



Laurence-Moon-Bardet-Biedl Society
Registered Charity Nos: 1027384 and SCO41839

TRUSTEES' REPORT AND ACCOUNTS

FOR THE YEAR ENDED 31 DECEMBER 2014

FOR

LAURENCE-MOON-BARDET-BIEDL SOCIETY



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Administration Details

Main Address:

Laurence-Moon-Bardet-Biedl Society
1 Blackthorn Avenue
Southborough
Tunbridge Wells
Kent
TN4 9YA

Tel: (01633) 718415

Web Page: www.lmbbs.org.uk

The Laurence-Moon-Bardet-Biedl Society (known as LMBBS) is a Registered Charity in England and Wales (1027384) and in Scotland (SCO41839)

Board of Trustees:

Phil Humphreys (Chairman)
Steve Burge (Vice Chairman)
Kevin Sales (Treasurer)
Julie Sales (Secretary)
Allan Clark
Chris Humphreys (Conference Organiser)
Tonia Hymers (Newsletter Editor)
Emma Oates (Fundraising Co-ordinator)
Richard Zimble
Claire Eccles

President: Professor Philip Beales BSc LMSSA
MD FRCP

Patrons: Baroness Helena Kennedy
Of The Shaws Q.C.
Ryan Jones Bsc (Hons)

Professional Advisors:

Bankers: Barclays Bank PLC

Independent Accounts Examiner:

M. Bannister of Fryza Bannister Financials Ltd



Laurence-Moon-Bardet-Biedl Syndrome

Laurence-Moon-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 LMBBS 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 only around 480 affected individuals known to us in the UK) can mean a delayed diagnosis and lack of adequate local health care.



Structure, Governance and Management

The Laurence-Moon-Bardet-Biedl Society was established in 1993 and is the only registered charity supporting people with Laurence-Moon-Bardet-Biedl Syndrome, their families and carers. The aims of the Society are to preserve and protect the health and promote the welfare of persons who have LMBBS, and to advance the education of the medical and educational professionals and the general public on the subject of LMBBS. The governing document of the Society is a Constitution, which was adopted on 1st August 1993. The Board of Trustees is responsible for the governance of the charity. The Society now consists of approximately 656 families and 137 professionals. Full membership of the Society is open to any adult who has Laurence-Moon-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 Society.

Trustees

Trustees are elected during the annual general meeting of the Society. The Chairman and Honorary Officers of the Society hold office for one year, but are eligible for re-election annually. They must be ex officio members of the Society, 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 Issues

There are the following policies in place: Child Protection Policy, Equal Opportunities Policy, Confidentiality Policy, Complaints Procedure, Grievance Procedure, Disciplinary Policy/Procedure and Data Protection Policy. Criminal Records Bureau checks are carried out prior to commencement of employment, trusteeship and volunteering duties. CRB checks are carried out regularly in line with statutory requirements. Child Protection Training is undertaken by those working or volunteering with children or young people.

The Laurence-Moon-Bardet-Biedl Society has been entered in the Scottish Charity Register with charity number SC041839 under the Charities and Trustee Investment (Scotland) Act 2005. Since 2012, the LMBBS is a member of the Fundraising Standards Board.



Objectives and Activities

The main **objectives** of the Laurence-Moon-Bardet-Biedl Society are:

- To preserve and protect the health and promote the welfare of persons affected by Laurence-Moon-Bardet-Biedl Syndrome and their families.
- To advance the education of the medical and educational professions and the general public on the subject of Laurence-Moon-Bardet-Biedl Syndrome and its implications for the family.

The main **activities** the Society undertakes in pursuance of its objectives are:

- Provision of help line.
- Production of information leaflets.
- Organisation of an annual weekend family conference, bringing those with the syndrome together with interested professionals and experts, providing families and affected adults with access to the latest medical information and research, in addition to vital social opportunities.
- Production of regular newsletters and an annual conference report.
- Regularly updated Web Site
- Attendance at relevant seminars and conferences, for example Sight Village London and Birmingham, raising awareness of the syndrome and Society.
- Management of LMBBS Clinics Ltd, providing support and facilitation services alongside the NHS.



LMBBS Clinics Ltd

The Laurence-Moon-Bardet-Biedl Society has a contract with the National Specialised Commissioning Team (NSCT) 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. LMBBS Clinics Limited (company number 07257216) is a wholly owned subsidiary of the Laurence-Moon-Bardet-Biedl Society and is incorporated in England and Wales. The board of Directors manages the contract and funding and employs staff who facilitate and attend the clinics, providing support to those who attend, before, during and after the appointment.

The requirements of the contract with the NSCT are:

- To maximise access to NHS provided services for patients with Laurence-Moon-Bardet-Biedl Syndrome (LMBBS)
- To provide support for patients affected by LMBBS and their families.
- To provide information relating to services provided for patients with LMBBS and relevant health promotion and lifestyle information to maximise the health and life chances of people living with LMBBS.

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 LMBBS, 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 LMBBS and their families/carers and are distributed to our members in accessible formats, as well as being available on the LMBBS website. We manage the LMBBS 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

Phil Humphreys

Chairman, LMBBS Management Committee

Once again, it has been another busy year for the Society. Since the inception of our successful BBS clinics (we are now entering our fifth year), our membership continues to increase annually, uniting those with Bardet-Biedl Syndrome, their families and carers in coping strategies, support and above all friendship. We are grateful to all those who have supported the Society throughout the year, generously giving up their time.

We welcomed Claire Eccles on to the Committee in 2014, however one vacancy was left unfilled. This year, both myself and Chris are retiring from the committee, which will create a further two vacancies. The remaining committee is dedicated to maintaining the stability of the charity, however we hope to see new trustees come forward with lots of energy and enthusiasm to support the trustees in their quest to move forward with purpose. My thanks go to the committee, volunteers and employees, for their unstinting commitment throughout the year; the Society would be unable to achieve its goals, were it not for those dedicated individuals working quietly in the background.

Looking at further changes ahead, the Board of Trustees propose that our charity changes its name from the Laurence-Moon-Bardet-Biedl Society to Bardet-Biedl Syndrome UK. Voting will be held at our coming AGM. We will all be sad to say goodbye to LMBBS, however it is right that we should keep up with the medical terminology to ensure that those diagnosed with what is now known as Bardet-Biedl Syndrome can find us quickly and tap into the wealth of information and support that we can offer.

It would be remiss of me not to thank Professor Philip Beales and his team for their unwavering commitment to researching BBS and to providing the best level of care for our families, for without their dedication, we would not be where we are today. As I have said in previous years our BBS Clinics are a vital part of the work of the Society. I thank our Clinic Co-ordinators for the excellent support they provide to our families; I know that this work is greatly appreciated by all who attend.

An essential part of our work is to raise awareness of BBS. We now have a team of volunteers who represent us at Sight Village in London, Birmingham and Scotland, attending day courses and conferences involving other organisations where relevant. A red letter day in our calendar is Rare Disease Day UK, where we are fortunate to be represented in England, Scotland and Wales. We thank all those involved. In October 2014 we were represented at the Ciliopathy Conference in Paris by Drina, Michael and Richard Parker. We all thank Drina and Michael for their continued representation of us on the Board of the Ciliopathy Alliance.

Our annual Family Conference 2014 was once again a tremendous success with record numbers attending, including a contingent of delegates from BBS Norway. Our thanks must go, for this continuing success, to Chris Humphreys, Tonia Hymers and Julie Sales who

work tirelessly to ensure that the weekend offers eminent speakers and applicable workshops, giving members and professionals alike, an opportunity to gain more knowledge about BBS.

I reported in 2014 that we had been successful in our bid to Jeans for Genes for a grant to employ a Child Development Officer. We are pleased to announce that we have two new part time members on our team who are already proving to be an asset in Clinics and have many new ideas for activities, family days and breaks over the coming year.



National Co-ordinator's Report

Chris Humphreys

LMBBS National Co-ordinator
BBS Clinics Admin Co-ordinator

I have had another busy year and have received many requests and enquiries from families, carers and professionals, from UK and overseas, via telephone and email.

We are now renowned worldwide for our excellent specialised clinics and often receive enquiries from overseas patients wanting to access this valued service.

Our Twitter and Facebook pages have proven to be a popular method of communication for many of our members, allowing them to chat informally about the different aspects of living with BBS. Our Newsletters and Conference Reports provide an excellent source of information and I continue to seek out information and news from members for our Newsletter Editor.

Our annual family conference remains a pivotal aspect of my role as I lead the committee with the organisation of this much valued weekend. Conference 2014 was yet another success for the Society, with increased and diverse attendance. We welcomed a contingent from BBS Norway and since then have also welcomed them at our specialist clinics in a fact finding capacity.

I receive many requests for the Society to be represented at various conventions including Rare Disease UK, where we have been ably represented by our regional members in England and Wales. Our keen band of volunteers are also happy to represent the Society at disability awareness and information events such as Sight Village in London, Birmingham and Scotland.

In addition to the above, I liaise with organisations such as EURODIS (European Organisation for Rare Diseases), Orphanet (portal for rare diseases and orphan drugs), NCVO (National Council for Voluntary Organisations), ensuring the information they hold about LMBBS is accurate. I also complete surveys and questionnaires as appropriate. I assist with the compilation of information for the annual trustees report, committee meetings and the Society's AGM, however providing a point of contact, disseminating information and giving help and advice continues to be of prime importance in my role.

This will be my final report as National Co-ordinator. I feel privileged over the past 21 years to have held this and other roles on the LMBBS Committee.



Activity Report: Clinics and Charity

Tonia Hymers

Julie Sales

We have had another extremely busy and challenging year, working alongside the specialist NHS BBS Clinics. The charity has a 'rolling contract' in place with NHS England, which is renewed annually. The number of patients we support has risen from 190 in 2010 to 484 in 2015.

New referrals continue to trickle in, with 45 coming into the service over the past year. We now have approximately 295 adults and 189 children on our clinics database; follow-up appointments at all four centres continue to run at around 18-22 monthly. In year one, we supported approximately 169 patients across 22 clinics; in year five we supported approximately 260 patients across 32 clinics and the service continues to grow. We continue to be supported by our volunteer support workers on clinic days and we are extremely grateful for their continued commitment.

Patient feedback continues to be overwhelmingly positive with the majority of patients marking themselves as being 'very happy' with their experience. 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 smooth running of the service. In December 2014, all four centres came together in Birmingham, to discuss best practice and results from the previous year. Once again we submitted an annual report to the commissioning team, together with service user data.

Much of our work is done outside of clinics: providing family and patient support, liaising with families and clinicians, facilitating clinics, producing newsletters and managing the database and website and with the introduction of our Benefit and Social Care Assessment, we have never been busier. The assessment enables us to identify where families or individuals need extra support and we regularly receive thank you messages from those patients and families who we have helped in this way. We frequently refer families and patients to Social Services on their behalf, where they have requested this support; we write to schools in connection with the new Education, Health and Care Plans; we request benefits application forms on behalf of patients and assist with their completion where appropriate and we have supported school placement requests and blue badge requests. The ways in which we can support our families are many and the results are rewarding.

Following the charity's successful application for a grant from Genetic Disorders UK, as part of the Jeans for Genes programme, in the Autumn of 2014 candidates were interviewed for the role of Children's Development Officer. The successful candidates were Jackie Kearnes and Angela Scudder, who joined the charity in January on a one year contract. Plans are underway for family days, activity weekends, exercise initiatives and a Christmas Party. We look forward to working with both Jacquie and Angela over the coming year to ensure the success of these exciting events.

Our medical booklet is nearing completion, with the majority of the text now in place. This project has been a collaboration between the LMBB Society and Clinicians, with input and suggestions from patients and parents. Our aim is that the finished product will be a patient friendly resource that will prove invaluable to all those living with the syndrome and the key professionals involved in their care. The next stage is to look at layout and pictures, gather references and obtain final clinical approval.

We have no doubt that the coming year will prove as challenging and rewarding as the last and we look forward to meeting and supporting many more families and individuals over the coming year.



Fundraising Review

Emma Oates

Fundraising Co-ordinator

The Laurence-Moon-Bardet-Biedl Society has continued to fundraise in very diverse ways, despite the ongoing tough economic climate and the committee are very grateful to all members, family and friends who have contributed to our fundraising efforts. Every bit of the money goes directly where it is needed: producing information about LMBBS and the Society, raising awareness and education, family support and towards staging our annual family conference, which is a real arm of support and friendship to all those who attend.

Our main fundraising event of 2014 was a cycle ride from London to Paris, organised by two of our BBS families. This raised in excess of £4500 and the Society is very grateful to all those who rode and who donated. Many of our members have taken on personal challenges and organised some pretty diverse fundraising events. A second cycle ride fundraiser, a four day tour around Holland, is planned for July 2015. We also have three runners in the London Marathon and many other activities and events coming up throughout the year.

The committee and trustees are very grateful to all those who volunteer and freely give up their time to support the charity in its vital work and without this support, much of our work would not be possible.



Financial Review

Kevin Sales

LMBBS Treasurer and LMBBS Clinics Financial Director

For the financial year, 1st January 2014 to 31st December 2014, the Society received an income of £35,319.00, which is a decrease of around £6,500.00 compared to 2013.

The Society's expenses for the same period have reduced to £38,420.00, a decrease of just over £4,000.00 compared with 2013. This decrease reflects the reduction in publications; the Society did not produce a winter newsletter and worked on the Medical Booklet instead. Overall the charity made a loss of just over £3,000.00 in 2014.

As noted in this year's accounts, we have over £1,800.00 of unsold merchandise and the Society aims to sell much of this at the 2015 Family Conference at competitively reduced prices. The Marathon Bond in the sum of £480.00 relates to our Silver Bond place in the Virgin London Marathon in 2015.

We have received the first instalment of our grant from Genes for Jeans and have employed Jacquie Kearns and Angela Scudder on this project which is seeing dividends already. The second instalment is due in March 2015.

In financially challenging times, every charity relies on its regular donors and regular income to enable its core work to continue. We do have a 'Friends of the LMBBS' scheme, with many of our members making regular donations or holding fundraising events. Around £3,000.00 is paid into the charity account every year, via standing order by our 'Friends'. We aim to increase awareness and subsequently membership of this scheme, which would strengthen the charity financially.

Although there are several fundraising ventures in the pipeline, Conference 2015 will leave the charity short of funds and we are unsure at present whether Conference 2016 will be a weekend event. To secure the future of the charity financially, it is imperative that we develop some reserves and we can only do this with the ongoing committed support of our members.

In summary, the Society's main expense is the Annual Family Conference, however we have seen this cost reduce quite considerably this past year. Our second largest expense is the production and distribution of our publications. We produce two Newsletters and a Conference Report annually and all editions are available in hard copy, audio CD, via email and via our web page. Reproduction of leaflets is also a considerable expense.

As a committee, we are truly grateful to all our volunteers and fundraisers for their continued support of the charity, as without their concerted efforts, we would be unable to meet our goals and objectives.

Declaration

The trustees declare that they have approved the Trustees Report above.

Signed on behalf of the Charity's Trustees.



Independent examiner's report on the accounts

Section A

Independent Examiner's Report

**Report to the trustees/
members of**

Laurence Moon Bardet Biedl Society

**On accounts for the year
ended**

31 December 2014

**Charity no
(if any)**

1027384
SCO41839

Set out on pages

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(2) of the Charities Act 2011 (the 2011 Act) or under Regulation 10(1)(a) to (c) of the Charities Accounts (Scotland) Regulations 2006 (the 2006 Regulations) and that an independent examination is needed. The charity is preparing accrued accounts and I am qualified to undertake the examination by being a qualified member of the Association of Chartered Certified Accountants.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act 2011 and under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act);
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 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 the general Directions given by the Charity Commission and is in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. 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 you as 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**

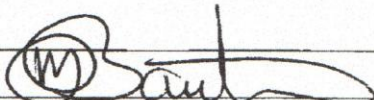
In connection with my examination, no matter has come to my attention:

(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 2011 Act and section 44 (1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act and section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Accounts Regulations

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.

Signed:  Date: 27/2/2015

Name: Fryza Bannister Financials Limited

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

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

Section B Disclosure

Only complete if the examiner needs to highlight material problems.



Receipts and payments accounts

For the period from	01-Jan-14	To	31-Dec-14
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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	3,500
Donations and Fundraising	20,476	-	-	20,476	21,602
Conference Delegates Contributions	5,247	-	-	5,247	5,176
Friends Account	4,231	-	-	4,231	3,441
Sales of Promotional Goods/Xmas Cards	928	-	-	928	838
Marathon Donations	294	-	-	294	2,174
Gift Aid	2,043	-	-	2,043	3,174
Interest	10	-	-	10	10
Weather Lottery	50	-	-	50	175
Refunds	-	-	-	-	-
Raffle/Tombola	2,040	-	-	2,040	1,650
LMBBS Clinics Reimbursements	-	-	-	-	-
Sub total (Gross income for AR)	35,319	5,000	-	40,319	41,741
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	35,319	5,000	-	40,319	41,741
A3 Payments					
Family Conference	24,844	-	-	24,844	24,257
Travel-Trustees	1,407	-	-	1,407	1,864
Accommodation	1,425	-	-	1,425	-
Printing/Tapes	5,356	-	-	5,356	6,620
Telephone, Postage, Stationery	2,161	-	-	2,161	1,823
Purchase of Promotional Goods	1,244	-	-	1,244	2,828
Unsold Promotional Goods	- 1,852	-	-	- 1,852	-
IT Consumables	434	-	-	434	577
Insurance/Data Protection	525	-	-	525	535
Subscriptions	230	-	-	230	591
Refunds	-	-	-	-	1,172
Miscellaneous	614	-	-	614	464
Exhibitions	773	-	-	773	1,289
Professional Fees	-	-	-	-	-
Courses	-	-	-	-	698
CRB Forms	773	-	-	773	105
Bank Charges	6	-	-	6	-
Marathon Bond	480	-	-	480	-
Sundry Adjustment	-	-	-	-	1
Sub total	38,420	-	-	38,420	42,824
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	38,420	-	-	38,420	42,824
Net of receipts/(payments)	- 3,101	5,000	-	1,899	- 1,083
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	37,611	-	-	37,611	38,694
Total funds this year end	34,510	5,000	-	39,510	37,611

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	32,658	5,000	-
	Stock of Promotional Goods	1,852	-	-
		-	-	-
	Total cash funds	34,510	5,000	-

(agree balances with receipts and payments account(s))

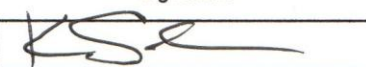
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

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
	KEVIN SALES	27/2/15

