

THE LOWE SYNDROME TRUST
FINANCIAL STATEMENTS
30 JUNE 2004

Charity Number 1081241

GROMAN & COMPANY

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

THE LOWE SYNDROME TRUST

FINANCIAL STATEMENTS

YEAR ENDED 30 JUNE 2004

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THE LOWE SYNDROME TRUST

TRUSTEES ANNUAL REPORT

YEAR ENDED 30 JUNE 2004

The trustees have pleasure in presenting their report and the unaudited financial statements of the charity for the year ended 30 June 2004.

The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" issued in October 2000 in preparing the annual report and financial statements of the charity.

Objects of the charity, principal activities and organisation of our work

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. The charity is organised so that the Trustees meet regularly, both to manage the day to day administration and to organise fundraising initiatives.

The Lowe Syndrome 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 charity is run by a family with a child with Lowe Syndrome from their home, and all activities are by unpaid volunteers. All the resources are borrowed or donated and so the charity has minimal administrative overhead costs and no assets. All funds raised are used for medical research and the charity has a voluntary medical research board that peer review and recommend the grant awards. In June 2004 the charity was awarded a commendation by charity finance magazine in the healthcare and medical research category. This annual report and all accounts are maintained on the charity website [http:](http://)

Developments, activities and achievements this year

I am delighted to report that a total of approximately £150,000 was able to be committed in grant awards in 2004 and three main grants were awarded of £50,000 each. Medical research funded by the charity is underway at Gt Ormond St hospital London (GOSH), University College London (UCL), Imperial College (London and Barcelona) and Dundee University Biocenter in Scotland. The charity continues to be approached for help in seed funding world class research projects and if enough funds can be raised next year the trustees will offer another major grant of up to £50,000 and organise an international symposium on Lowe Syndrome.

The charity has been unsuccessful in grant applications such as to the Department of Health (NHS) and has been disappointed to find that most well known charities such as Comic Relief will not fund medical research. Lorraine Thomas, chair of trust has met with Peter Greenaway, Assistant Director of the NHS following meetings with Sir John Pattison, Director of Research and Development at the NHS and with Lord Warner, Parliamentary Under Secretary of State.

In the UK, Lowe Syndrome is usually a clinical diagnosis (cataracts in both eyes, floppy baby, failure to thrive and kidney problems) and in my son's case, took six years. We now know it is caused by the low level of an essential enzyme and may also be detected as a DNA mutation. GOSH have now successfully cultured UK Lowe Cells from urine samples, and as well as using the cells for their own kidney research are sharing the cells with the other projects. Imperial are researching an inexpensive chemistry test for the enzyme that might also lead to being able to synthesize the enzyme.

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(continued)

Dundee Biocenter and University College London are using advanced techniques to examine the cell defects. In October 2003 the Thomas family appeared on GMTV with Dr John Lucocq awarding the Dundee research grant. In April 2004 the family and Dr Lucocq were interviewed by breakfast GMTV presenter Lorraine Kelly who is Dundee University's first female rector.

The main setbacks in achieving the aims of the charity - prevention, treatment and cure for Lowe syndrome - other than funding and lack of NHS support - is that cell sharing has been delayed by red tape such as ethics regulations and the ability to collate and share information such as the incidence of Lowe syndrome and relating cell samples to symptoms is hampered by patient record confidentiality. The charity does not keep any information on Lowe patients. The charity is affiliated to the Lowe Syndrome Association USA (LSA) who maintains an international LSA membership list and holds conventions for Lowe Syndrome families.

Fundraising and Events

The charity is entirely funded by voluntary donations and volunteer fundraising both of which enable the charity to meet its objectives. The tremendous efforts that are made on Charities behalf by unpaid (and unexpensed!) volunteers, celebrities, patrons and the medical advisory board are very much appreciated. During the year there were several events, both large and small, and they are all highly valued and important for the awareness and funds they bring to the charity.

In May 2004 Lorraine Thomas chair of the trust was one of three finalists nominated for the Good Housekeeping/Olsen Inspirational Woman of the Year Award for 2004 and featured in a 3-page article in Good Housekeeping magazine.

In April 2004 the actor Tom Conti broadcast the BBC Radio 4 Charity Appeal for the Lowe Syndrome Charity and this raised almost £8,000. Unfortunately although the script and the broadcast itself was by unpaid volunteers, the BBC declined to allow a copy of the broadcast to be made available on the charity website "for copyright reasons". GMTV provided copies of both the Dundee TV broadcasts for the website.

LST supporters ran in the Flora Light Women's Challenge, a fun run in Hyde Park in September. Forty women donned LST T-shirts and raised £4,000. LST supporters also took part in the 10 km Two Castles Race in Kenilworth in June, raising £400. A BT Funday raised £2,700, including a £1,000 contribution from EMC Computer Systems who like BT have generously supported the Trust since its formation. November's Nutcracker Ball was a fabulous event in Mayfair that raised £30,000 in donations - the most raised at a single event yet. Charity patron Jono Coleman made a speech, fellow patron Tony Hadley drew the raffle, and Mark Lamarr conducted the auction for an amazing array of donated goods, including the most sought after item of the evening: an England World Cup rugby shirt signed by the team that fetched £6,000. In May a "Ladies who lunch" hosted by TV presenter Tris Payne was held at the Rose and Crown Highgate and raised £4000.

Many organizations chose LST as their official charity including Golders Hill School, which raised £3,000, Abbots Hill School £500, Bertrum House School £143.64 and Highgate

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TRUSTEES ANNUAL REPORT

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(continued)

Pre Prep School who raised £1000. Woolworths Finchley Road have nominated the Trust as their charity of the year as did Marks & Spencer Temple Fortune who asked Lowe Syndrome sufferer Oscar Thomas to open up their new styled store in December, presenting a cheque to the Trust for £150.00.

Transactions and financial position

£65,925 was raised in funding, entirely from voluntary donations. £13,606 was spent on medical research grants, and expenses for fundraising events such as for venue hire and catering costs, amounted to £11,746. The charity holds funds of £171,686 at 30 June 2004 and of this amount, £150,000 was committed in medical research projects over a period of up to 3 years. The charity has so far awarded six research grants and has taken a novel approach to medical research, in that all the medical researchers across the projects are encouraged to work together, and payments are only made subject to results. Grants are advertised in Nature magazine and RDinfo. Grant payments are staged according to a schedule and conditional upon milestones having been achieved. The milestones are detailed in the grant applications and payments are detailed in the grants section of the accounts.

Patrons

The patrons of the charity are as follows:-

Tony Hadley, Vannessa Feltz, Jono Coleman, Tom Conti, Richard Park, Tris Payne, Susie Webb.

The Scientific & Medical Advisory Board

The Scientific and Medical Advisory Board are as follows:-

Professor Bruce Caterson, Professor of Research in Orthopaedics and Biochemistry, Cardiff University
Dr Anthony Norden, Addenbrookes Hospital, Cambridge

Dr William van't Hoff, Consultant Nephrologist, GOSH.

Professor Robert Unwin, Professor of Nephrology & Physiology, UCL.

Professor Shamshad Cockcroft, Department of Physiology, UCL.

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

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

Dr David Taylor Ophthalmic Surgeon, GOSH

Mike Harrison Consultant in Pediatric Dentistry, Guys Hospital London

Statement on Risks and Reserves

The trustees will not allow the charity to be exposed to any financial risks. The charity makes no financial commitments other than grant awards and expenses incurred for fundraising events and medical research meetings. All key information for the charity is copied and stored by three trustees. All key information is filed by computer and stored on two separate web hosting sites webfusion and homechoice. In the event of all the trustees being unable to administer the charity, a solicitor would be paid to take over the administration of the remaining grant payments and after all the funds exhausted, the last donations returned to the donors.

THE LOWE SYNDROME TRUST

TRUSTEES ANNUAL REPORT

YEAR ENDED 30 JUNE 2004

(continued)

Bank Accounts

The charity has two bank accounts and the charity is registered with CAF for donations. One bank account is Barclays Hampstead cheque account and for banking cash donations, and the other is a postal account with Abbey National business banking. All cheques have to be countersigned by two Trustees. There are no E-banking facilities and there is no petty cash.

Trustees' responsibilities

In preparing those financial statements, the trustees are required to select suitable accounting policies and then apply them consistently, making judgements and estimates that are reasonable and prudent. The trustees must also prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue its activities.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charity SORP 2000. 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.

The trustees

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

Mrs. L. Thomas (Chair)

Mr. J. Ross

Mrs. U. Reidy

Mrs. C. Mitchell

Mrs. C. McNaught

Signed by order of the trustees

77 West Heath Road
London
NW3 7TH

A. THOMAS
Treasurer

Approved by the trustees on 27th April 2005

THE LOWE SYNDROME TRUST
INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES
YEAR ENDED 30 JUNE 2004

We report on the unaudited accounts of the charity for the year ended 30 June 2004 set out on pages 8 to 11.

RESPECTIVE RESPONSIBILITIES OF THE TRUSTEES AND THE INDEPENDENT EXAMINER

As the charity's Trustees you are responsible for the preparation of the accounts; you consider that the audit requirement of section 43(2) of the Charities Act 1993 does not apply. It is my responsibility to state, on the basis of the procedures specified in the General Directions given by the Charities Commissioners under section 43(7)(b) of the Act, whether particular matters have come to our attention.

BASIS OF INDEPENDENT EXAMINER'S REPORT

Our examination was carried out in accordance with the general directions given by the Charities Commissioners. An independent 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 we 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 to 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

Honorary Accountants
GROMAN & COMPANY
Chartered Accountants

28th April 2005

THE LOWE SYNDROME TRUST
STATEMENT OF FINANCIAL ACTIVITIES
YEAR ENDED 30 JUNE 2004

	Note	Total Funds 2004 £	Total Funds 2003 £
INCOMING RESOURCES			
Donations	2	31,525	70,987
Income from charitable trading activities:			
Fundraising income	3	34,400	–
Interest receivable	4	3,979	2,638
TOTAL INCOMING RESOURCES		<u>69,904</u>	<u>73,625</u>
RESOURCES EXPENDED			
Costs of generating funds:			
Fundraising and publicity	5	7,789	–
Charitable expenditure:			
Costs in furtherance of charitable objects	6	13,606	10,350
Management and administration	7	3,957	15,388
TOTAL RESOURCES EXPENDED		<u>25,352</u>	<u>25,738</u>
NET INCOMING RESOURCES FOR THE YEAR		44,552	47,887
Balances brought forward		<u>127,134</u>	<u>79,247</u>
Balances carried forward		<u>171,686</u>	<u>127,134</u>

All movements are in Unrestricted Funds

The notes on pages 10 to 11 form part of these financial statements.

THE LOWE SYNDROME TRUST

BALANCE SHEET

30 JUNE 2004

	Note	2004 £	2003 £
CURRENT ASSETS			
Cash at bank		171,686	127,134
NET CURRENT ASSETS		<u>171,686</u>	<u>127,134</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>171,686</u>	<u>127,134</u>
FUNDS			
Unrestricted		171,686	127,134
TOTAL FUNDS		<u>171,686</u>	<u>127,134</u>

These financial statements were approved by the members of the committee on the 27th April 2005 and are signed on their behalf by:

MRS. L. THOMAS
Chair

The notes on pages 10 to 11 form part of these financial statements.

THE LOWE SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 30 JUNE 2004

1. ACCOUNTING POLICIES

Basis of accounting

The financial statements have been prepared under the historical cost convention and in accordance with the Statement of Recommended Practice "Accounting and Reporting by Charities" (SORP 2000) and the Charities Act 1993.

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.

2. DONATIONS

	Total Funds 2004 £	Total Funds 2003 £
Miscellaneous donations	28,705	70,987
Give as You Earn	2,820	-
	<u>31,525</u>	<u>70,987</u>

3. FUNDRAISING INCOME

	2004 £	2003 £
Income from events	34,400	-
	<u>34,400</u>	<u>-</u>

4. INTEREST RECEIVABLE

	Total Funds 2004 £	Total Funds 2003 £
Bank interest receivable	3,979	2,638
	<u>3,979</u>	<u>2,638</u>

THE LOWE SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 30 JUNE 2004

5. FUNDRAISING AND PUBLICITY

	Total Funds 2004 £	Total Funds 2003 £
Event expenses	<u>7,789</u>	<u>11,569</u>

6. COSTS IN FURTHERANCE OF CHARITABLE OBJECTS

	Total Funds 2004 £	Total Funds 2003 £
Research grants paid	<u>13,606</u>	<u>10,350</u>

7. TOTAL RESOURCES EXPENDED

	Grants paid and other costs £	Total Funds 2003 £
Direct charitable expenditure	13,606	10,350
Fundraising and publicity	7,789	11,569
Management and administration	3,957	3,819
	<u>25,352</u>	<u>25,738</u>

No salaries or wages have been paid to employees, including the members of the committee, during the year.

THE LOWE SYNDROME TRUST
MANAGEMENT INFORMATION
YEAR ENDED 30 JUNE 2004

**The following page does not form part of the statutory financial statements
which are the subject of the independent examiner's report on page 7.**

THE LOWE SYNDROME TRUST
DETAILED STATEMENT OF FINANCIAL ACTIVITIES
YEAR ENDED 30 JUNE 2004

	2004		2003	
	£	£	£	£
INCOME				
Miscellaneous donations		28,705		70,987
Give as You Earn		2,820		-
Bank interest receivable		3,979		2,638
Fundraising income		34,400		-
TOTAL INCOME		<u>69,904</u>		<u>73,625</u>
COSTS OF GENERATING FUNDS:				
Event expenses	7,789		11,569	
		7,789		11,569
CHARITABLE EXPENDITURE:				
Research grants paid	13,606		10,350	
		13,606		10,350
MANAGEMENT AND ADMINISTRATION				
Printing, postage & stationery	2,439		1,990	
Bank charges	262		338	
Computer costs	-		88	
Advertising	756		584	
T-shirts, caps & balloons	500		819	
		3,957		3,819
TOTAL EXPENDITURE		<u>25,352</u>		<u>25,738</u>
NET INCOMING RESOURCES FOR THE YEAR		<u>44,552</u>		<u>47,887</u>