

The Lowe Syndrome Trust
Unaudited Financial Statements
30 June 2025

A. I. GROMAN FCA
Chartered accountants
Groman and Company
Chartered Accountant and Independent Examiner
5 Violet Hill
St. John's Wood
London
NW8 9EB

The Lowe Syndrome Trust

Trustees' Annual Report

Year ended 30 June 2025

The trustees present their report and the unaudited financial statements of the charity for the year ended 30 June 2024.

Reference and administrative details

Registered charity name The Lowe Syndrome Trust

Charity registration number 1081241

Principal office C/o Rosenberg Solicitors
673 Finchley Road, London, NW2 2JP

The trustees Mr. J. Laycock (Chair)
Mr. Michael Fenning
Mrs. A Lanzara

Charity Patrons Mr J Ross OBE
Ms. Penny Lancaster
Mr. Christopher Biggins
Ms. Susie Webb
Mr. Tris Payne
Mr. Mathieu Flamini
Mr. Oliver Evans
Ms. Lisa Voice
Mr Mark Emms

Medical Research Advisory Board Dr Jenny Gallop, The Gurdon Institute, University of Cambridge
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, OBE Professor of Glaucoma & Ocular Healing & Consultant Ophthalmic Surgeon
Professor Helen Cross, Head of Neuroscience Unit, UCL
Dr. Nimalan Maruthaner, Royal Free Hospital / UCL
Professor Robert Kleita, 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

Trustees' Annual Report *(continued)*

Year ended 30 June 2025

Company secretary	A. Thomas (Treasurer)
Independent examiner	A.I. Groman FCA Groman and Company Chartered Accountant and Independent Examiner 5 Violet Hill St. John's Wood London NW8 9EB

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 discuss strategic planning and development of the trust, administer grants and run fundraising initiatives. There is now an (unpaid) volunteer Chief Executive Officer (CEO) Andrew Thomas appointed on 21st June 2019, husband of the late Lorraine Thomas who founded the charity. The CEO 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. The charity also now employs one part-time administrator to manage day-to-day charity functioning. Occasionally, 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 site

The Lowe Syndrome Trust

Trustees' Annual Report *(continued)*

Year ended 30 June 2025

OBJECTIVES AND ACTIVITIES

The Trust is the only charity in the UK that supports families affected by Lowe syndrome and is a key initiator and funder of global medical research into Lowe syndrome.

The objective of the charity is to provide support and resources for UK families affected by the condition and to encourage medical research. Lowe Syndrome, also known as oculocerebrorenal syndrome (OCRL), is a genetic condition which affects eyes (babies are born with congenital Cataracts), kidneys, brain and general development. The DNA mutation overlaps with a kidney condition called Dents2 Disease and so the charity also supports Dents families.

The Charity is a listed non-commercial Partner of the National Institute for Health Research (NIHR). Being part of NIHR network means that Lowe Syndrome Trust can award research funds as a result of open competition across England with high quality peer review. Further, fund research that is of clear value to the NHS and take account of the Department of Health and NHS priorities and needs in their research funding strategies.

The charity works alongside international affiliations, such as Lowe Syndrome Association (LSA) in the USA, Europe and India. The charity supports UK family outreach and Lowe related meetings, for example sponsored Jenny Gallop in partnership with the Gurdon Institute Cambridge to attend the Lowe Syndrome Association USA conference in June 2024, and the charity attended Rarefest Cambridge November 24, where Jenny presented on Lowe Syndrome. The LST also sponsors and supports family networking such as the "Lowe Syndrome Parents" Facebook.

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.

The charity is for the benefit of UK families affected by the Lowe Syndrome Condition, to help them access local social and NHS services and for social and NHS professionals to understand the condition and offer the best support and treatments. To do that, the charity works with other UK charities, to fundraise to offer grants to seed fund medical and social research, international research meetings and clinical trials for recently discovered drug treatments.

GRANT MAKING POLICY

The charity website is used by UK families and UK NHS England. The grant strategy is to collaborate with other Lowe Syndrome research institutions. Past medical research grants were to "seed fund" basic research on different aspect of the condition, now the focus is on supporting clinical trials, including expensing medical research meetings on Lowe Syndrome.

Grants are awarded on the advice of the Lowe Syndrome Trust Scientific Advisory Board. Grant applications are shared with Lowe Syndrome associations in other countries that also offer research grants, including the Lowe Syndrome Association (LSA) in USA and European associations.

The grant applications are peer reviewed and the trust's scientific advisory board advise on the grant award. Research 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 on the charity website. The committed grant funding liability is shown in the accounts.

The Lowe Syndrome Trust

Trustees' Annual Report *(continued)*

Year ended 30 June 2025

MAJOR CHANGES

To reduce costs the charity office has been closed and the address will be postal only. The website formerly .com, has been moved to a new provider and registered as lowetrust.org.uk.

FUNDRAISING

The charity will continue to fundraise, and benefited from an extension of the grant period from the National Lottery Community Fund, suspended during COVID, and now ends in June 2025. The Grant funded a part time charity administrator, general running costs and towards self sufficiency in fund raising, and to fund UK England family outreach meetings.

PLANS FOR FUTURE PERIODS.

The Charity is working alongside the Lowe Syndrome Association (LSA), ALISO (Italy) and Sanford Research Coordination of Rare Diseases at Sanford (CoRDS) in USA to establish a medical research data base specifically for Lowe and Dents 2 syndrome for families to record their details and medical history that can be used for research and clinical trials.

Following the International Medical Research Summit in TIGEM Naples Italy, partially funded by a grant from the charity to Gurdon Institute Cambridge University, we have announced three potential drug therapies and the charity awarded funding a grant of £20,000 for clinical trials in Rome at the GESU Bambino Hospital and £15,000 for a follow-on International Medical Research Summit in October 2024 hosted by Purdue University USA, and includes funding expenses for a research student.

The Charity hopes to be able use surplus lottery funds to fund further UK England family outreach meetings planned for London and Bristol in 2025/26.

FINANCIAL SUMMARY AND RESERVES

The statement of Financial Activities shows income for the year of £19,707 (2024 - £38,104) and total expenditure of £49,414 (2024 - £28,794).

The expenditure included charity running costs, office closure costs and expenses for family outreach and medical research meetings. During this period there total grant payments of £29,496,

Purdue University Medical Conference £12,015

GESU Bambino Hospital Clinical Trials £17,391

The total funds carried forward were £39,903 (2024 – £69,610).

CONCLUDING REMARKS

The charity would like to say thank you to our supporters, donors and volunteers. It has been a long and challenging journey from discovering the Lowe Syndrome Gene Mutation, NHS services to test for the DNA mutation, through to the discovery of potential drug treatments and clinical trials for drug therapies that may be able to reverse the condition.

Andrew Thomas, CEO Lowe Syndrome Trust

The trustees' annual report was approved on and signed on behalf of the board of trustees by:

The Lowe Syndrome Trust

Independent Examiner's Report to the Trustees of The Lowe Syndrome Trust

Year ended 30 June 2025

I report to the trustees on my examination of the financial statements of The Lowe Syndrome Trust ('the charity') for the year ended 30 June 2025.

Responsibilities and basis of report

As the trustees of the charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the charity's financial statements carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the charity as required by section 130 of the Act; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

A.I. Groman FCA
Independent Examiner

Groman and Company
Chartered Accountant and Independent Examiner
5 Violet Hill
St. John's Wood
London
NW8 9EB

The Lowe Syndrome Trust
Statement of Financial Activities
Year ended 30 June 2025

		2025		2024
		Unrestricted	Total funds	Total funds
	Note	funds £	£	£
Income and endowments				
Donations and legacies	4	19,124	19,124	37,484
Investment income	5	583	583	620
Total income		<u>19,707</u>	<u>19,707</u>	<u>38,104</u>
Expenditure				
Expenditure on charitable activities	6,7	49,414	49,414	28,794
Total expenditure		<u>49,414</u>	<u>49,414</u>	<u>28,794</u>
Net (expenditure)/income and net movement in funds		<u>(29,707)</u>	<u>(29,707)</u>	<u>9,310</u>
Reconciliation of funds				
Total funds brought forward		69,610	69,610	60,300
Total funds carried forward		<u>39,903</u>	<u>39,903</u>	<u>69,610</u>

The statement of financial activities includes all gains and losses recognised in the year.
All income and expenditure derive from continuing activities.

The notes on pages 8 to 12 form part of these financial statements.

The Lowe Syndrome Trust

Statement of Financial Position

30 June 2025

	Note	2025 £	£	2024 £
Current assets				
Cash at bank and in hand		40,923		70,630
Creditors: amounts falling due within one year	11	<u>1,020</u>		<u>1,020</u>
Net current assets			<u>39,903</u>	<u>69,610</u>
Total assets less current liabilities			<u>39,903</u>	<u>69,610</u>
Net assets			<u>39,903</u>	<u>69,610</u>
Funds of the charity				
Restricted funds			–	17,239
Unrestricted funds			<u>39,903</u>	<u>52,371</u>
Total charity funds	12		<u>39,903</u>	<u>69,610</u>

These financial statements were approved by the board of trustees and authorised for issue on, and are signed on behalf of the board by:

Mr J Laycock (Chair)
Trustee

The notes on pages 8 to 12 form part of these financial statements.

The Lowe Syndrome Trust
Notes to the Financial Statements
Year ended 30 June 2025

1. General information

The charity is a public benefit entity and a registered charity in England and Wales and is unincorporated. The address of the principal office is London.

2. Statement of compliance

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (Charities SORP (FRS 102)) and the Charities Act 2011.

3. Accounting policies

Basis of preparation

The financial statements have been prepared on the historical cost basis, as modified by the revaluation of certain financial assets and liabilities and investment properties measured at fair value through income or expenditure.

The financial statements are prepared in sterling, which is the functional currency of the entity.

Going concern

There are no material uncertainties about the charity's ability to continue.

Judgements and key sources of estimation uncertainty

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported. These estimates and judgements are continually reviewed and are based on experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

Fund accounting

Unrestricted funds are available for use at the discretion of the trustees to further any of the charity's purposes.

Designated funds are unrestricted funds earmarked by the trustees for particular future project or commitment.

Restricted funds are subjected to restrictions on their expenditure declared by the donor or through the terms of an appeal, and fall into one of two sub-classes: restricted income funds or endowment funds.

The Lowe Syndrome Trust

Notes to the Financial Statements *(continued)*

Year ended 30 June 2025

3. Accounting policies *(continued)*

Incoming resources

All incoming resources are included in the statement of financial activities when entitlement has passed to the charity; it is probable that the economic benefits associated with the transaction will flow to the charity and the amount can be reliably measured. The following specific policies are applied to particular categories of income:

- income from donations or grants is recognised when there is evidence of entitlement to the gift, receipt is probable and its amount can be measured reliably.
- legacy income is recognised when receipt is probable and entitlement is established.
- income from donated goods is measured at the fair value of the goods unless this is impractical to measure reliably, in which case the value is derived from the cost to the donor or the estimated resale value. Donated facilities and services are recognised in the accounts when received if the value can be reliably measured. No amounts are included for the contribution of general volunteers.
- income from contracts for the supply of services is recognised with the delivery of the contracted service. This is classified as unrestricted funds unless there is a contractual requirement for it to be spent on a particular purpose and returned if unspent, in which case it may be regarded as restricted.

Resources expended

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is classified under headings of the statement of financial activities to which it relates:

- expenditure on raising funds includes the costs of all fundraising activities, events, non-charitable trading activities, and the sale of donated goods.
- expenditure on charitable activities includes all costs incurred by a charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities.
- other expenditure includes all expenditure that is neither related to raising funds for the charity nor part of its expenditure on charitable activities.

All costs are allocated to expenditure categories reflecting the use of the resource. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs are apportioned between the activities they contribute to on a reasonable, justifiable and consistent basis.

Tangible assets

All fixed assets are initially recorded at cost.

Depreciation

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

Equipment	- 33% straight line
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The Lowe Syndrome Trust

Notes to the Financial Statements *(continued)*

Year ended 30 June 2025

3. Accounting policies *(continued)*

Impairment of fixed assets

A review for indicators of impairment is carried out at each reporting date, with the recoverable amount being estimated where such indicators exist. Where the carrying value exceeds the recoverable amount, the asset is impaired accordingly. Prior impairments are also reviewed for possible reversal at each reporting date.

For the purposes of impairment testing, when it is not possible to estimate the recoverable amount of an individual asset, an estimate is made of the recoverable amount of the cash-generating unit to which the asset belongs. The cash-generating unit is the smallest identifiable group of assets that includes the asset and generates cash inflows that largely independent of the cash inflows from other assets or groups of assets.

For impairment testing of goodwill, the goodwill acquired in a business combination is, from the acquisition date, allocated to each of the cash-generating units that are expected to benefit from the synergies of the combination, irrespective of whether other assets or liabilities of the charity are assigned to those units.

4. Donations and legacies

	Unrestricted Funds £	Restricted Funds £	Total Funds 2025 £
Donations			
Miscellaneous donations	1,609	–	1,609
Grants			
Lottery Grant	17,515	–	17,515
CAF GAYE	–	–	–
	<u>19,124</u>	<u>–</u>	<u>19,124</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
Donations			
Miscellaneous donations	4,243	–	4,243
Grants			
Lottery Grant	–	33,181	33,181
CAF GAYE	60	–	60
	<u>4,303</u>	<u>33,181</u>	<u>37,484</u>

5. Investment income

	Unrestricted Funds £	Total Funds 2025 £	Unrestricted Funds £	Total Funds 2024 £
Bank interest receivable	<u>583</u>	<u>583</u>	<u>620</u>	<u>620</u>

The Lowe Syndrome Trust

Notes to the Financial Statements *(continued)*

Year ended 30 June 2025

6. Expenditure on charitable activities by fund type

	Unrestricted Funds	Restricted Funds	Total Funds
	£	£	2025
Grants payable	29,496	–	29,496
Support costs	19,918	–	19,918
	<u>49,414</u>	<u>–</u>	<u>49,414</u>
	Unrestricted Funds	Restricted Funds	Total Funds
	£	£	2024
Grants payable	–	–	–
Support costs	12,852	15,942	28,794
	<u>12,852</u>	<u>15,942</u>	<u>28,794</u>

7. Expenditure on charitable activities by activity type

	Grant funding of activities	Support costs	Total funds	Total fund
	£	£	2025	2024
Principal activity	29,496	18,898	48,394	27,774
Governance costs	–	1,020	1,020	1,020
	<u>29,496</u>	<u>19,918</u>	<u>49,414</u>	<u>28,794</u>

8. Staff costs

The total staff costs and employee benefits for the reporting period are analysed as follows:

	2025	2024
	£	£
Wages and salaries	<u>15,942</u>	<u>15,942</u>

The average head count of employees during the year was 1 (2024: 1).

No employee received employee benefits of more than £60,000 during the year (2024: Nil).

9. Trustee remuneration and expenses

SORP 2015 requires the following statement to be made:- no remuneration or other benefits from employment with the charity or a related entity were received by the trustees.

The Lowe Syndrome Trust

Notes to the Financial Statements *(continued)*

Year ended 30 June 2025

10. Tangible fixed assets

	Equipment £	Total £
Cost		
At 1 July 2024 and 30 June 2025	<u>16,917</u>	<u>16,917</u>
Depreciation		
At 1 July 2024 and 30 June 2025	<u>16,917</u>	<u>16,917</u>
Carrying amount		
At 30 June 2025	<u>—</u>	<u>—</u>
At 30 June 2024	<u>—</u>	<u>—</u>

11. Creditors: amounts falling due within one year

	2025 £	2024 £
Accruals and deferred income	<u>1,020</u>	<u>1,020</u>

12. Analysis of charitable funds

Unrestricted funds

	At 1 July 2024 £	Income £	Expenditure £	At 30 June 2025 £
General Funds	(30,390)	19,707	(49,414)	(60,097)
Unrestricted fund -Grant payable	50,000	—	—	50,000
Designated Fund - General office administration	50,000	—	—	50,000
	<u>69,610</u>	<u>19,707</u>	<u>(49,414)</u>	<u>39,903</u>

	At 1 July 2023 £	Income £	Expenditure £	At 30 June 2024 £
General Funds	(39,700)	4,923	(12,852)	(47,629)
Unrestricted fund -Grant payable	50,000	—	—	50,000
Designated Fund - General office administration	50,000	—	—	50,000
	<u>60,300</u>	<u>4,923</u>	<u>(12,852)</u>	<u>52,371</u>

The Lowe Syndrome Trust

Management Information

Year ended 30 June 2025

The following pages do not form part of the financial statements.

The Lowe Syndrome Trust
Detailed Statement of Financial Activities
Year ended 30 June 2025

	2025 £	2024 £
Income and endowments		
Donations and legacies		
Miscellaneous donations	1,609	4,243
Lottery Grant	17,515	33,181
CAF GAYE	—	60
	<u>19,124</u>	<u>37,484</u>
 Investment income		
Bank interest receivable	583	620
	<u>—</u>	<u>—</u>
 Total income	<u><u>19,707</u></u>	<u><u>38,104</u></u>
 Expenditure		
Expenditure on charitable activities		
Wages and salaries	15,942	15,942
Rent	—	2,800
Insurance	884	167
Families Outreach and Travel costs	527	6,926
Legal and professional fees	1,020	1,020
Telephone	1,525	1,939
Other office costs	1	—
Grants payable	29,515	—
	<u>49,414</u>	<u>28,794</u>
 Total expenditure	<u><u>49,414</u></u>	<u><u>28,794</u></u>
 Net (expenditure)/income	<u><u>(29,707)</u></u>	<u><u>9,310</u></u>

The Lowe Syndrome Trust

Notes to the Detailed Statement of Financial Activities

Year ended 30 June 2025

	2025 £	2024 £
Expenditure on charitable activities		
Principal activity		
<i>Grant funding activities</i>		
Grant charitable activity	29,496	—
<i>Support costs</i>		
Salaries and contract workers	15,942	15,942
Rent and security	—	2,800
Insurance	884	167
Families Outreach and Travel costs	527	6,926
Telephone	1,525	1,939
Office costs	1	—
Advertising	19	—
	18,898	27,774
Governance costs		
Governance costs - accountancy fees	1,020	1,020
Expenditure on charitable activities	49,414	28,794