

THE LOWE SYNDROME TRUST
FINANCIAL STATEMENTS
30 JUNE 2016

Charity Number 1081241

A I GROMAN FCA
Chartered Accountants
Groman & Company, Chartered Accountants
5 Violet Hill
St. John's Wood
London NW8 9EB

THE LOWE SYNDROME TRUST

MEMBERS OF THE BOARD AND PROFESSIONAL ADVISERS

Registered charity name The Lowe Syndrome Trust

Charity number 1081241

Trustees

Mrs. L. Thomas (Chair/CEO)

Mr. J. Ross

Mrs. C. Mitchell

Ms. P. Biziou

Mr. J. Laycock

Charity Patrons

Baroness Susan Greenfield

Sir Richard Sykes

Mr. Tony Hadley

Mr. Jonathan Coleman

Ms. Penny Lancaster

Mr. Tom Conti

Mr. Christopher Biggins

Ms. Susie Webb

Mr. Tris Payne

Mr. Mathieu Flamini

Mr. Michael Fennings

Ms. Melanie Chisholme

Ms. Seville Bulpitt

Mr. Richard Desmond

Ms. Lisa Voice

Medical Research Advisory Board

Dr. Detlef Brockenhauer, Consultant Nephrologist,
GOSH

Professor Robert Unwin, Professor of Nephrology &
Physiology, UCL

Professor Shamshad Cockcroft, Dept of Physiology,
UCL.

Dr. Philip Beales, Hon. Consultant in Clinical
Genetics, ICH.

Dr. Peter Cullen, School of Medical Sciences,
University of Bristol

Mike Harrison, Consultant in Paediatric
Dentistry, Guys Hospital London

Professor Peng Tee Khaw, Professor of Glaucoma &
Ocular Healing & Consultant Ophthalmic Surgeon

Professor Helen Cross, Head of Neuroscience Unit,
UCL

Dr. Nimalan Maruthainer, Royal Free Hospital / UCL

Professor Robert Kleta, Chair of Nephrology,
Royal Free Hospital / UCL

Dr. Richard Sandford, Honorary Consultant in
Medical Genetics, University of Cambridge

Dr. Rudiger Woscholski, Senior Lecturer, Imperial
College London

THE LOWE SYNDROME TRUST

MEMBERS OF THE BOARD AND PROFESSIONAL ADVISERS *(continued)*

Independent Examiner

A I Groman
Groman & Company, Chartered Accountants
5 Violet Hill
St. John's Wood
London NW8 9EB

Bankers

Santander UK Plc
301 St Vincent Street
Glasgow
G2 5NT

Barclays Bank Plc
28 Hampstead High Street
London NW3 1QB

Lloyds TSB
106 Kilburn High Road
Kilburn
London NW6 4HY

THE LOWE SYNDROME TRUST
TRUSTEES ANNUAL REPORT *(continued)*
YEAR ENDED 30 JUNE 2016

The trustees present their report and the unaudited financial statements of the charity for the year ended 30 June 2016.

REFERENCE AND ADMINISTRATIVE DETAILS

Reference and administrative details are shown in the schedule of members of the board and professional advisers on pages 1 to 2 of the financial statements.

THE TRUSTEES

The trustees who served the charity during the period were as follows:

Mrs. L. Thomas (Chair/CEO)
Mr. J. Ross
Mrs. C. Mitchell
Ms. P. Biziou
Mr. J. Laycock

Note: Mrs. C McNaught resigned as a trustee on 24 December 2016.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing Document

The charity is constituted by a Declaration of Trust made on the 17 March 2000 with the object of educating the public in all matters relating to the Lowe Syndrome, to promote research into its causes and treatment, and to disseminate the results of such research.

Appointment, induction & training of Trustees

The trustees are appointed following a meeting with other trustees (at least 4 present). The trustee is given a formal letter of appointment. New trustees undergo an orientation to brief them on their legal obligations under charity law, the content of the Deed of Trust, the committee and decision making processes and the recent financial performance of the charity. Trustees are encouraged to attend appropriate external training events where these will facilitate the undertaking of their role.

Organisation

The charity is organised so that the Trustees meet regularly, both to manage the day to day activities, administer grants and run fundraising initiatives. There is one (unpaid) full time executive Lorraine Thomas, who both manages the charity and organises fundraising initiatives. Most of the activities of the charity are carried out by (unpaid) Trustees, Patrons, Medical Research Board members and Volunteers. Temporary staff are contracted for specific tasks such as filing, gathering and disseminating information, managing mailshots, producing newsletters and leaflets, and maintaining the office laptops, printers and website.

Risk management

The trustees have a risk management strategy which comprises:-

- The charity will not take any financial risks. The charity will only commit expenditure covered by the actual bank balance.
- To minimise the risk of fraud, the charity has two different bank accounts, one a postal deposit account and a cheque account requiring two trustee's signatures.
- The charity maintains all important information on two external hosting sites.

THE LOWE SYNDROME TRUST

TRUSTEES ANNUAL REPORT *(continued)*

YEAR ENDED 30 JUNE 2016

OBJECTIVES AND ACTIVITIES

The objective of the charity is to encourage medical research for better treatment of Lowe Syndrome, better support and information for Lowe Syndrome families and medical professionals through the lifecycle of the disease. Lowe Syndrome, also called the oculocerebrorenal syndrome of Lowe (OCRL), is characterized by children born with cataracts in eyes, Fanconi (Kidney) syndrome, muscle weakness, neurological dysfunction (autism) and developmental delay.

The Trust is the only charity in the UK working for children and their families with Lowe Syndrome and is the major charity initiating and funding global medical research into Lowe Syndrome. The charity has also now helped define a new classification of Dents Disease - called Dents II - and so also supports families affected by the Dents disease and have produced a Lowe/Dents information leaflet.

The Charity is now a listed non-commercial Partner of the National Institute for Health Research (NIHR). These are organisations that award research funds as a result of open competition across England with high quality peer review; fund research that is of clear value to the NHS; and take account of Department of Health and NHS priorities and needs in their research funding strategies.

The charity is also working alongside and affiliated to global Lowe Syndrome family support groups including the Lowe Syndrome Association (LSA) USA and RareConnect - a joint venture of European medical research groups EURORDIS and NORD.

The charity is run by a family with a child with Lowe Syndrome. Resources are mostly altruistic, borrowed or donated and so the charity has had minimal administrative overhead costs. All funds raised are used to further medical research and the charity also benefits from an unpaid medical research board that peer review and recommend the grant awards.

PUBLIC BENEFIT

We have referred to the guidance contained in the Charity Commissions general guidance on public benefit when reviewing our aims and objectives and in planning our future services. In particular the board of trustees consider how our planned services will contribute to the aims and objectives they have set.

GRANT MAKING POLICY

The research strategy is each of the medical research project grants examines a different aspect of the disease. The medical researchers are encouraged to share information, genetic materials and collaborate together.

Grants are awarded on the advice of the Lowe Syndrome Trust Scientific Advisory Board of Professors. The grant applications are reviewed and peer reviewed. When all reviews are received, a meeting is set up when the Lowe scientific advisory board convenes to discuss the reviews and whether a grant should be funded. Trustees are informed accordingly. Grant award funding is typically committed over a 3 year budget period and payments are invoiced according to a schedule and conditional upon milestones having been achieved.

New Grants are advertised in "Nature" magazine and "Rdinfo". The committed grant funding liability is shown in the accounts.

THE LOWE SYNDROME TRUST

TRUSTEES ANNUAL REPORT *(continued)*

YEAR ENDED 30 JUNE 2016

SERIOUS INCIDENTS REPORTS

The Charity Commission state that if a charity has an income of £25,000 or more, they must state if any serious incidents took place in the last year, including any that they should have reported but did not.

There have been no serious incidents.

ACHIEVEMENTS AND PERFORMANCE

Medical research and activities

During the accounting period the charity continued funding and collaboration of strategic medical research projects and enabled breakthrough research papers to be published. A summary of the major research projects, events and activities that were funding during the accounting period were as follows:

- Purdue University USA: Cellular phenotypes of Lowe syndrome patient's cells
- Manchester University UK: Animal (Zebra Fish) Model
- Imperial College UK: Chemical Biological Model and Test for OCRL
- University College London (UCL) Royal Free Hospital UK: Kidney Cell defects
- Birmingham University UK project into Lowe Syndrome Behaviour, for which £100,000 funding was approved during the last period.
- The charity overview leaflet was updated:
www.lowetrust.com/pdfs/loweflyer.pdf.
- A new campaign leaflet - Lowe Syndrome Charity The Story so Far - was designed, produced and printed www.lowetrust.com/pdfs/LST_StorySoFar_2015.pdf

One of the difficulties we face in research into Lowe Syndrome is the diverse array of symptoms that arise in different parts of the body - especially the eyes, brain, muscles and kidneys - and how these are linked. We know what the underlying cause is: a genetic mutation resulting in a defective version of an enzyme called OCRL, which leads to a subtle metabolic imbalance. However, we still do not fully understand how and why this imbalance causes the symptoms seen in Lowe Syndrome, and this is one of the key aims of the research we are funding. Under the guidance of our Scientific Advisory Board, the research is designed to investigate Lowe Syndrome and answer a number of key questions:

- What is going on at the genetic/biochemical level?
- How does the metabolic imbalance affect the function of individual cells?
- What is the effect upon whole organs - esp. eyes, brain, kidneys?
- Can Lowe Syndrome be modelled in other organisms to help develop possible drugs?

Recently there have been some exciting steps forward in answering these questions, which have advanced our understanding of Lowe Syndrome and encouraged us in our search for a cure. The reports from each of the projects we are funding are documented on the Lowe Trust Website.

One of the most exciting findings was made by Dr Claudio Aguilar (Purdue University, USA) working with Prof Philip Beales (UCL UK) who discovered that cells from Lowe Syndrome patients share similar abnormalities with a group of other developmental diseases known as ciliopathies. This is a major breakthrough as it means Lowe Syndrome is not just an isolated disease but is linked to other conditions so we can also benefit from research into them, especially in the area of drug development.

Another exciting breakthrough has been made by Dr Rudiger Woscholski (ICL Imperial College London), who has been working on developing a chemical compound that will reduce the metabolic imbalance caused by the defective OCRL enzyme. The research has produced a promising candidate compound which can be used as a tool to more easily diagnose Lowe Syndrome and ultimately may provide a first step towards potential drugs to treat Lowe Syndrome.

THE LOWE SYNDROME TRUST
TRUSTEES ANNUAL REPORT *(continued)*
YEAR ENDED 30 JUNE 2016

In order to test any potential drugs and treatments, as well as to further study what is happening in Lowe Syndrome at a cellular level, it is vitally important to develop models of Lowe Syndrome in other organisms. Through research funded by the LST there have been two major breakthroughs. Professor Martin Lowe at Manchester University who has received further grants to continue the research has generated a model in zebrafish, which recapitulates Lowe Syndrome symptoms in kidneys and the nervous system. They are now starting a drug screen to identify compounds to restore kidney function, as well as distributing these fish to other labs investigating other aspects of Lowe Syndrome. In the USA at University of California, Professor Robert Nussbaum (UCSF) has created a mouse strain which models the abnormal kidney function seen in Lowe Syndrome patients.

At a molecular level, a number of our projects are investigating the function of the OCRL enzyme by looking at what other molecules it interacts with inside cells, and what interactions are disrupted by the mutations in Lowe Syndrome. Dr Pietro De Camilli and Dr Laura Swan (Yale - USA), have shown defective OCRL cannot bind two other proteins called APPL1 and Ses1/2, thought to be involved in targeting OCRL to the correct part of the cell.

As a result of a projects funded by the LST, Prof Robert Kleta, Dr Detlef Bockenhauer and Prof Robert Unwin (Great Ormond Street Hospital / Royal Free Hospital / UCLH) and collaborators described a new disease mechanism in kidneys, shedding light onto how the kidney works and providing ideas about how to better diagnose and treat the kidney problems seen in Lowe syndrome.

The following is a letter from Robert Unwin, Professor of Nephrology & Physiology – St Peter’s Chair, University College Hospital:

23/03/2017

I am writing to you as Chairman of the Lowe Syndrome Trust’s Scientific Advisory Board (SAB). I wanted to highlight the work and success of this small charity founded by Lorraine Thomas in June 2000.

The research funded to date has been of high scientific quality and impact, and has brought together many researchers from different fields that would probably not have collaborated on studies of this rare disease without the catalyst and support of the Lowe Trust. I think it is true to say that the Trust has put Lowe research ‘on the map’ and attracted serious science and scientists to try to understand what is often a complex and devastating disease for those affected and their families.

*What is sometimes not always appreciated outside of medical science and research is that research into one disease, especially a rare inherited disease, **can often reveal important insights into other diseases**, and this has been particularly true of Lowe syndrome research. A ‘cure’ is still the ultimate objective, but many benefits have accrued from the research that has been funded up to now, not least in establishing a community of researchers working together and collaborating closely. The biennial scientific meetings (research symposia) organised by the Trust have also been a great success and provided an opportunity to bring together basic scientists and medical doctors who look after patients, and for the research funded by the Trust to be presented, and for new areas of research to be identified and discussed. Advances are being made such that treatments to improve the lives of those affected by Lowe syndrome can and will be developed.*

The Trust has funded many projects in the UK and in the US. As an example of one of the many Lowe Trust projects underway is one at Manchester University in the laboratory of Professor Martin Lowe, who has made a number of important discoveries as a result of 3 grants from the LST totalling just under £500,000. A significant breakthrough has been the generation of a small zebrafish model of Lowe syndrome. This model exhibits many of the features seen in patients with the disease, particularly affecting the kidneys and brain, and has shed light on what may be key mechanisms disturbing kidney

THE LOWE SYNDROME TRUST
TRUSTEES ANNUAL REPORT *(continued)*
YEAR ENDED 30 JUNE 2016

and brain cell function. Moreover, this model can potentially be used to screen for new drug treatments that can correct these abnormalities. Martin and his team have made this zebrafish model of Lowe syndrome widely available to other researchers, for example, the research group of Dr Scott Baraban at the University of California San Francisco who works on epilepsy, and Dr Yang Sun at the Indian University School of Medicine, who works on eye disorders, including cataract and glaucoma. The model is freely available from Martin Lowe for research.

From this brief update on what the Trust has funded so far, I hope you can appreciate the importance of what has been achieved. Other projects funded by the Trust have been at Imperial College London, University College London, Moorfield's Eye Hospital, Dundee University, Cambridge University, Great Ormond Street Hospital, the Royal Free Hospital, the Institute of Child Health, Yale University (USA), the University of California and Purdue University (USA).

Having had contact with the Trust from its early days and seen how it has developed (thanks to the unstinting efforts of Lorraine and her Trustees), given its small size, I think the progress has been both astounding and outstanding. The Trust has helped to raise awareness of Lowe syndrome and to boost its scientific profile, as well as its wider recognition among doctors, the public, and our politicians; it has also helped to highlight the needs and importance of other 'rare diseases'.

Thanks to your on-going support, Lorraine has managed to do all this almost single-handedly, and you should be congratulated.

On behalf of the SAB, thank you.

Sincerely,

Robert Unwin

FUNDRAISING

The Trust volunteers continually work on awareness and fundraising, holding fundraising events, running marathons, enticing schools and business to raise funds, payroll giving through company give-as-you-earn, wills to charity, trust funding and company schemes.

The Trust is only funded through voluntary donations as previous funding from the Big Lottery for Lowe Family and community support has ended.

The charity overview leaflet was updated: www.lowetrust.com/pdfs/loweflyer.pdf.

A new campaign leaflet - Lowe Syndrome Charity The Story so Far - was designed, produced and printed. The weblink was retained as www.lowetrust.com/pdfs/LST_StorySoFar_2015.pdf

The charity continued to support Lowe syndrome families and doctors and others associated with the disease and continued fundraising via various means such as applying for grants to major Trusts and companies.

PLANS FOR FUTURE PERIODS

The Trust continues to support families and medical professionals throughout the UK and Ireland and in some instances Europe. The Trust will continue with its fundraising campaigns to further Lowe Syndrome research.

Planning is in progress for the next international Lowe Syndrome Trust Symposium to be held in December 2018, as in previous years, at the prestigious location of the Royal Society in Pall Mall, London. The charity has also approached a potential Trustee who has medical research expertise.

THE LOWE SYNDROME TRUST
TRUSTEES ANNUAL REPORT *(continued)*
YEAR ENDED 30 JUNE 2016

CONCLUDING REMARKS

What is sometimes not always appreciated outside of medical science and research is that research into one disease, especially a rare inherited disease, often reveals important insights into other diseases, and this has been particularly true of Lowe syndrome research. A 'cure' is still the ultimate objective, but many benefits have accrued from the research that has been funded up to now, not least in establishing a community of researchers working together and collaborating closely.

FINANCIAL SUMMARY AND RESERVES

The statement of Financial Activities shows income for the year of £42,431 (2015 - £127,619) and total expenditure of £218,427 (2015 - £204,014). The deficit of £175,996 (2015 Deficit - £76,395) is after the total grants paid during the year for medical research projects totalling £187,746 (2015 - £152,183).

The main Medical Research grant payments and expenditure during the year were to:

Purdue University USA £61,361
Manchester University extension UK £28,421
UCLM University College London Hospitals UK £5,833
ICL Imperial College London UK £37,500
Birmingham University UK £23,907

Reserves

The present level of funding and reserves are considered adequate to support the running of the charity for the year ahead and cover the committed research grants.

Of the charity's funds carried forward of £211,300, a total of £140,886 is designated as funds for continuing committed research grants leaving enough funding to continue the commitments of the charity of £70,414.

INDEPENDENT EXAMINER

A. I. Groman FCA has been re-appointed as independent examiner for the ensuing year.

Signed by order of the trustees

A. Thomas (Treasurer)
Charity Secretary

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THE LOWE SYNDROME TRUST

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE LOWE SYNDROME TRUST

YEAR ENDED 30 JUNE 2016

I report on the accounts of the charity for the year ended 30 June 2016 which are set out on pages 10 to 15.

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) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 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 REPORT

My examination was carried out in accordance with the 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 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
 - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Acthave 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.

A. I. Groman FCA
Independent Examiner

Groman & Company, Chartered Accountants
5 Violet Hill
St. John's Wood
London NW8 9EB

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THE LOWE SYNDROME TRUST
STATEMENT OF FINANCIAL ACTIVITIES

YEAR ENDED 30 JUNE 2016

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2016 £	Total Funds 2015 £
INCOME AND ENDOWMENTS					
Donations and legacies	2	41,261	–	41,261	124,295
Investment income	3	1,170	–	1,170	3,324
TOTAL INCOME		<u>42,431</u>	<u>–</u>	<u>42,431</u>	<u>127,619</u>
EXPENDITURE					
Expenditure on raising funds:					
Costs of raising donations and legacies	4	(968)	–	(968)	(750)
Expenditure on charitable activities	5/6	(217,459)	–	(217,459)	(203,264)
TOTAL EXPENDITURE		<u>(218,427)</u>	<u>–</u>	<u>(218,427)</u>	<u>(204,014)</u>
NET OUTGOING RESOURCES FOR THE YEAR		(175,996)	–	(175,996)	(76,395)
RECONCILIATION OF FUNDS					
Total funds brought forward		387,296	–	387,296	463,691
TOTAL FUNDS CARRIED FORWARD		<u>211,300</u>	<u>–</u>	<u>211,300</u>	<u>387,296</u>

The Statement of financial activities includes all gains and losses in the year.

All of the above amounts relate to continuing activities.

The notes on pages 12 to 15 form part of these financial statements.

THE LOWE SYNDROME TRUST

BALANCE SHEET

30 JUNE 2016

	Note	2016 £	£	2015 £	£
FIXED ASSETS					
Tangible assets	8		–		–
CURRENT ASSETS					
Cash at bank		212,500		391,376	
CREDITORS: Amounts falling due within one year	9	<u>(1,200)</u>		<u>(4,080)</u>	
NET CURRENT ASSETS			211,300		387,296
TOTAL ASSETS LESS CURRENT LIABILITIES			<u>211,300</u>		<u>387,296</u>
NET ASSETS			<u>211,300</u>		<u>387,296</u>
FUNDS OF THE CHARITY					
Restricted income funds	10		–		–
Unrestricted income funds	11		<u>211,300</u>		<u>387,296</u>
TOTAL CHARITY FUNDS			<u>211,300</u>		<u>387,296</u>

These financial statements have been prepared in accordance with the Financial Reporting Standard for Smaller Entities (effective January 2015).

These financial statements were approved by the members of the committee and authorised for issue on the and are signed on their behalf by:

.....
Mrs. L. Thomas (Chair/CEO)

The notes on pages 12 to 15 form part of these financial statements.

THE LOWE SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 30 JUNE 2016

1. ACCOUNTING POLICIES

Basis of accounting

The financial statements have been prepared under the historical cost convention, as modified by the revaluation of certain fixed assets and investments measured at market value. The financial statements have been prepared in accordance with the Financial Reporting Standard for Smaller Entities (effective January 2015), and the requirements of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Entities (effective January 2015) (SORP 2015).

Fixed assets

All fixed assets are initially recorded at cost.

Incoming resources

Fund raising income and donations are included in incoming resources when they are received except when the donors specify that they must be used in future accounting periods or donors conditions have not been fulfilled, then the income is deferred. The income from fundraising ventures is shown gross.

Resources expended

Resources expended are included in the statement of financial activities on an accrual basis, inclusive of any VAT, which cannot be recovered. Expenditure, which is directly attributable to specific activities, has been included in these cost categories. Where costs are attributable to more than one activity, they have been apportioned across the cost categories on a basis consistent with the use of these resources.

Cost of generating funds includes salaries, direct expenditure and overhead costs of the staff who promote fundraising including events.

Governance costs are those incurred in connection with administration of the charity and compliance with constitutional and statutory requirements.

Fundraising costs

Fundraising expenditure comprises costs incurred in inducing people and organisations to contribute financially to the charity's work. This includes the cost of advertising for donations and the staging of special fundraising events.

Funds

Restricted funds are to be used for specific purpose as laid down by the donor. Expenditure, which meets these criteria, is charged to the fund together with a fair allocation of management and administrative costs.

Unrestricted funds are donations and other incoming resources received or generated for the charitable purposes.

Designated funds are unrestricted funds earmarked by the management committee for particular purposes.

THE LOWE SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 30 JUNE 2016

2. DONATIONS AND LEGACIES

	Unrestricted Funds £	Restricted Funds £	Total Funds 2016 £
Donations			
Miscellaneous donations	10,111	–	10,111
Gift Aid - tax rebate	2,500	–	2,500
Major donors	28,310	–	28,310
Grants receivable			
Giving.com	48	–	48
Charities Aid Foundation	292	–	292
	<u>41,261</u>	<u>–</u>	<u>41,261</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £
Donations			
Miscellaneous donations	104,188	–	104,188
Grants receivable			
Big Lottery Fund	–	14,790	14,790
Giving.com	4,246	–	4,246
Charities Aid Foundation	1,071	–	1,071
	<u>109,505</u>	<u>14,790</u>	<u>124,295</u>

3. INVESTMENT INCOME

	Unrestricted Funds £	Total Funds 2016 £	Unrestricted Funds £	Total Funds 2015 £
Bank interest receivable	<u>1,170</u>	<u>1,170</u>	<u>3,324</u>	<u>3,324</u>

4. COSTS OF RAISING DONATIONS AND LEGACIES

	Unrestricted Funds £	Restricted Funds £	Total Funds 2016 £
Costs of generating income	<u>968</u>	<u>–</u>	<u>968</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £
Costs of generating income	<u>–</u>	<u>750</u>	<u>750</u>

THE LOWE SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 30 JUNE 2016

5. COSTS OF CHARITABLE ACTIVITIES BY FUND TYPE

	Unrestricted Funds £	Restricted Funds £	Total Funds 2016 £
Grants payable	187,746	–	187,746
Symposiums and research meetings	–	–	–
Support costs	24,713	–	24,713
Trustee's expenses	5,000	–	5,000
	<u>217,459</u>	<u>–</u>	<u>217,459</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £
Grants payable	152,183	–	152,183
Symposiums and research meetings	11,398	7,673	19,071
Support costs	1,372	30,638	32,010
	<u>164,953</u>	<u>38,311</u>	<u>203,264</u>

6. COSTS OF CHARITABLE ACTIVITIES BY ACTIVITY TYPE

	Core activities £	Support costs £	Total Funds 2016 £	Total Funds 2015 £
Charitable activity - Core activity	–	23,114	23,114	28,938
Charitable activity – Trustee's expenses	–	5,000	5,000	–
Grants payable	187,746	–	187,746	152,183
Symposiums and research meetings	–	–	–	19,071
Governance costs	–	1,599	1,599	3,072
	<u>187,746</u>	<u>29,713</u>	<u>217,459</u>	<u>203,264</u>

7. STAFF COSTS AND EMOLUMENTS

Total staff costs were as follows:

	2016 £	2015 £
Wages and salaries – Temporary staff	3,535	4,169
Social security costs	–	–
	<u>3,535</u>	<u>4,169</u>

No employee received remuneration of more than £60,000 during the year (2015 - Nil).

THE LOWE SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 30 JUNE 2016

8. TANGIBLE FIXED ASSETS

	Equipment £
COST	
At 1 July 2015 and 30 June 2016	<u>16,917</u>
DEPRECIATION	
At 1 July 2015 and 30 June 2016	<u>16,917</u>
NET BOOK VALUE	
At 30 June 2016	<u>–</u>
At 30 June 2015	<u>–</u>

9. CREDITORS: Amounts falling due within one year

	2016 £	2015 £
Accruals and deferred income	<u>1,200</u>	<u>4,080</u>

10. RESTRICTED INCOME FUNDS

There have been no movements on restricted funds during the year ended 30 June 2016.

11. UNRESTRICTED INCOME FUNDS

	Balance at 1 Jul 2015 £	Income £	Expenditure £	Transfers £	Balance at 30 Jun 2016 £
Research grants	232,521	–	(187,746)	96,111	140,886
General office administration	23,942	–	(23,942)	50,000	50,000
General Funds	<u>130,833</u>	<u>42,431</u>	<u>(6,739)</u>	<u>(146,111)</u>	<u>20,414</u>
	<u>387,296</u>	<u>42,431</u>	<u>(218,427)</u>	<u>–</u>	<u>211,300</u>

12. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Net current assets £	Total £
Unrestricted Income Funds:		
Designated Funds	190,886	190,886
General Funds	<u>20,414</u>	<u>20,414</u>
Total Funds	<u>211,300</u>	<u>211,300</u>

THE LOWE SYNDROME TRUST
MANAGEMENT INFORMATION
YEAR ENDED 30 JUNE 2016

**The following page does not form part of the statutory financial statements
which are the subject of the independent examiner's report on page 9.**

THE LOWE SYNDROME TRUST
DETAILED STATEMENT OF FINANCIAL ACTIVITIES
YEAR ENDED 30 JUNE 2016

	2016		2015	
	£	£	£	£
INCOMING RESOURCES				
DONATIONS AND LEGACIES				
Miscellaneous donations	10,111		104,188	
Gift Aid - tax rebate	2,500		–	
Major donors	28,310		–	
Big Lottery Fund	–		14,790	
Giving.com	48		4,246	
Charities Aid Foundation	292		1,071	
	<u>41,261</u>		<u>124,295</u>	
INVESTMENT INCOME				
Bank interest receivable	1,170		3,324	
	<u>1,170</u>		<u>3,324</u>	
TOTAL INCOME	<u>42,431</u>		<u>127,619</u>	
EXPENDITURE				
COSTS OF RAISING DONATIONS AND LEGACIES				
Fundraising & publicity	968		750	
CHARITABLE ACTIVITIES				
Staff costs - Wages & Salaries	3,535		4,169	
Establishment - Rent	7,250		4,820	
Establishment - Insurance	955		717	
Motor and travel costs - Other	5,862		9,085	
Trustee's expenses	5,000		–	
Office expenses - Telephone	2,729		2,616	
Office expenses - Other	2,221		25,360	
Bank charges	440		521	
Computer & website costs	122		721	
Grants payable	187,746		152,183	
	<u>215,860</u>		<u>200,192</u>	
GOVERNANCE COSTS				
Accountancy fees	1,410		2,040	
Costs of trustees' meetings	189		1,032	
	<u>1,599</u>		<u>3,072</u>	
TOTAL EXPENDITURE	<u>218,427</u>		<u>204,014</u>	
NET OUTGOING RESOURCES FOR THE YEAR	<u>(175,996)</u>		<u>(76,395)</u>	