The Lowe Syndrome Trust Unaudited Financial Statements 30 June 2023

A. I. GROMAN FCA

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

Trustees' Annual Report

Year ended 30 June 2023

The trustees present their report and the unaudited financial statements of the charity for the year ended 30 June 2023.

Reference and administrative details

Registered charity name The Lowe Syndrome Trust

Charity registration number 1081241

Principal office 673 Finchley Road

> London NW2 2JP

The trustees Mr. J. Laycock (Chair)

> Mr. Michael Fenning Mrs. C. Mitchell Ms. P. Biziou

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. J Ross

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 Opthalmic 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 Dr Jenny Gallop, The Gurdon Institute, University of Cambridge

Trustees' Annual Report (continued)

Year ended 30 June 2023

Company secretary A. Thomas (Treasurer)

Independent examiner A.I. Groman FCA

Groman and Company

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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 sites.

Trustees' Annual Report (continued)

Year ended 30 June 2023

OBJECTIVES AND ACTIVITIES

The goal of Lowe Syndrome Trust is to encourage medical research for a more effective treatment of Lowe syndrome, as well as to provide support and informational resources for medical professionals and families affected by Lowe syndrome, from the moment of diagnosis. Lowe syndrome, also known as oculocerebrorenal syndrome (OCRL), is a debilitating genetic condition which affects eyes, kidneys, muscles, normal development and neurological functioning.

The charity is voluntarily run by a family with a child, now an adult, with Lowe Syndrome, with minimal administrative overhead costs. All funds raised are used to further medical research and support Lowe syndrome families and medical professionals. The Charity also benefits from an unpaid medical and scientific advisory board that advises the charity on all medical and scientific aspects, such as peer review and recommendations as to the grant awards.

The Trust is the only charity in the UK that supports children with Lowe syndrome and their families, and one of the key initiators and funders of global medical research into Lowe syndrome, covering different facets from animal models and genetic research to behavioural profile of Lowe syndrome.

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.

Moreover, the Trust works alongside international affiliations, such as Lowe Syndrome Association (LSA) in the USA. LST is also in regular contact with and assist self-established family support groups, such as "Lowe Syndrome Parents" support group on 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.

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 on the charity website. The committed grant funding liability is shown in the accounts.

MAJOR CHANGES AND SERIOUS INCIDENTS REPORTS

During the period Jonathan Ross has stepped down as a trustee to continue as a patron. Patron Mike Fenning has agreed to become a trustee. There were no other major changes or incidents.

Trustees' Annual Report (continued)

Year ended 30 June 2023

ACHIEVEMENTS AND PERFORMANCE

MEDICAL RESEARCH AND ACTIVITIES

After the Covid freeze, the charity resumed activities and fundraising, starting with confirming all our charity patrons, supporters and families.

In March 2023 - there was an LST charity visit to The Gurdon Institute, University of Cambridge CEO Andrew Thomas and son Oscar visited the Gallop lab to share experiences, discuss recent drug discoveries and working together to promote research.

We are delighted to announce that Dr Jenny Gallop agreed to become a member of the LST medical board.

In May 2023 the charity sponsored the Lowe international medical conference in TIGEM Naples Italy through a grant to Gurdon Institute. The conference was a huge success in gathering together 40 delegates from 6 countries and 20 research institutions. It was agreed The charity will work together with other Lowe groups such as LSA USA, AISLO and stakeholders with common grant award processes and sharing resources to jumpstart potential clinical trials for the newly discovered drug therapies.

During the accounting period, the Trust continued to support the previous grant award to Perdue University USA initially awarded in May 2021, a 3 year project to 2023 under Dr Ruben Aguilar, Assistant Head and Showalter Faculty Scholar, Department of Biological Sciences, Purdue University USA. The grant to Purdue is to research 'Reactivation of Ocrl1 function in Lowe Syndrome', testing possible drugs in the laboratory to see if they could be used to help treat Lowe syndrome. Ocrl1 is the enzyme that is mutated in Lowe syndrome and the research confirmed specific drugs may be able to restore its function.

The charity researched recently announced NHS genetic services for DNA testing, at-home blood and kidney monitoring services and published a new NHS GP and family section on the website.

FUNDRAISING

The Big lottery suspended payments during the period. Lowe Syndrome Trust continued to raise awareness and funding for the charity, such as celebrity Patrons appearing on the TV. We regularly appeal various foundations to raise donations and encourage the visibility of Lowe syndrome and of charity's work. Additionally, the Lowe syndrome community occasionally raises money for the through gofundme and Facebook fundraisers

FINANCIAL SUMMARY AND RESERVES

The statement of Financial Activities shows income for the year of £3,860 (2022 - £18,566) and total expenditure of £ 67,150 (2022 - £69,554). The net expenditure of £63,290 (2022 - 50,988) is after the total grants paid during the year for medical research projects totalling £40,000 (2022 - £37,360). The main Medical Research grant payments and expenditure during the year were to:

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

Gurdon Institute Cambridge University £15000
Perdue Aguilar lab USA USA £25000

FUTURE

The charity will promote the Cerebra Neurological survey. The Cerebra Network for Neurodevelopmental Disorders is a collaborative research network, working across the UK at the University of Birmingham, Aston University, University of Surrey, and University of Warwick – you can find out more about the team at www.cerebranetwork.com. The LST will be reaching out to families to participate in the BEOND that is an ambitious survey exploring wellbeing, behaviour, sleep, health,

Trustees' Annual Report (continued)

Year ended 30 June 2023

FUTURE (continued)

emotion, and development in people with a variety of genetic syndromes, intellectual disability, and neurodevelopmental disorders.

The charity received proposals for pilot clinical trials and has set aside £20,000. The charity will also set aside £15,000 towards a Lowe Medical conference summit in 2024.

The charity will resubmit for a resumption of the Big Lottery grant towards outreach and assistance with up to 50 families in UK and will publish a guide to Lowe Adult care. The guide will cover all aspects of transition from Children and Special Educational Needs (SEN) to Adults with learning difficulties, legal, social services and needs assessments, benefit entitlement, supported employment, placement and support in residential care.

It is hoped that through the outreach program families will be assisted to register for BEOND and NHS genetics services and databases for DNA mutation analysis and health monitoring and some families can be identified for potential clinical trials.

The charity will also publish a 2023 Newsletter and ensure distribution to UK families.

Andrew Thomas, CEO Lowe Syndrome Trust

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

Independent Examiner's Report to the Trustees of The Lowe Syndrome Trust Year ended 30 June 2023

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 2023.

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:

- 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

Statement of Financial Activities

Year ended 30 June 2023

	U	nrestricted	2023 Restricted		2022
	Note	funds	funds	Total funds	Total funds
Income and endowments		_	_	_	~
Donations and legacies Investment income	4 5	3,582 278	_	3,582 278	18,539 27
Total income		3,860	_	3,860	18,566
Expenditure Expenditure on charitable activities Other expenditure	6,7 8	48,942 76	18,132 –	67,074 76	69,520 34
Total expenditure		49,018	18,132	67,150	69,554
Net expenditure and net movement	in				
funds		(45,158) ———	(18,132) ———	(63,290)	(50,988)
Reconciliation of funds		105 459	40 422	422 F00	474 577
Total funds brought forward		105,458	18,132	123,590	174,577
Total funds carried forward		60,300		60,300	123,589

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

Statement of Financial Position

30 June 2023

	2023			2022
	Note	£	£	£
Current assets Cash at bank and in hand		61,320		124,609
Creditors: amounts falling due within one year	13	1,020		1,020
Net current assets			60,300	123,589
Total assets less current liabilities			60,300	123,589
Net assets			60,300	123,589
Funds of the charity				
Restricted funds			_	18,132
Unrestricted funds			60,300	105,457
Total charity funds	14		60,300	123,589

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

Notes to the Financial Statements

Year ended 30 June 2023

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 673 Finchley Road, London, NW2 2JP.

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.

Notes to the Financial Statements (continued)

Year ended 30 June 2023

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

Notes to the Financial Statements (continued)

Year ended 30 June 2023

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 cashgenerating 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 2023 £
Donations Miscellaneous donations Give as You Earn		3,434 -	<u>-</u>	3,434 -
Grants Lottery Grant CAF GAYE		148 3,582	- - -	148 3,582
Donations		Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Miscellaneous donations Give as You Earn		2,675 27	_ _	2,675 27
Grants Lottery Grant CAF GAYE		170 2,872	15,667 - 1 <u>5,667</u>	15,667 170 18,539
Investment income				
	Unrestricted	Total Funds	Unrestricted	Total Funda

5.

	Unrestricted	Total Funds	Unrestricted	Total Funds
	Funds	2023	Funds	2022
	£	£	£	£
Bank interest receivable	278	278	27	27

Notes to the Financial Statements (continued)

Year ended 30 June 2023

6. Expenditure on charitable activities by fund type

Grants payable Support costs	Unrestricted Funds £ 40,000 8,942	Restricted Funds £ – 18,132	Total Funds 2023 £ 40,000 27,074
	48,942	18,132	67,074
Grants payable Support costs	Unrestricted Funds £ 37,360 1,230	Restricted Funds £ - 30,930	Total Funds 2022 £ 37,360 32,160
	38,590	30,930	69,520

7. Expenditure on charitable activities by activity type

	Activities undertaken directly £	Support costs £	Total funds 2023 £	Total fund 2022 £
Principal activity	_	24,208	24,208	30,930
Grants payable	40,000	_	40,000	37,360
Governance costs	_	2,866	2,866	1,230
	40,000	27,074	67,074	69,520

8. Other expenditure

	Unrestricted	Total Funds	Unrestricted	Total Funds
	Funds	2023	Funds	2022
	£	£	£	£
Bank charges	76	76	34	34

9. Staff costs

The average head count of employees during the year was 1 (2022: 1).

No employee received employee benefits of more than £60,000 during the year (2022: Nil).

10. 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.

11. Independent Examiner Fees

	2023	2022
	£	£
Independent Examiner Fees	1,020	1,020

Notes to the Financial Statements (continued)

Year ended 30 June 2023

12. Tangible fixed assets

				Equipment £	Total £
	Cost At 1 July 2022 and 30 June 2023			16,917	16,917
	Depreciation At 1 July 2022 and 30 June 2023			16,917	16,917
	Carrying amount At 30 June 2023				
	At 30 June 2022				
13.	Creditors: amounts falling due with	nin one year		2023	2022
	Accruals and deferred income			£ 1,020	£ 1,020
14.	Analysis of charitable funds Unrestricted funds				
		At 1 July 2022 £	Income £	Expenditure £	At 30 June 2023 £
	General Funds	5,458	3,860	(49,018)	(39,700)
	Designated Fund - Grants Payable Designated Fund - General office	50,000	-	-	50,000
	administration	50,000	_	_	50,000
		105,458	3,860 ====	(49,018) ====	60,300
		At 1 July 2021 £	Income £	Expenditure £	At 30 June 2022 £
	General Funds Designated Fund - Grants Payable Designated Fund - General office	41,182 50,000	2,899 -	(38,624)	5,457 50,000
	administration	50,000	_	_	50,000
		141,182	2,899	(38,624)	105,457
15.	Restricted funds				
		At 1 July 2022 £	Income £	Expenditure £	At 30 June 2023 £
	Big Lottery Fund	18,132		(18,132)	
		At 1 July 2021 £	Income £	Expenditure 3	At 30 June 2022 £
	Big Lottery Fund	33,395	15,667	(30,930)	18,132 =====

Management Information

Year ended 30 June 2023

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

Detailed Statement of Financial Activities

Year ended 30 June 2023

	2023 £	2022 £
Income and endowments		
Donations and legacies Miscellaneous donations Give as You Earn	3,434	2,675 27
Lottery Grant	_	15,667
CAF GAYE	148	170
	3,582	18,539
Investment income	070	07
Bank interest receivable	278 —	<u>27</u>
Total income	3,860	18,566
Expenditure		
Expenditure on charitable activities Wages and salaries	15,962	15,910
Rent	5,560	9,099
Insurance	1,131	671
Other motor/travel costs	1,476	2,302
Legal and professional fees	1,020	1,230
Telephone Other office costs	1,846	2,529
Other office costs Grants payable	79 40,000	419 37,360
	67,074	69,520
Other expenditure		
Bank charges	<u>76</u>	34
Total expenditure	67,150	69,554
Net expenditure	(63,290)	(50,988)

Notes to the Detailed Statement of Financial Activities

Year ended 30 June 2023

	2023 £	2022 £
Expenditure on charitable activities Principal activity Support costs	_	-
Salaries and contract workers Rent and security	15,962 5,560	15,910 9,099
Insurance Motor and travel costs	1,131 1,476	671 2,302
Telephone Office costs	1,846 79	2,529 419
	26,054	30,930
Grants payable Activities undertaken directly		
Grants payable	40,000	37,360
Governance costs Governance costs – legal and professional fees Governance costs - accountancy fees	- 1,020	230 1,020
	1,020	1,230
Expenditure on charitable activities	67,074	69,520