

THE LOWE SYNDROME TRUST
FINANCIAL STATEMENTS
30 JUNE 2008

Charity Number 1081241

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)
 Mr. J. Ross
 Mrs. C. Mitchell
 Mrs. C. McNaught
 Ms. P. Biziou

Independent examiner Groman & Company
 5 Violet Hill
 St. John's Wood
 London NW8 9EB

Bankers Barclays Bank Plc
 28 Hampstead High Street
 London NW3 1QB

Principle & registered office 77 West Heath Road
 London
 NW3 7TH

THE LOWE SYNDROME TRUST

TRUSTEES ANNUAL REPORT *(continued)*

YEAR ENDED 30 JUNE 2008

The trustees have pleasure in presenting their report and the unaudited financial statements of the charity for the year ended 30 June 2008.

REFERENCE AND ADMINISTRATIVE DETAILS

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

THE TRUSTEES

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

Mrs. L. Thomas (Chair)

Mr. J. Ross

Mrs. C. Mitchell

Mrs. C. McNaught

Ms. P. Biziou

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.

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 sometimes contracted for specific tasks such as mailshots, newsletters and leaflets.

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 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.

OBJECTIVES AND ACTIVITIES

The objective of the charity is to raise awareness of Lowe Syndrome and to stimulate medical research for better treatment of Lowe Syndrome. Lowe Syndrome, also called the oculocerebrorenal syndrome of Lowe (OCRL), is characterized by babies born with cataracts in both eyes, Fanconi (Kidney) syndrome, muscle weakness, neurological dysfunction and developmental delay.

The Trust is the only charity in the UK working for children and their families with Lowe Syndrome and is the only UK charity initiating and funding medical research into Lowe Syndrome.

THE LOWE SYNDROME TRUST

TRUSTEES ANNUAL REPORT *(continued)*

YEAR ENDED 30 JUNE 2008

The charity is run by a family with a child with Lowe Syndrome. Resources are mostly 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 has a voluntary medical research board that peer review and recommend the grant awards.

There is a strategy to each of the medical research project grants with each examining a different aspect of the disease; however the medical researchers are encouraged to actively work together. Grant payments are staged according to a schedule and conditional upon milestones having been achieved. Grants are advertised in "Nature" magazine and "Rdinfo".

ACHIEVEMENTS AND PERFORMANCE

The charity's unpaid trustees and volunteers undertook an unprecedented amount of work during this period, raising an amazing amount of £400,00 through voluntary donations and fundraising events, and also in administering 5 existing research project grants, and announcing 3 new medical research projects totalling £240,000.

The Trust continued funding existing medical research projects at Imperial College London for enzyme synthesis, Moorefield's Eye Hospital for Cataract research, University College London and Dundee University Biocenter into Cell Trafficking..

In December 2007 the charity organised and funded an international medical symposium at the Royal Society in London with over 50 leading international researchers, medical professionals and parents to present and discuss the disease, current research underway and ideas for future projects.

Major fundraising events during this period included the September 2007 Gala Ball hosted by trustee Mr Jonathan Ross with entertainment by Russell Watson, Newton Faulkner and Beverley Knight, and reported in Hello! Magazine. The Old Cranleigh Charity Ball '07 – was held in Madame Tussauds London in October 2007 with performances by patron Tony Hadley and Heather Small, and in May 2008 a Gala Charity Event was held, hosted by patron Christopher Biggins with performances by Bryan Ferry and Escala.

The charity continued with its work writing to Trusts, Companies and Schools to highlight the disease and the need for donations to fund vital research. Articles appeared in "Hello", "OK"! and "North West" magazines and also a "Lowe Bracelet" was produced. The annual Lowe Cycle Challenge took place in Tuscany.

The Charity was featured in BBC news programmes for a new grant award to Manchester University to use Zebra Fish as an animal model for Lowe Syndrome. This was reported by the BBC as a novel approach to medical research for not just Lowe Syndrome but other conditions including cancer research. Imperial College London magazine also featured the Lowe Syndrome Trust funding enzyme research by the chemical biology facility.

FINANCIAL REVIEW

The statement of Financial Activities shows income for the year of £449,892 and total expenditure of £253,189. The surplus of £196,703 is made up of net of outgoings for medical research projects. The total expenditure for medical research projects totalled £137,382.

THE LOWE SYNDROME TRUST

TRUSTEES ANNUAL REPORT *(continued)*

YEAR ENDED 30 JUNE 2008

The main Medical Research grant payments and expenditure during the period	£
Dundee University, Scotland UK	11,863
Moorefield's Eye Hospital UK	17,000
University College London (UCL) UK	10,867
University of California San Francisco (UCSF) USA –1 st Project	43,676
UCSF USA –2 nd Project	44,316
Medical Symposium and meetings UK	8,058
Miscellaneous	<u>1,602</u>
	<u>137,382</u>

Reserves

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

PLANS FOR FUTURE PERIODS

The charity continued to receive what the medical research board considered to be outstanding applications for medical research projects from worldwide medical research bodies.

Having reviewed the financial position, the charity awarded three new grants for medical research projects totalling £240,000, to fund three new and different approaches to help treatments for Lowe syndrome. The awards commit the charity to further fundraising and the administration of further grant payments and collaboration between researchers to 2010.

In February 2008 the first grant award of £72,000 was announced to Dr Lowe at Manchester University to create a Zebra Fish model of Lowe Syndrome. In the long term, it is hoped that zebra fish will serve as a model system for experimenting with chemicals that suppress the symptoms of Lowe syndrome in the hope of one day finding a cure.

The second grant announced of £80,000 was to Purdue University in Indiana, USA where a team led by Dr Claudio Aguilar, will study the cellular consequences of Lowe syndrome. Dr Aguilar said: "Our laboratory recently found that cells from Lowe syndrome patients are deficient for crawling and spreading on biological surfaces. Since these processes play a crucial role during embryo development, we believe that this faulty behaviour may contribute to the onset of the disease. Thanks to the support provided by the Lowe Syndrome Trust, we are going to be able to investigate the causes of these abnormalities. Ultimately, we hope that a better understanding of the underlying mechanism will help to design new therapeutic approaches to fight this debilitating disease".

The third grant awarded will be used to help continue work already underway at Imperial College, London. Drs. Woscholski and Vilar have been developing chemical tools for the detection of the substrates of the OCRL1 enzyme since 2003.

THE LOWE SYNDROME TRUST
TRUSTEES ANNUAL REPORT *(continued)*
YEAR ENDED 30 JUNE 2008

RESPONSIBILITIES OF THE TRUSTEES

Law applicable to charities in England and Wales requires the Trustees to prepare financial statements for each financial year. Under that law the trustees have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). The financial statements are required by law to give a true and fair view of the state of affairs of the charity and of the surplus or deficit of the charity for that period.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which enable them to ensure that the financial statements comply with the Charities Act 1993. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Signed by order of the trustees

A. THOMAS
Treasurer

21 April 2009

THE LOWE SYNDROME TRUST
INDEPENDENT EXAMINER'S REPORT
YEAR ENDED 30 JUNE 2008

We report on the accounts of the charity for the year ended 30 June 2008 set out on pages 7 to 14.

RESPECTIVE RESPONSIBILITIES OF TRUSTEES AND INDEPENDENT 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 43(2) of the Charities Act 1993 (the 1993 Act)) and that an independent examination is needed.

It is our responsibility to:

- examine the accounts (under section 43(3)(a) of the 1993 Act);
- to follow the procedures laid down in the General Directions given by the Charity Commission (under section 43(7)(b) of the 1993 Act); and
- to state whether particular matters have come to my attention.

BASIS OF INDEPENDENT EXAMINER'S STATEMENT

Our examination was carried out in accordance with the General Directions given by the Charities Commissioners. 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 I do not express an audit opinion on the view given by the accounts.

INDEPENDENT EXAMINER'S STATEMENT

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

- (1) which gives us reasonable cause to believe that in any material respect the requirements:
 - (a) to keep accounting records in accordance with section 41 of the Act; and
 - (b) to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Acthave not been met; or
- (2) to which, in our opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

5 Violet Hill
St. John's Wood
London NW8 9EB

Groman & Company
Chartered Accountants

22 April 2009

THE LOWE SYNDROME TRUST
STATEMENT OF FINANCIAL ACTIVITIES
YEAR ENDED 30 JUNE 2008

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2008 £	Total Funds 2007 £
INCOMING RESOURCES					
Incoming resources from generating funds:					
Voluntary income	2	308,411	32,042	340,453	149,991
Investment income	3	12,658	–	12,658	6,017
Incoming resources from charitable activities	4	<u>96,781</u>	<u>–</u>	<u>96,781</u>	<u>56,028</u>
TOTAL INCOMING RESOURCES		<u>417,850</u>	<u>32,042</u>	<u>449,892</u>	<u>212,036</u>
RESOURCES EXPENDED					
Costs of generating funds:					
Costs of generating voluntary income	5	(63,536)	(9,004)	(72,540)	(32,259)
Charitable activities	6/7	(154,206)	(25,424)	(179,630)	(96,029)
Governance costs	8	<u>(1,019)</u>	<u>–</u>	<u>(1,019)</u>	<u>(982)</u>
TOTAL RESOURCES EXPENDED		<u>(218,761)</u>	<u>(34,428)</u>	<u>(253,189)</u>	<u>(129,270)</u>
NET INCOMING RESOURCES FOR THE YEAR	9	199,089	(2,386)	196,703	82,766
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>241,292</u>	<u>2,386</u>	<u>243,678</u>	<u>160,913</u>
TOTAL FUNDS CARRIED FORWARD		<u>440,381</u>	<u>–</u>	<u>440,381</u>	<u>243,679</u>

The Statement of Financial Activities includes all gains and losses in the year and therefore a statement of total recognised gains and losses has not been prepared.

All of the above amounts relate to continuing activities.

The notes on pages 8 to 13 form part of these financial statements.

THE LOWE SYNDROME TRUST

BALANCE SHEET

30 JUNE 2008

	Note	2008 £	£	2007 £	£
FIXED ASSETS					
Tangible assets	11		881		1,762
CURRENT ASSETS					
Cash at bank		441,302		242,798	
CREDITORS: Amounts falling due within one year	12	<u>(1,802)</u>		<u>(881)</u>	
NET CURRENT ASSETS			439,500		241,917
TOTAL ASSETS LESS CURRENT LIABILITIES			<u>440,381</u>		<u>243,679</u>
NET ASSETS			<u>440,381</u>		<u>243,679</u>
FUNDS					
Restricted income funds	13		–		2,386
Unrestricted income funds	14		<u>440,381</u>		<u>241,293</u>
TOTAL FUNDS			<u>440,381</u>		<u>243,679</u>

These financial statements were approved by the members of the committee on the 21 April 2009 and are signed on their behalf by:

MRS. L. THOMAS (CHAIR)

The notes on pages 8 to 13 form part of these financial statements.

THE LOWE SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 30 JUNE 2008

1. ACCOUNTING POLICIES

Basis of accounting

The financial statements have been prepared under the historical cost convention and in accordance with applicable United Kingdom accounting standards, the Statement of Recommended Practice "Accounting and Reporting by Charities" issued in March 2005 (SORP 2005) and the Charities Act 1993.

Fixed assets

All fixed assets are initially recorded at cost.

Depreciation

Depreciation is calculated so as to write off the cost of an asset, less its estimated residual value, over the useful economic life of that asset as follows:

Equipment - 33% Straight Line

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.

THE LOWE SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 30 JUNE 2008

1. ACCOUNTING POLICIES *(continued)*

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 2008

2. VOLUNTARY INCOME

	Unrestricted Funds £	Restricted Funds £	Total Funds 2008 £	Total Funds 2007 £
Donations				
Miscellaneous donations	153,858	–	153,858	83,865
Gift Aid - tax rebate	10,234	–	10,234	–
Grants receivable				
Big Lottery Fund	–	32,042	32,042	30,200
Giving.com	143,091	–	143,091	35,826
Charities Aid Foundation	1,228	–	1,228	100
	<u>308,411</u>	<u>32,042</u>	<u>340,453</u>	<u>149,991</u>

3. INVESTMENT INCOME

	Unrestricted Funds £	Total Funds 2008 £	Total Funds 2007 £
Bank interest receivable	<u>12,658</u>	<u>12,658</u>	<u>6,017</u>

4. INCOMING RESOURCES FROM CHARITABLE ACTIVITIES

	Unrestricted Funds £	Total Funds 2008 £	Total Funds 2007 £
Income from charitable events	<u>96,781</u>	<u>96,781</u>	<u>56,028</u>

5. COSTS OF GENERATING VOLUNTARY INCOME

	Unrestricted Funds £	Restricted Funds £	Total Funds 2008 £	Total Funds 2007 £
Fundraising & publicity	<u>63,536</u>	<u>9,004</u>	<u>72,540</u>	<u>32,259</u>

6. COSTS OF CHARITABLE ACTIVITIES BY FUND TYPE

	Unrestricted Funds £	Restricted Funds £	Total Funds 2008 £	Total Funds 2007 £
Grants payable	137,382	–	137,382	75,573
Symposiums	7,110	–	7,110	4,259
Support costs	9,714	25,424	35,138	16,197
	<u>154,206</u>	<u>25,424</u>	<u>179,630</u>	<u>96,029</u>

THE LOWE SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 30 JUNE 2008

7. COSTS OF CHARITABLE ACTIVITIES BY ACTIVITY TYPE

	Core activities £	Support costs £	Total Funds 2008 £	Total Funds 2007 £
Charitable activity	–	35,138	35,138	16,197
Grants payable	137,382	–	137,382	75,573
Symposiums	7,110	–	7,110	4,259
	<u>144,492</u>	<u>35,138</u>	<u>179,630</u>	<u>96,029</u>

8. GOVERNANCE COSTS

	Unrestricted Funds £	Total Funds 2008 £	Total Funds 2007 £
Accountancy fees	919	919	882
Costs of trustees' meetings	100	100	100
	<u>1,019</u>	<u>1,019</u>	<u>982</u>

9. NET INCOMING RESOURCES FOR THE YEAR

This is stated after charging:

	2008 £	2007 £
Depreciation	<u>881</u>	<u>881</u>

10. STAFF COSTS AND EMOLUMENTS

Total staff costs were as follows:

	2008 £	2007 £
Wages and salaries	9,401	4,648
Social security costs	–	–
	<u>9,401</u>	<u>4,648</u>

THE LOWE SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 30 JUNE 2008

10. STAFF COSTS AND EMOLUMENTS *(continued)*

Particulars of employees:

The average number of employees during the year, calculated on the basis of full-time equivalents, was as follows:

	2008	2007
	No	No
Number of administrative staff	<u>1</u>	<u>1</u>

No employee received emoluments of more than £60,000 during the year (2007 - Nil). A total of £33,334.52 of charity costs were paid on behalf of the charity by L. Thomas and were re-imbursed by the charity. Trustees received no remuneration.

11. TANGIBLE FIXED ASSETS

	Equipment £
COST	
At 1 July 2007 and 30 June 2008	<u>2,643</u>
DEPRECIATION	
At 1 July 2007	881
Charge for the year	<u>881</u>
At 30 June 2008	<u>1,762</u>
NET BOOK VALUE	
At 30 June 2008	<u>881</u>
At 30 June 2007	<u>1,762</u>

12. CREDITORS: Amounts falling due within one year

	2008	2007
	£	£
Accruals	<u>1,802</u>	<u>881</u>

13. RESTRICTED INCOME FUNDS

	Balance at 1 Jul 2007	Incoming resources	Outgoing resources	Balance at 30 Jun 2008
	£	£	£	£
Big Lottery Fund	<u>2,386</u>	<u>32,042</u>	<u>(34,428)</u>	<u>—</u>

THE LOWE SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 30 JUNE 2008

14. UNRESTRICTED INCOME FUNDS

	Balance at 1 Jul 2007 £	Incoming resources £	Outgoing resources £	Transfers £	Balance at 30 Jun 2008 £
Research grants	196,292	–	–	199,089	395,381
General office administration	30,000	–	–	–	30,000
Fundraising cycling event	15,000	–	–	–	15,000
General Funds	–	417,850	(218,761)	(199,089)	–
	<u>241,292</u>	<u>417,850</u>	<u>(218,761)</u>	<u>–</u>	<u>440,381</u>

THE LOWE SYNDROME TRUST
MANAGEMENT INFORMATION
YEAR ENDED 30 JUNE 2008

**The following page does not form part of the statutory financial statements
which are the subject of the independent examiner's report on page 5.**

THE LOWE SYNDROME TRUST
DETAILED STATEMENT OF FINANCIAL ACTIVITIES
YEAR ENDED 30 JUNE 2008

	2008		2007
	£	£	£
INCOMING RESOURCES			
VOLUNTARY INCOME			
Miscellaneous donations	153,858		83,865
Gift Aid - tax rebate	10,234		-
Big Lottery Fund (BLF)	32,042		30,200
Giving.com	143,091		35,826
Charities Aid Foundation	1,228		100
	<u>340,453</u>		<u>149,991</u>
INVESTMENT INCOME			
Bank interest receivable	12,658		6,017
INCOMING RESOURCES FROM CHARITABLE ACTIVITIES			
Other income from charitable activities	96,781		56,028
	<u>449,892</u>		<u>212,036</u>
TOTAL INCOMING RESOURCES			
RESOURCES EXPENDED			
COSTS OF GENERATING VOLUNTARY INCOME			
Legal & professional	3,991		3,548
Office expenses	9,004	BLF	4,958
Fundraising & publicity	59,545		23,753
	<u>72,540</u>		<u>32,259</u>

THE LOWE SYNDROME TRUST
DETAILED STATEMENT OF FINANCIAL ACTIVITIES
YEAR ENDED 30 JUNE 2008

		2008		2007
		£	£	£
CHARITABLE ACTIVITIES				
Lottery funded Salaries	BLF		9,401	4,648
Rent	BLF		5,501	5,124
Travel costs			3,978	2,014
Web design & consultancy fees	BLF		10,000	883
Office expenses	Part BLF		5,236	2,934
Depreciation			881	881
Bank charges			141	596
Grants payable			137,382	74,690
Symposiums and meetings			7,110	4,259
			<u>179,630</u>	<u>96,029</u>
GOVERNANCE COSTS				
Accountancy fees			919	882
Costs of trustees' meetings			100	100
			<u>1,019</u>	<u>982</u>
TOTAL RESOURCES				
EXPENDED				
			<u>253,189</u>	<u>129,270</u>
NET INCOMING RESOURCES				
FOR THE YEAR				
			<u>196,703</u>	<u>82,766</u>