



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

TRUSTEES' REPORT AND ACCOUNTS

FOR THE YEAR ENDED 31st DECEMBER 2017

FOR

BARDET-BIEDL SYNDROME UK



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Administration Details

Main Address:

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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.

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, Fundraising Co-ordinator
Dianne Hand, Trustee
Margarita Sweeney-Baird, Trustee



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 around 544 affected 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 730 patients/family members and 124 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.

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.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2017

BBS UK and BBS UK Clinics Ltd process and store information in accordance with:

- ✓ The Data Protection Act 1998
- ✓ 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 experienced 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

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.

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Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2017

- 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 2018. 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 and booklets such as the BBS UK Medical Booklet and 'Who we are and how we can help' leaflets. All our publications are made available in large print, CD and audio recordings via our website and through our YouTube channel.
- 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; Richard Zimble, 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.

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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 Guy's Hospital, London and Birmingham Children's Hospital and Queen Elizabeth Hospital, Birmingham. The requirements of the contract with the National Specialised Commissioning Team are:

- To maximise access to NHS provided services for patients with Bardet-Biedl Syndrome (BBS)
- To provide support for patients affected by BBS and their families.
- To provide information relating to services provided for patients with BBS and 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 Zimbler, Chairman

The charity has had another busy year planning, organising and supporting in 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 2017 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 their hotel. The 2017 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 last year. Since last year's AGM, Emma Oates has stepped down from her role as Fundraising Co-ordinator and would like to continue as a Trustee in the upcoming year and I would like to thank her for the work she has done. Margarita Sweeney-Baird is retiring from her role as a trustee from the committee and I would like to thank her for all of her hard work for the charity and wish her well for the future. Since becoming Chairman I have valued my role and feel my confidence has grown step by step. I would like to continue in this role and develop my skills and attend events to raise awareness of BBS.

The charity had its second adult social weekend and this was attended by 25 adults and 6 support staff and we are already planning to organise our third adult social weekend for later this year. The family activity weekend has been rearranged for June 2018 and will be 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 events 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, Sight Village in Birmingham and Manchester and Tonia represented the team at the Cambridge Rare Disease Summit. The charity has now formed a Scientific Advisory Board. This is to provide greater support in the research of BBS and will be a useful mechanism to assist and collaborate with others in the national and international communities. We value and welcome the Board's founding members who are Professor Phil Beales, Dr Elizabeth Forsythe and Dr Helen May-Simera and we look forward to working more closely with them.

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Our financial position needs to continue to strengthen and there has been a lot of hard work in developing fundraising initiatives. We have made good progress with the CIO conversion and at the end of last year the Board of Trustees decided to recruit an administration officer to support the charity with its governance and projects. 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 volunteers and clinicians 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 the smooth re-structure of the running of the support services and for all their dedicated support to the Board of Trustees and charity projects as well.

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



BBS UK Family Support Team

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

2017 was a year of restructure and change as BBS UK said goodbye to Julie Sales who retired in July. Julie had been the Adults Service Lead for several years and had volunteered for the charity for around 20 years, so it was a big change for the charity, company and team. BBS UK presented Julie with gifts and flowers at the Annual Family Conference in recognition of her contribution over the years.

BBS UK were very grateful to Julie for the advance notice given of her retirement and in June we welcomed Amy Clapp to the Clinics Support Team which allowed for a smooth handover. Julie's departure prompted a service review and subsequent restructure, with the service being split geographically: Amy became the Support Officer for the Birmingham Service, Angela Scudder the Support Officer for the London Service and Tonia Hymers the Service Manager. Angela and Amy have really enjoyed getting to know their patient group and the team have developed a good working relationship with each other and their colleagues at the Trusts.

The BBS UK Annual Audit Meeting was held in November in London 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. BBS UK's presentation outlined the service restructure, benefits of third sector involvement and the increasing demands being placed on the service through growth versus static funding. 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

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Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2017

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.

It was gratifying to hear Service Leads and NHS England expressing how important and valued BBS UK's service provision is. 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 also 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.

The number of patients on our database has risen from 190 in 2010 to 567 in 2018 with 19 child and 18 adult new referrals coming into the service during 2017; we now have approximately 365 adults and 202 children on our database. We have seen an increase in the numbers of new referrals received which has inevitably 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.

The BBS UK membership and patient group is ethnically diverse, with approximately 58% identifying themselves 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 and were delighted to be accepted onto the programme. Funding, mentoring and workshops are provided across a three year period to help patient organisations join together to support families that have an increased risk of having children with genetic conditions within diverse backgrounds and who have difficulty accessing mainstream services. The project will enable 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. We really enjoyed working with the BDB team during Year 1 and benefitted from the experience and knowledge of other members and professionals involved with the project. In September we attended a workshop and presented our project to date, the presentation was well received as was our end of year report and successful application for Year 2 funding.

Late summer, the Cambridge Rare Disease Network invited patient organisations to design and submit a poster about their Rare Disease and Patient Group ahead of their summit in November. Guidelines and suggested headings were given and BBS UK's poster was based on content from the Medical Information Booklet. We were delighted to be one of five groups shortlisted and invited to give a five minute pitch at the event.

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The theme we were given was 're-imagining the patient pathway' and we were asked to come up with three wishes for our pitch. Most of the other groups wished for a specialised clinics service and as we did, a treatment for their condition. In the poster, our hopes and aspirations focused on a future where the symptoms of BBS are treatable or manageable, that babies and children today won't go blind in the future and won't face a lifetime struggling with obesity.

For the BBS UK Patient Journey, we identified four stages: Pre-Diagnosis, Diagnosis, Treatment and Future Management. The poster describing the four stages has been well received and adopted by other groups for adaptation.

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 due for review by the BBS clinics teams in 2018 and will be updated and reprinted.

We are currently working on the Bardet-Biedl Syndrome Information Booklet for Schools, a Transition Handbook (titles to be confirmed) and an Introducing BBS booklet which will be made available in other languages. 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. We are delighted to retain Certification with the Information Standard, a testament to BBS UK's commitment to excellence.

The Family Support Team worked hard alongside the Board of Trustees to ensure another excellent Conference in 2017, and Conference 2018 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 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 third Family Activity Weekend to be held in June 2018 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.

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In November we held our second Adults Social Weekend at the Cobden Hall Hotel in Birmingham. We had great fun bowling after a lovely, but noisy meal at Frankie and Benny's, 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 went to the Birmingham Hippodrome to see Sunset Boulevard. Before the show we enjoyed a 'touch tour' and a lovely afternoon tea. Following the performance we had dinner at a curry house before retiring back to the hotel for another evening of chat and laughter. We are planning another social weekend for 2018 and hope to include another visit to the fabulous Birmingham Hippodrome.

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 families and individuals over the coming year.



Fundraising Review

Dianne Hand, Fundraising Team

Bardet-Biedl Syndrome UK is immensely grateful to everyone who has supported the Charity by fundraising during the past year. There are many different ways in which people have found a way to help raise funds, with some people having undertaken some phenomenal personal challenges to raise incredible amounts thanks to the generosity of their supporters. Thank you to everyone who has held a fundraising event and to everyone who has encouraged others to support their fundraising efforts on behalf of BBS UK. One off donations have been much appreciated and the Friends of BBS UK scheme, which is available for people who like to contribute on a regular basis, is continuing to grow.

Every penny counts and goes directly where it is needed, including family support, production of newsletters and information booklets and towards our Annual Family Conference and Adult and Family activity weekends which offer huge support and friendship to many of our members. We cannot do these things without your generosity.

Thanks to a grant from Jeans for Genes, Tonia Hymers is currently in the process of putting together information booklets, including a support booklet for young people in education. And thanks to further impressive work by Tonia and the support team we have been accepted on the 'Breaking Down Barriers' Project for a second year which gives us additional funds towards working with minority ethnic groups. 'Breaking Down Barriers' is a 3 year project organised by Alstrom Syndrome UK and is funded by The Sylvia Adams Charitable Trust and we would like to thank everyone involved for this worthwhile opportunity.

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It is so important that we have the opportunity to implement different projects through funding and so we have recently started working with a Fundraising Mentor who is going to help us access funding from grants and explore other fundraising opportunities that are out there. We also aim to increase merchandise availability so that you have access to some useful accessories and resources whilst raising awareness of BBS UK.

We will continue to develop our presence on social media and on the website as well as keeping you informed in the Newsletters. We will happily share your fundraising stories and publicise any fundraising events because your experiences and ideas will help to motivate and encourage others. The BBS Clinics Team knows the BBS community so well and feeds back to the Charity Committee about the ways in which the money raised can be most effective. We fundraise so that we can make a difference. The more we raise, the more we can do and we thank everyone who is trying to help us achieve the best for BBS UK, you truly are appreciated.

2017 Funders

In 2017 the charity was funded by The Sylvia Adams Charitable Trust for the 'Breaking Down Barriers' Project. Our appreciation and thanks goes to them for supporting BBS UK.



The Sylvia Adams Charitable Trust



Financial Review

Laura Dowswell, Treasurer

Income during 2017 was £51,217 compared to £63,940 in 2016, which includes a restricted grant of £5,000.

Expenditure during 2017 was £40,238 compared to £30,813 in 2016. Therefore income has reduced and expenditure increased compared to 2016.

During 2016 BBS UK received £29,414 in donations and fundraising; however in 2017 this had fallen to £20,808. Similarly, in 2016 we had marathon runners who raised £5,990 compared to just £50 this year, although 2017 saw bike rides raise a total of £6,494.

Income from the 'Friends Scheme' has increased and this is an important income stream for BBS UK as it is regular monthly amounts and helps the charity to plan ahead. We'd like to thank all those of you who have signed up to the scheme and if anyone else wishes to sign up please contact me as the 'Friends of BBS UK' standing order leaflets are available, so please do share them with family and friends and to anyone who might like to support us.

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Expenditure remains well controlled although the costs of the annual conference is the largest item of expenditure at £14,334 and naturally the costs rise each year. Other one off costs in 2017 have been the purchase of new promotional stock/merchandise, and the costs associated with the CIO conversion.

As of the 31st December 2017, the charity had total funds of £82,101. Of this £13,648 is restricted and relates to specific grants which will be spent in 2018.

A realistic and prudent budget has been set for 2018 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 at 31 December 2017 were £82,101. These are represented by; restricted funds of £13,468, designated funds (for committed expenditure) of £41,323 and general funds of £27,310 which is free reserves. In early 2017 trustees of the charity reviewed the reserves policy and decided that free reserves should be sufficient to cover nine months ongoing costs. In 2018 these costs are budgeted at £59,727 less £41,323 = £18,404 for the full year.

The reserves held as of the 31st December 2017 available as general funds would represent in excess of 12 months expenditure and therefore trustees consider the current level of reserves to be adequate.

	£
Total funds held at 31 December 2017	82,101
Less:	
Restricted fund	(13,648)
Designated fund (family weekend)	(15,000)
Designated fund (children's weekend)	(5,996)
Designated fund (adults activities)	(5,200)
Designated fund (website)	(5,000)
Designated fund (admin officer)	(8,000)
Designated fund (CIO conversion)	(1,627)
Designated fund (freelance fundraiser)	(500)
Free reserves at 31 st December 2017	27,310



Declaration

The Trustees declare that they have approved the 2017 Annual Report

Signed on behalf of the Charity Trustees

A handwritten signature in black ink, appearing to read "Richard Zimble", written over a horizontal line.

Richard Zimble, Chair

Date: 27th March 2018



Receipts and payments accounts

For the period from	01-Jan-17	To	31-Dec-17
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Section A Receipts and payments

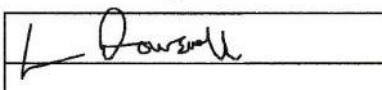
	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Grants		5,000	-	5,000	12,000
Donations and Fundraising	20,808		-	20,808	29,414
Activity Contributions		187	-	187	194
Avon Tyrell Contributions				-	1,960
Adult Social Weekend Contributions	3,150			3,150	-
Friends Account	7,079		-	7,079	6,474
Annual Family Weekend Contributions	3,269			3,269	2,319
Sales of Promotional Goods/Xmas Cards	380		-	380	569
Marathon Donations	50		-	50	5,990
Gift Aid	3,523		-	3,523	3,589
Interest	5		-	5	10
Weather Lottery	107		-	107	59
Bike Rides	6,494		-	6,494	-
Raffle/Tombola	990		-	990	913
Bursaries AFVS)	175			175	420
Refunds (FRSB)				-	29
Transfer from Unrestricted Fund	-		-	-	-
Sub total (Gross income for AR)	46,030	5,187	-	51,217	63,940
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	46,030	5,187	-	51,217	63,940
A3 Payments					
Family Conference			-	-	-
J4G Project Costs				-	556
BDB		4,969		4,969	
Whitmore Lakes		400		400	
Travel-Trustees	1,386		-	1,386	1,365
J4G Employee Travel Costs				-	-
Accommodation	1,998		-	1,998	2,105
J4G Activities		420		420	237
Avon Tyrell				-	3,316
Annual Family Weekend	14,334			14,334	11,982
Adult Social Weekend	3,880			3,880	1,417
Fundraising Costs				-	-
Marathon				-	-
Bike Ride	1,120			1,120	-
AFVS	670			670	420
Printing/Tapes	3,663		-	3,663	3,902
Telephone, Postage, Stationery	1,751		-	1,751	1,831
Franking Machine Lease only	171			171	
Purchase of Promotional Goods	1,484		-	1,484	854
Stock Movement			-	-	1,482
IT Consumables			-	-	21
Courses				-	-
Insurance/Data Protection	396		-	396	390
Subscriptions	130		-	130	321
Refunds	318		-	318	210
Miscellaneous	173		-	173	30
Exhibitions	324		-	324	312
Transfer to Restricted Fund			-	-	-
Committee Training				-	-
CRB Forms	78		-	78	62
Bank Charges			-	-	-
Marathon Bond			-	-	-
Company Ringfenced	1,700			1,700	
CIO Conversion	873			873	
Sundry Adjustment				-	-
Sub total	34,449	5,789	-	40,238	30,813

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2017

A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	34,449	5,789	-	40,238	30,813
Net of receipts/(payments)	11,581	- 602	-	10,979	33,127
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	56,872	14,250	-	71,122	37,995
Cash funds this year end	68,453	13,648	-	82,101	71,122

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	68,453	13,648	-
		-	-	-
		-	-	-
	Total cash funds	68,453	13,648	-
	(agree balances with receipts and payments account(s))			
		<input type="checkbox"/> OK	<input type="checkbox"/> OK	<input type="checkbox"/> OK
B2 Other monetary assets	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
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	
		Laura Dowswell	04/04/2018	

Independent examiner's report on the accounts



CHARITY COMMISSION FOR ENGLAND AND WALES

Section A Independent Examiner's Report

Report to the trustees/ members of

Bardet Biedl Syndrome UK

On accounts for the year ended

31 December 2017	Charity no (if any)	1027384 SC041839
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Set out on pages

18 and 19

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 ("the Charities Act") and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act, and
- to state whether particular matters have come to my attention

Basis of independent examiner's statement

My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31st December 2017

**Independent
examiner's statement**

In connection with my examination, no material matters have come to my attention (~~other than that disclosed below~~*) which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

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

** Please delete the words in the brackets if they do not apply.*

Signed:  Date: 27 | 3 | 18

Name: Michael Bannister

Relevant professional qualification(s) or body (if any): Chartered Certified Accountants

Address: The Stables, Goblands Farm, Cemetery Lane
Hadlow, KENT TN11 0LT

Section B Disclosure

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