of people affected by Bardet-Biedl Syndrome.

Treasurers Report

Laura Dowswell, Treasurer

Income during 2018 was £97,945 compared to £51,217 in 2017. 2018 saw an unprecedented year of fundraising in which donations of £72,875 were received compared to £20,808 in the previous year.

Expenditure during 2018 was £63,298 compared to £40,238 in 2017. The increase in expenditure was due to several reasons; more social and family weekend activity, the employment of an admin officer, and costs of a new website. Core expenditure remains well controlled although the costs of the annual conference is the largest item of expenditure at £13,785 and naturally the costs rise each year.

At the end of 2018 the Charity had total funds of £116,748. Of this £7,466 is restricted and relates to specific grants which will be spent in 2019.

A realistic and prudent budget has been set for 2019 which will enable the core activities and objectives of the Charity to be carried out, but as ever Trustees are mindful of the uncertainty of the future financial situation.

Last year we spoke about the need for the Charity to build up reserves to ensure its long-term sustainability. This need still remains, and is one of the priorities. Apart from the grant which is restricted for a specific project, the Charity receives no external funding and relies solely on the committed and ongoing support of its members.

The Committee 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.

BBS UK Reserves and Designated Funds

The Charity funds as at 31 December 2018 were £116,748.

These are represented by restricted funds of £7,466, designated fund (for committed expenditure) £15,193 annual family weekend, £8,700 adults' activities, £8,700 children's activity weekend, £12,000 staff costs and £35,000 research fund. This leaves general funds of £29,689 which is free reserves.

In early 2018, Trustees of the Charity reviewed the reserves policy and decided that free reserves should be sufficient to cover six months ongoing costs. In 2019 these costs are budgeted at £102,778 less £87,059 designated funds = £29,689 for the full year.

The reserves at the end of 2018 available as general funds would represent in excess of 12 months' expenditure and therefore trustees consider the current level of reserves to be adequate.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2018

	£
Total funds held at 31 December 2018	116,748
Less:	
Restricted fund	(7,466)
Designated fund (family weekend)	(15,193)
Designated fund (adults' activities)	(8,700)
Designated fund (children's activity weekend)	(8,700)
Designated - staff costs	(12,000)
Designated fund (research fund)	(35,000)
Free reserves at 31 December 2018	<u>29,689</u>

Declaration

The Trustees declare that they have approved the 2018 Annual Report

Signed on behalf of the Board of Trustees



Richard Zimble, Chair

Date: 3rd April 2019

BBS UK Annual Accounts and Independent Examiners Report



CHARITY COMMISSION
FOR ENGLAND AND WALES

Bardet-Biedl Svdrome UK		1027384	CC16a
Receipts and payments accounts			
For the period from	01-Jan-18	To 31-Dec-18	

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					
Grants			-	-	5,000
Donations and Fundraising	72,875		-	72,875	20,808
Activity Contributions			-	-	187
Childrens Family Weekend	2,152			2,152	-
Adult Social Weekend Contributions	5,269			5,269	3,150
Friends Account	7,012		-	7,012	7,079
Annual Family Weekend Contributions	2,145			2,145	3,269
Sales of Promotional	1,329		-	1,329	380
Marathon Donations			-	-	50
Gift Aid	4,870		-	4,870	3,523
Interest	67		-	67	5
Weather Lottery	51		-	51	107
Bike Rides			-	-	6,494
Raffle/Tombola	406		-	406	990
Bursaries AFVS)				-	175
Refunds (FRSB)	151			151	-
Transfer from Restricted Fund	1,618		-	1,618	-
Sub total (Gross income for AR)	97,945	-	-	97,945	51,217
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	97,945	-	-	97,945	51,217

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2018

A3 Payments

Family Conference			-	-	-
J4G Project Costs		1,513		1,513	-
BDB		3,052		3,052	4,969
Whitmore Lakes				-	400
Travel-Trustees	1,267		-	1,267	1,386
Accommodation	1,081		-	1,081	1,998
J4G Activities				-	420
Childrens Family Weekend	4,428			4,428	-
Annual Family Weekend	13,785			13,785	14,334
Adult Social Weekend	9,990			9,990	3,880
Fundraising Costs					-
Marathon	396			396	-
Santa Run	100			100	
Bike Ride				-	1,120
AFVS				-	670
Admin Officer	5,540			5,540	-
Equipment	713			713	-
Recruitment Advertising	670			670	-
Printing/Tapes, Publications	6,137		-	6,137	3,663
Telephone, Postage, Stationery	2,263		-	2,263	1,751
Franking Machine Lease only	186			186	171
Purchase of Promotional Goods	985		-	985	1,484
Stock Movement			-	-	-
IT Consumables	120		-	120	-
Courses				-	-
Insurance/Data Protection	443		-	443	396
Subscriptions	545		-	545	130
Refunds	1,272		-	1,272	318
Miscellaneous			-	-	173
Exhibitions	194		-	194	324
CRB Forms	84		-	84	78
Bank Charges				-	-
GDPR/Staff	286		-	286	
Company Ringfenced				-	1,700
Website	5,000			5,000	-
CIO Conversion	855			855	873
Freelance Fundraiser	775			775	-
Transfer to Unrestricted Fund		1,618		1,618	-
Sundry Adjustment			-	-	-
Sub total	57,115	6,183	-	63,298	40,238

A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-

Total payments	57,115	6,183	-	63,298	40,238
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Net of receipts/(payments)	40,830	- 6,183	-	34,647	10,979
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	68,452	13,649	-	82,101	71,122
Cash funds this year end	109,282	7,466	-	116,748	82,101

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	109,282	7,466	-
		-	-	-
		-	-	-
	Total cash funds	109,282	7,466	-

(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
	Laura Dowswell	27/03/2019



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 2018

**Charity no
(if any)**

1027384
Sc041839

Set out on pages

15 TO 17 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 31/12/2018.

**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:

Ivor Mark Fryza

Date:

4 APRIL 2019

Name:

IVOR MARK FRYZA BA(HONS) FCCA

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

ASSOCIATION OF 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).

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

A large, empty rectangular box with a thin black border, occupying the majority of the page's width and height. It is intended for the user to provide details as instructed in the text to the left.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2018