



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

# **TRUSTEES' REPORT AND ACCOUNTS**

**FOR THE YEAR ENDED 31<sup>st</sup> DECEMBER 2016**

**FOR**

**BARDET-BIEDL SYNDROME UK**





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## **Administration Details**

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**Main Address:**

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

**Tel:** (01892) 685311

**Web Page:** [www.bbsuk.org.uk](http://www.bbsuk.org.uk)

**Email:** [info@bbsuk.org.uk](mailto: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:**

Steve Burge, Chairman (April 2016 – November 2016)  
Richard Zimble, Vice-Chair  
Laura Dowswell, Treasurer  
Abbie Geeson, Secretary  
Emma Oates, Fundraising Co-ordinator  
Graham Longly, Trustee  
Stefan Crocker, Trustee  
Dianne Hand, Trustee  
Margarita Sweeney-Baird, Trustee

## Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31<sup>st</sup> December 2016



## Bardet-Biedl Syndrome

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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

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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 1<sup>st</sup> August 1993.

The Board of Trustees is responsible for the governance of the charity. The charity now consists of approximately 706 families and 133 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 Chairman and 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 has the following policies in place: Child Protection, Safeguarding Vulnerable Adults, Equal Opportunities, Confidentiality, Complaints, Grievance, Disciplinary, Finance, Use of Email, Social Media Moderation, Conflict of Interest and Data Protection Policy. This year BBS UK has also developed and adopted its Information Governance, Business Continuity and Volunteer policies.

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.



## **Objectives and Activities**

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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:

## **Bardet-Biedl Syndrome UK**

Report of the Trustees and Statement of Financial Activities for the year ended 31<sup>st</sup> December 2016

- Our Annual Family Weekend 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. The charity also holds its AGM and over 215 members attend the weekend.
- 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. We hold two activity weekends and three day trips during the year which are attended by 170 members in total.
- 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. The YPG come together twice a year and the AFG meet once a year and also connect via Skype.
- Our helpline provides a vital outreach service. This support helps 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 2017. Our Facebook page facilitates the development of an online community that self supports with members helping each other through the challenges often faced; we have closed groups for the charity members and for the Adult Focus Group.
- 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, for example Sight Village London, support raising awareness of the syndrome and charity. Over the past year, the charity has attended the Genetic Disorders Leadership Symposium, Cerebra Conference: Mental Health & Wellbeing for young people with Autism, Rare disease workshop and Ciliopathy Alliance Conference which has given us the opportunity to learn from experts, share best practices and network.



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, Julie Sales, 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 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 liaison 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, Acting Chairman, BBS UK Management Committee

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I would like to welcome everyone to the 2017 BBS UK Annual General Meeting (AGM). I Richard Zimble have been the acting chair of BBS UK for the last 6 months as in November 2016 Steve Burge stepped down as Chairman. Graham Longly is also retiring as a Trustee and I would like to take the opportunity to thank Steve and Graham for all their hard work and all that they have done for the charity over the years. I would like to wish them all the best for the future. BBS UK is hoping to have three new observers appointed by the end of this year's AGM who may come on as full trustees next year. I would also like to thank the trustees for all of their continued hard work and contributions to the charity.

The 2016 BBS UK conference was deemed a great success with new and old members attending with a wealth of information, advice and good times had by all. Since our last AGM BBS UK has carried out many activities such as zoo trips, the Avon Tyrrell weekend and Duxford Christmas Party for children and their families. The charity has also had its first adult social weekend where the adults went to the Cobden Hotel in Birmingham. The adults had a trip out, ten pin bowling and a meal at Frankie & Benny's, the feedback from those who attended thought it was a great weekend. We have around 45 volunteers that support our projects and I would like to thank them all for their help and support throughout the year as without you it wouldn't be possible.

The clinics are being well attended with numbers continuing to grow and networks between patients being formed. I would like to thank Julie, Tonia, Angela and all of the volunteers and clinicians at all of the hospitals for the continued smooth running of the BBS UK Clinics.

BBS UK has now received our Information Standard accreditation. I would like to thank Tonia for all her hard work in getting this implemented. To date we have also implemented new BBS UK policies and procedures which are now in place.

I would also like to thank all of the members for organising fundraising events and donations throughout the year. We have also been successful in being awarded grants from both Jeans for Genes for our Information Project and The Sylvia Adams Charitable Trust for our Breaking Down Barriers project. BBS UK is planning to hold all our children, families and adult events again in 2017 and BBS UK will continue to develop our existing and new projects. We are also continuing to take forward the change of legal structure to become a Charitable Incorporated Organisation (CIO).

I look forward to seeing you all during the 2017 conference and I hope everyone has an enjoyable time at this year's conference.





**BBS UK Family Support Team**

Tonia Hymers, Children's Service Manager; Julie Sales, Adults Service Manager; Angela Scudder, Family Support Worker

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What a rewarding and enjoyable year it has been, working alongside the specialist BBS Clinics and developing the support and service provided by BBS UK. New patients continue to trickle in and we are 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. Unfortunately, the number of clinics provided is fixed, which inevitably means the gap between appointments for our patients is stretching out and we are working with the teams to look at ways of managing this effectively.

The number of patients on our database has risen from 190 in 2010 to 544 in 2017 and new referrals continue to trickle in, with 16 children and 10 adults coming into the service during 2016. We now have approximately 359 adults and 185 children on our database and follow-up appointments at all four centres continue to run at around 18-22 months.

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 positive. Patients and their families often tell us it is the best clinic they have attended, which is entirely due to the fantastic team of clinicians and support staff that we are lucky to have in the service.

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 are becoming increasingly 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.

BBS UK Family Support Worker, Kate Zaczek left the team in the summer of 2016 and Angela Scudder took on extra hours to support both the adults and children's services. Julie Sales, Adults Service Manager, has made the difficult decision to retire in September 2017 after nearly 20 years of working with BBS UK to focus on her family and health. The team are very grateful to Julie for the advance notice given and have been working with the Board of Directors and clinics teams to ensure a smooth transition and restructure of the service. Tonia Hymers will extend her role to become Service Manager and recruitment is underway to engage an additional team member.

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

## **Bardet-Biedl Syndrome UK**

Report of the Trustees and Statement of Financial Activities for the year ended 31<sup>st</sup> December 2016

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 will be 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.

During the second half of 2016, BBS UK committed to completing NHS England's Information Governance Toolkit, an online system which allows organisations to assess themselves or be assessed against Information Governance policies and standards. It has been a worthwhile process resulting in the production of additional policies, procedures and processes and ultimately a strengthening of the charity and company.

The new BBS UK Medical Information Booklet was launched at the BBS UK Family Conference 2016 and has been incredibly well received. Copies are available in hard copy, CD and PDF and can be found on the BBS UK website and the BBS UK YouTube channel. Our next projects are the Bardet-Biedl Syndrome Information Booklet for Schools and a Transition Handbook (titles to be confirmed). These publications are being funded by Genetic Disorders UK, within their Jeans for Genes programme and we are incredibly grateful for their support. The Information Booklet for Schools is underway and is a collaboration between BBS UK, young patients/parents and staff working in schools with young students who have the syndrome. We will soon commence work on the Transition Handbook and both publications will be produced within the NHS England Information Standard framework. We are delighted to retain Certification with the Information Standard for another year, 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 2016, and Conference 2017 is shaping up 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. We are also grateful to the volunteer care team who enable our guests to go to Drayton Manor Theme Park or bowling, or have fun in the BBS UK Crèche, and enable their parents to listen to the presentations and attend the workshops; we are blessed to be so very well supported.

In May, we took a group of families to the Special Children's Day at London Zoo for the second year running and once again everyone had a fabulous time. It is so

## **Bardet-Biedl Syndrome UK**

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beneficial for our families to meet up in a relaxed non-medical environment and we aim to take many more families in May 2017.

In September we had another fantastic weekend at Avon Tyrrell Outdoor Activity Centre in the beautiful New Forest. During the weekend, our families enjoyed archery, hi-ropes, an assault course, zip-wire, orienteering and pedaloos. In the evenings we enjoyed crafts, table football and had a bonfire followed by a movie and popcorn! We also used the opportunity to have a second meeting of our Young People's group and together we began work on the BBS UK 'education booklet'. 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. Unfortunately the centre is no longer suitable for our families, so we are looking for an alternative, more central venue for 2017.

Also in September, we held our first Adults Social Weekend at the Cobden Hall Hotel in Birmingham. 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 went bowling and had dinner at Frankie and Benny's before retiring back to the hotel for another evening of chat and laughter. We are planning another social weekend for 2017 and hope to include an audio described theatre trip.

We have no doubt that the coming year will prove as challenging and rewarding as the last, especially with the planned staff and service structure changes, 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**

Emma Oates, Fundraising Co-ordinator, BBS UK Management Committee

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Bardet-Biedl Syndrome UK has seen another interesting year of fundraising. This remains a big challenge in an economically unstable environment and the Trustees are very grateful to all family, friends, service users and anyone else for all their fundraising efforts during the past year.

The year has seen many people taking on personal challenges, be it running, walking or something else as well as people holding fundraising events such as coffee mornings, events held in schools and colleges or sports clubs. We have also received a wide and varied amount of donations, including two substantially large donations and a large legacy for which we are extremely grateful.

Despite all this wonderful work, fundraising remains crucial to the effective running of the charity and to ensure that our essential work and activities can continue. We strongly encourage all members and friends to consider how they can help us raise money to make certain that we can continue to offer the help and support which many of our members need and rely upon.

If anyone has a passion and the time to help us raise money or help us to research grant giving bodies, then please do get in touch.

In the meantime and to reiterate, the Trustees and Committee of BBS UK would like to extend a huge thank you to all those who give up their free time to assist us in the smooth running of the charity by fundraising. We really are very grateful.



## **2016 Funders**

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In 2016 the charity was funded by two grants from Jeans 4 Genes and The Sylvia Adams Charitable Trust. Our appreciation and thanks goes to them both for supporting BBS UK.

Supported by



The Sylvia Adams Charitable Trust





## **Financial Review**

Laura Dowswell, Treasurer, BBS UK Management Committee

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### Treasurers Report Year end 2016

Income during 2016 was £63,940 compared to £59,796 in 2015, which includes restricted grants totalling £12,000 for Jeans 4 Genes and Breaking Down Barriers projects. Expenditure during 2016 is £30,813 compared to £61,311 in 2015.

At last year's AGM, the Committee gave out the message that the charity's finances were of huge concern and if things didn't improve then it would have been unlikely that the charity could hold the conference as a whole weekend event. Thankfully there was an increase in income during 2016. We received one-off donations of around £18,000 with one being a legacy of £10,000. We also had marathon runners who raised a total of £5,990. However, it is unlikely that we will receive these donations during 2017 which means that we will see a reduction in income. Without this, and excluding the restricted grants, the income would have been £33,940 to carry out the charities core activities.

After last year's conference where we highlighted the Friends Scheme, lots of you kindly donated and set up Standing Orders which have resulted in an increase in income from the Friends scheme of approximately £2,000 per year (averaged over a whole year).

Expenditure during 2016 has reduced significantly compared to 2015. The annual conference costs have reduced by approx £6,000 following changes to the booking process and cost cutting measures. There weren't any costs incurred for Jeans 4 Genes project during 2016 as there had been in 2015. Other costs remain comparable and are well controlled.

A realistic and prudent budget has been set for 2017 which will enable the core activities and objectives of the charity to be accrued out, but as ever we 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 and this need still remains, and is one of the priorities. Apart from the two grants which are for specific projects, 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**

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The Charity funds as at 31 December 2016 were £71,122.

These are represented by restricted funds of £15,850, designated fund (for committed expenditure) £15,000 annual family weekend, £2,000 adults' activities £2,500 CIO conversion and general funds of £35,772 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 2017 these costs are budgeted at £51,563 less £35,350 designated funds = £15,543 for the full year.

The reserves at the end of 2016 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 2016	71,122
Less:	
Restricted fund	(15,850)
Designated fund (family weekend)	(15,000)
Designated fund (adults' activities)	(2,000)
Designated fund (CIO conversion)	(2,500)
Free reserves at 31 December 2016	35,772



## **Declaration**

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The Trustees declare that they have approved the 2016 Annual Report

Signed on behalf of the Charity Trustees:

A handwritten signature in black ink, appearing to be 'R. [unclear]'.

Date: 07.04.2017





**BBS UK Independent Examiners Report and Annual Accounts**



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

**Section A Independent Examiner's Report**

<b>Report to the trustees/ members of</b>	Bardet-Biedl Syndrome UK		
<b>On accounts for the year ended</b>	31 December 2016	<b>Charity no (if any)</b>	1027384 SCO41839
<b>Set out on pages</b>	1 to 3		

**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.

**Independent examiner's statement**

In connection with my examination, no matter has come to my attention (other than that disclosed below \*)

1. which gives me reasonable cause to believe that in, any material respect, the requirements:
  - to keep accounting records in accordance with section 130 of the Charities Act; and
  - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act have not been met; or
2. to which, in my opinion, attention should be drawn 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:** 10<sup>th</sup> March 2017

**Name:** Michael Bannister

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

**Bardet-Biedl Syndrome UK**

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**Address:**

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

**Section B Disclosure**

Only complete if the examiner needs to highlight material problems.

# Bardet-Biedl Syndrome UK

Report of the Trustees and Statement of Financial Activities for the year ended 31<sup>st</sup> December 2016



CHARITY COMMISSION  
FOR ENGLAND AND WALES

Bardet-Biedl Syndrome UK  
1027384  
SC041839

CC16a

## Receipts and payments accounts

For the period from	01-Jan-16	To	31-Dec-16
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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 £
<b>A1 Receipts</b>					
Grants		12,000	-	12,000	12,740
Donations and Fundraising	29,414		-	29,414	18,285
Conference Delegates Contributions			-	-	5,130
Activity Contributions		194	-	194	1,509
Avon Tyrell Contributions		1,960	-	1,960	
Friends Account	6,474		-	6,474	4,733
Donations to Annual Family Weekend	2,319		-	2,319	-
Sales of Promotional Goods/Xmas Cards	569		-	569	756
Marathon Donations	5,990		-	5,990	3,802
Gift Aid	3,589		-	3,589	3,335
Interest	10		-	10	6
Weather Lottery	59		-	59	77
Bike Ride	-		-	-	4,307
Raffle/Tombola	913		-	913	617
Bursaries (AFVS)	420		-	420	-
Refunds (FRSB)	29		-	29	-
Transfer from Unrestricted Fund	-		-	-	4,500
<b>Sub total (Gross income for AR)</b>	<b>49,786</b>	<b>14,154</b>	<b>-</b>	<b>63,940</b>	<b>59,796</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>49,786</b>	<b>14,154</b>	<b>-</b>	<b>63,940</b>	<b>59,796</b>
<b>A3 Payments</b>					
Family Conference			-	-	23,389
J4G Project Costs		556	-	556	12,945
Travel-Trustees	1,365		-	1,365	1,587
J4G Employee Travel Costs			-	-	1,026
Accommodation	2,105		-	2,105	3,559
J4G Activities		237	-	237	1,930
Avon Tyrell		3,316	-	3,316	-
Annual Family Weekend	11,982		-	11,982	-
Adult Social Weekend	1,417		-	1,417	-
Fundraising Costs			-	-	-
Marathon			-	-	396
Bike Ride			-	-	825
AFVS	420		-	420	-
Printing/Tapes	3,902		-	3,902	4,612
Telephone, Postage, Stationery	1,831		-	1,831	2,754
Purchase of Promotional Goods	854		-	854	518
Stock Movement	1,482		-	1,482	370
IT Consumables	21		-	21	-
Courses			-	-	240
Insurance/Data Protection	390		-	390	408
Subscriptions	321		-	321	266
Refunds	210		-	210	140
Miscellaneous	30		-	30	-
Exhibitions	312		-	312	508
Transfer to Restricted Fund			-	-	4,500
Committee Training			-	-	670
CRB Forms	62		-	62	668
Bank Charges			-	-	-
Marathon Bond			-	-	-
Sundry Adjustment			-	-	-
<b>Sub total</b>	<b>26,704</b>	<b>4,109</b>	<b>-</b>	<b>30,813</b>	<b>61,311</b>




**Bardet-Biedl Syndrome UK**

Report of the Trustees and Statement of Financial Activities for the year ended 31<sup>st</sup> December 2016

A4 Asset and investment purchases, (see table)	-	-	-	-	-
<i>Sub total</i>	-	-	-	-	-
<b>Total payments</b>	<b>26,704</b>	<b>4,109</b>	<b>-</b>	<b>30,813</b>	<b>61,311</b>
<i>Net of receipts/(payments)</i>	<b>23,082</b>	<b>10,045</b>	<b>-</b>	<b>33,127</b>	<b>- 1,515</b>
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	33,790	4,205	-	37,995	39,510
<i>Cash funds this year end</i>	<b>56,872</b>	<b>14,250</b>	<b>-</b>	<b>71,122</b>	<b>37,995</b>

**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 £
<b>B1 Cash funds</b>	Cash at Bank	56,872	14,250	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>56,872</b>	<b>14,250</b>	<b>-</b>
	(agree balances with receipts and payments account(s))			
		OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
<b>B5 Liabilities</b>		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	17/03/2017	