

THE LOWE SYNDROME TRUST

England & Wales · Charity number 1081241

Details

Other names LOWE SYNDROME TRUST, LST

Status Registered

Legal form Other

Registered 2000-06-23

Register [View on the Charity Commission register](#)

Contact

Address Lowe Syndrome Trust
673 Finchley Road
London
NW2 2JP

Phone 07958444020

Email info@lowetrust.com

Website www.lowetrust.org.uk

Activities

Objects: TO EDUCATE THE PUBLIC IN ALL MATTERS RELATING TO THE LOWE SYNDROME, TO PROMOTE RESEARCH INTO ALL ITS CAUSES AND TREATMENT AND TO DISSEMINATE THE RESULTS OF SUCH RESEARCH.

Activities: TO RAISE AWARENESS OF LOWE SYNDROME, HELP FAMILIES INCLUSIVENESS AND TO STIMULATE GLOBAL MEDICAL RESEARCH FOR BETTER TREATMENT.

Classification

- **How:** Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities, The General Public/mankind

Geography

- Italy
- United States
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-06-30	£19,707	£49,414	-	-
2024-06-30	£38,104	£28,794	-	-
2023-06-30	£3,860	£67,150	-	-
2022-06-30	£18,566	£69,554	-	-
2021-06-30	£57,582	£56,722	-	-

Trustees

Name	Role	Appointed
Anastacia Lanzara		2024-02-23
Dr Joseph Laycock		2016-07-01
Micheal Fennings		2024-02-23

THE LOWE SYNDROME TRUST

England & Wales - Charity number 1081241

Accounts

The Lowe Syndrome Trust
Unaudited Financial Statements
30 June 2024

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 2024

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 (Appointed 23 February 2024)
Mrs. A Lanzara (Appointed 23 February 2024)

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 Kleta, Chair of Nephrology, Royal Free Hospital/UCL
Dr. Richard Sandford, Honorary Consultant in Medical Genetics, University of Cambridge
Dr. Rudiger Woscholski, Senior Lecturer, Imperial College London

The Lowe Syndrome Trust

Trustees' Annual Report

Year ended 30 June 2024

Company secretary	Mr. A Thomas (CEO)
Charity administration	Ms. A Bogdanova
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 three bank accounts with different banks. These are a postal business deposit account and a business savings account that are only authorised to transfer funds into the third account, that is a business e-banking account.
- The charity has retained the office address, that is a solicitors office used only for the postal address.

The Lowe Syndrome Trust

Trustees' Annual Report

Year ended 30 June 2024

OBJECTIVES AND ACTIVITIES

The Trust is the only charity in the UK that supports families affected by Lowe syndrome and 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 international medical research. Lowe Syndrome, also known as oculocerebrorenal syndrome (OCRL), is a genetic condition which affects eyes (born with congenital Cataracts), kidneys, brain and general development. The DNA mutation overlaps with a kidney condition called Dents 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 and other countries. The charity also organises UK family outreach meetings and held an outreach meeting in Cambridge near the Gurdon Institute in November 2023. The LST also supports family networking such as the "Lowe Syndrome Parents" Facebook.

PUBLIC BENEFIT

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, and to fundraise to offer grants to seed fund medical and social research, and international research meetings.

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

While the charity family support and website is for UK families and UK NHS England, The research grant strategy is to collaborate with international medical research institutions.

Grants are awarded on the advice of the Lowe Syndrome Trust Scientific Advisory Board. Past medical research grants were to "seed fund" basic research on different aspect of the condition, now the focus is on preparing for potential clinical trials.

Grant applications are shared with Lowe Syndrome associations in other countries that also offer research grants including the Lowe Syndrome Association (LSA) in USA. The grant applications are peer reviewed and the trust's scientific advisory board decide on the grant award. The 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

The charity accepted the resignation of two trustees and appointed two new Trustees, Mr. Michael Fenning (Appointed 23 February 2024), Mrs. A Lanzara (Appointed 23 February 2024).

To reduce costs the charity office has been closed and the address will be postal only, and the website moved to a new provider.

The Lowe Syndrome Trust

Trustees' Annual Report

Year ended 30 June 2024

FUNDRAISING

The charity will continue to fundraise, and benefits from an extension of the grant period from the National Lottery Community Fund, that was suspended during COVID period. The extension is to continue supporting a part time charity administrator until June 2025, for 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 with 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 syndrome for families to record their details and history of the disease.

Following the International Medical Research Summit in May 2023 in TIGEM Naples Italy, partially funded by a grant from the charity to Gurdon Institute Cambridge University, three potential drug therapies were announced.

The charity has committed £20,000 funding for potential clinical trials proposed under ERKNet, the European Reference Network for Rare Kidney Diseases by TIGEM/Gurdon Institute Cambridge University, and £15000 for a follow-on International Medical Research Summit in October 2024 hosted by Perdue University USA.

The Charity will plan and fund further UK England family outreach meetings planned for Newcastle and Bristol in 2024.

FINANCIAL SUMMARY AND RESERVES

The statement of Financial Activities shows income for the year of £38,104 (2023 - £3,860) and total expenditure of £28,794 (2023 - £67,150). The expenditure included charity running costs, office closure costs and funding family outreach meetings. During this period there were no grant payments. The total funds carried forward were £69,610 (2023 – £60,300).

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 and NHS services now available to test for the DNA mutation, knowing what the future holds for Lowe Syndrome children into adulthood and how best to care and support them, through to the excitement of potential 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 2024

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 2024.

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

The Lowe Syndrome Trust

Statement of Financial Activities

Year ended 30 June 2024

		2024		2023	
	Note	Unrestricted funds £	Restricted funds £	Total funds £	Total funds £
Income and endowments					
Donations and legacies	4	4,303	33,181	37,484	3,582
Investment income	5	620	–	620	278
Total income		<u>4,923</u>	<u>33,181</u>	<u>38,104</u>	<u>3,860</u>
Expenditure					
Expenditure on charitable activities	6,7	12,852	15,942	28,794	67,074
Other expenditure	8	–	–	–	76
Total expenditure		<u>12,852</u>	<u>15,942</u>	<u>28,794</u>	<u>67,150</u>
Net income/(expenditure) and net movement in funds					
		<u>(7,929)</u>	<u>17,239</u>	<u>9,310</u>	<u>(63,290)</u>
Reconciliation of funds					
Total funds brought forward		60,300	–	60,300	123,590
Total funds carried forward		<u>52,371</u>	<u>17,239</u>	<u>69,610</u>	<u>60,300</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 page 8 form part of these financial statements.

The Lowe Syndrome Trust

Statement of Financial Position

30 June 2024

	Note	2024 £	£	2023 £
Current assets				
Cash at bank and in hand		70,630		61,320
Creditors: amounts falling due within one year	13	<u>1,020</u>		<u>1,020</u>
Net current assets			<u>69,610</u>	<u>60,300</u>
Total assets less current liabilities			<u>69,610</u>	<u>60,300</u>
Net assets			<u>69,610</u>	<u>60,300</u>
Funds of the charity				
Restricted funds			17,239	–
Unrestricted funds			<u>52,371</u>	<u>60,300</u>
Total charity funds	14		<u>69,610</u>	<u>60,300</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 page 8 form part of these financial statements.

The Lowe Syndrome Trust
Notes to the Financial Statements
Year ended 30 June 2024

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.

The Lowe Syndrome Trust

Notes to the Financial Statements *(continued)*

Year ended 30 June 2024

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

The Lowe Syndrome Trust

Notes to the Financial Statements *(continued)*

Year ended 30 June 2024

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 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>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Donations			
Miscellaneous donations	3,434	–	3,434
Grants			
Lottery Grant	–	–	–
CAF GAYE	148	–	148
	<u>3,582</u>	<u>–</u>	<u>3,582</u>

5. Investment income

	Unrestricted Funds £	Total Funds 2024 £	Unrestricted Funds £	Total Funds 2023 £
Bank interest receivable	<u>620</u>	<u>620</u>	<u>278</u>	<u>278</u>

The Lowe Syndrome Trust

Notes to the Financial Statements *(continued)*

Year ended 30 June 2024

6. Expenditure on charitable activities by fund type

	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>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Grants payable	40,000	–	40,000
Support costs	8,942	18,132	27,074
	<u>48,942</u>	<u>18,132</u>	<u>67,074</u>

7. Expenditure on charitable activities by activity type

	Support costs £	Total funds 2024 £	Total fund 2023 £
Principal activity	27,774	27,774	26,054
Grants payable	–	–	40,000
Governance costs	1,020	1,020	1,020
	<u>28,794</u>	<u>28,794</u>	<u>67,074</u>

8. Other expenditure

	Unrestricted Funds £	Total Funds 2024 £	Unrestricted Funds £	Total Funds 2023 £
Bank charges	–	–	76	76
	<u>–</u>	<u>–</u>	<u>76</u>	<u>76</u>

9. Net income/(expenditure)

Net income/(expenditure) is stated after charging/(crediting):

	2024 £	2023 £
Loss on disposal of intangible assets	–	76
	<u>–</u>	<u>76</u>

10. Staff costs

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

	2024 £	2023 £
Wages and salaries	15,942	15,962
	<u>15,942</u>	<u>15,962</u>

The average head count of employees during the year was 1 (2023: 1).

No employee received employee benefits of more than £60,000 during the year (2023: Nil).

11. 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 2024

12. Tangible fixed assets

	Equipment £	Total £
Cost		
At 1 July 2023 and 30 June 2024	16,917	<u>16,917</u>
Depreciation		
At 1 July 2023 and 30 June 2024	16,917	<u>16,917</u>
Carrying amount		
At 30 June 2024	–	<u>–</u>
At 30 June 2023	–	<u>–</u>

13. Creditors: amounts falling due within one year

	2024 £	2023 £
Accruals and deferred income	<u>1,020</u>	<u>1,020</u>

14. Analysis of charitable funds

Unrestricted funds

	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>

	At 1 July 2022 £	Income £	Expenditure £	At 30 June 2023 £
General Funds	5,458	3,860	(49,018)	(39,700)
Unrestricted fund – Grant Payable	50,000	–	–	50,000
Designated Fund - General office administration	50,000	–	–	50,000
	<u>105,458</u>	<u>3,860</u>	<u>(49,018)</u>	<u>60,300</u>

Restricted funds

	At 1 July 2023 £	Income £	Expenditure £	At 30 June 2024 £
Big Lottery Fund	–	<u>33,181</u>	<u>(15,942)</u>	<u>17,239</u>

	At 1 July 2022 £	Income £	Expenditure £	At 30 June 2023 £
Big Lottery Fund	<u>18,132</u>	–	<u>(18,132)</u>	–

The Lowe Syndrome Trust

Management Information

Year ended 30 June 2024

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

The Lowe Syndrome Trust
Detailed Statement of Financial Activities
Year ended 30 June 2024

	2024 £	2023 £
Income and endowments		
Donations and legacies		
Miscellaneous donations	4,243	3,434
Lottery Grant	33,181	–
CAF GAYE	60	148
	<u>37,484</u>	<u>3,582</u>
Investment income		
Bank interest receivable	620	278
	<u>620</u>	<u>278</u>
Total income	<u><u>38,104</u></u>	<u><u>3,860</u></u>
Expenditure		
Expenditure on charitable activities		
Wages and salaries	15,942	15,962
Rent	2,800	5,560
Insurance	167	1,131
Families Outreach and Travel costs	6,926	1,476
Legal and professional fees	1,020	1,020
Telephone	1,939	1,846
Other office costs	–	79
Grants payable	–	40,000
	<u>28,794</u>	<u>67,074</u>
Other expenditure		
Bank charges	–	76
	<u>–</u>	<u>76</u>
Total expenditure	<u><u>28,794</u></u>	<u><u>67,150</u></u>
Net income/(expenditure)	<u><u>9,310</u></u>	<u><u>(63,290)</u></u>

The Lowe Syndrome Trust

Notes to the Detailed Statement of Financial Activities

Year ended 30 June 2024

	2024	2023
	£	£
Expenditure on charitable activities		
Principal activity		
Support costs		
Salaries and contract workers	15,942	15,962
Rent and security	2,800	5,560
Insurance	167	1,131
Families Outreach and Travel costs	6,926	1,476
Telephone	1,939	1,846
Office costs	-	79
	<u>27,774</u>	<u>26,054</u>
Grants payable		
Activities undertaken directly		
Grants payable	-	40,000
Governance costs		
Governance costs - accountancy fees	1,020	1,020
	<u>28,794</u>	<u>67,074</u>

THE LOWE SYNDROME TRUST

England & Wales - Charity number 1081241

Accounts

The Lowe Syndrome Trust
Unaudited Financial Statements
30 June 2021

A. I. GROMAN FCA
Independent Examiner
Groman and Company
Chartered Accountants
5 Violet Hill
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NW8 9EB

The Lowe Syndrome Trust

Trustees' Annual Report

Year ended 30 June 2021

The trustees present their report and the unaudited financial statements of the charity for the year ended 30 June 2021.

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. J. Ross 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. Michael Fennings Ms. Melanie Chisholme Ms. Seville Bulpitt Mr. Richard Desmond Ms. Lisa Voice
Medical Research Advisory Board	Dr. Detlef Brockenhauer, Consultant Nephrologist, GOSH Professor Robert Unwin, Professor of Nephrology & Physiology, UCL Professor Shamshad Cockcroft, Dept of Physiology, UCL. Dr. Philip Beales, Hon. Consultant in Clinical Genetics, ICH. Dr. Peter Cullen, School of Medical Sciences, University of Bristol Mike Harrison, Consultant in Paediatric Dentistry, Guys Hospital London Professor Peng Tee Khaw, Professor of Glaucoma & Ocular Healing & Consultant Ophthalmic Surgeon Professor Helen Cross, Head of Neuroscience Unit, UCL Dr. Nimalan Maruthainer, Royal Free Hospital / UCL Professor Robert 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 2021

CEO/ Company secretary Mr. A. Thomas (CEO/Treasurer)

Independent examiner A.I. Groman FCA
Groman and Company
Chartered Accountants
5 Violet Hill
St. John's Wood
London
NW8 9EB

STRUCTURE, GOVERNANCE AND MANAGEMENT

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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.

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 Lowe Syndrome Trust

Trustees' Annual Report *(continued)*

Year ended 30 June 2021

OBJECTIVES AND ACTIVITIES *(continued)*

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 now 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 in "Nature" magazine and "Rdinfo". The committed grant funding liability is shown in the accounts.

The Lowe Syndrome Trust

Trustees' Annual Report *(continued)*

Year ended 30 June 2021

MAJOR CHANGES AND SERIOUS INCIDENTS REPORTS

There were no major changes or incidents other than the charities activities continue to be partially suspended due to COVID restrictions.

ACHIEVEMENTS AND PERFORMANCE

MEDICAL RESEARCH AND ACTIVITIES

During the accounting period, the Trust awarded a new grant commitment of £50,000 to Purdue University USA on 14th May 2021. The research will be a 3 year project to 2023 carried out 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 Ocr1 function in Lowe Syndrome', testing possible drugs in the laboratory to see if they could be used to help treat Lowe syndrome. Ocr1 is the enzyme that is mutated in Lowe syndrome and it is thought specific drugs may be able to restore its function.

This award follows on from previous research projects the Lowe Syndrome Trust has contributed to for drug screening which showed certain compounds, including FDA approved drugs for other conditions, can also restore Ocr1 kidney function. This project will assess the ability of compounds to biochemically restore the enzyme activity of a panel of Lowe Syndrome patient Ocr1 variants and the effects upon various phenotypes.

These compounds include drugs such as Alpelisib originally designed for treating breast cancer. See Lowe Syndrome Trust news articles, 2021 Jenny Gallop Gurdon Institute, University of Cambridge & Zurich potential breakthrough on treatment for Lowe Syndrome Kidney disorder.

Dr Aguilar commented:

"Lowe Syndrome (LS) is a disease caused by mutations in the OCRL1 gene that unfortunately leads to the early death of affected children and has no cure. However, this project aims to change such scenario.

Our results indicate that a substantial number of patients bear Ocr1 mutated proteins with intact enzymatic regions but locked in a non-functional structure. Therefore, we hypothesize that these Ocr1 patient mutated proteins can re-acquire functionality by action of drugs able to stabilize their enzymatically active form. Indeed, our lab recently identified a group of compounds (including FDA-approved drugs) as able to restore the activity of different Ocr1 patient mutants and to suppress a readout LS cellular phenotype. Nevertheless, their generalized applicability to multiple patient Ocr1 variants and suppression of multiple phenotypes needs to be assessed and is the focus of this project. Therefore, here we will test the compounds' ability to biochemically restore the enzyme activity of a panel of patient Ocr1 variants and to suppress multiple patient phenotypes. This study will produce the first available Ocr1-specific agents able to reinstate functionality; therefore, this project has a very high translational impact".

The charity continued to fund and support research into Lowe syndrome. As such, the Lowe Syndrome Trust resumed support for the research group in Manchester University, whose goal is to investigate the zebrafish model of Lowe syndrome. This model recapitulates many symptoms seen in Lowe syndrome such as neurological and renal impairment, which allows researchers to explore the underlying mechanisms. Genetically modified strains of zebrafish are used to easily assess kidney function, which contributes to a screen that identifies drugs that may be used to treat Lowe syndrome. The explored drugs are already approved to use in humans, therefore any positive results from the screen can be rapidly translated into medical practice.

Other continuation grants include Telethon Institute in Naples, where researchers continue to investigate cellular mechanisms underlying Lowe syndrome. As such, their efforts focused on developing a "repositioning" pharmacological approach for the cure of Lowe syndrome, with identified drugs to be tested on the mouse model of the disease.

The Lowe Syndrome Trust

Trustees' Annual Report *(continued)*

Year ended 30 June 2021

MEDICAL RESEARCH AND ACTIVITIES *(continued)*

Funding awarded during previous accounting periods also yielded a substantial number of scientific papers that were published during this accounting period in high-impact peer-reviewed journals, such as Nature. Sponsored research groups and labs, such as those at Purdue University and Imperial College London, continuously aid the progression of our knowledge and understanding of Lowe syndrome. The following articles are examples of published work produced with support and funding from Lowe Syndrome Trust:

- Madhivanan et al. (2020). Lowe syndrome patient cells display mTOR- and RhoGTPase-dependent phenotypes alleviated by rapamycin and statins. - Purdue University, USA.
- Berquez et al. (2020). The phosphoinositide 3-kinase inhibitor alpelisib restores actin organization and improves proximal tubule dysfunction in vitro and in a mouse model of Lowe syndrome and Dent disease. - University of Zurich, Switzerland.
- Preston et al. (2019). A role for OCRL in glomerular function and disease. - University of Manchester, UK.
- Yarwood et al. (2020). Membrane trafficking in health and disease. - University of Manchester, UK.
- Reeh et al. (2020). Design, synthesis and evaluation of a tripodal receptor for phosphatidylinositol phosphates. - Imperial College London, UK.

FUNDRAISING

Lowe Syndrome Trust continuously works to raise awareness and funding for the charity, such as celebrity Patrons appearing on the TV. We regularly appeal to the government and various foundations and companies 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 Trust through Facebook fundraisers.

Lowe Syndrome Trust continues to benefit from a 5-year grant from the National Lottery Community Fund. The aim of the project is to forge a mutual support network of families, with the charity as the central hub, and also to raise awareness of the disease among medical professionals, social workers and the general public. The grant is spread across 5 years, and part of the funds is dedicated to increase the independent capabilities of the Trust.

FINANCIAL SUMMARY AND RESERVES

The statement of Financial Activities shows income for the year of £57,582 (2020 - £43,148) and total expenditure of £56,722 (2020 - £75,520). The net income of £860 (2020 Deficit - £32,372) is after the total grants paid during the year for medical research projects totalling £29,115 (2020 - £47,541).

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

Manchester University	£13,213
Matties Italy	£15,902

Reserves

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

Of the charity's funds carried forward of £173,717 (2019 £206,089), a total of £50,000 (2019 £60,000) is designated as funds for continuing committed research grants leaving enough funding to continue the commitments of the charity of £96,361 (2019 £120,613).

The Lowe Syndrome Trust

Trustees' Annual Report *(continued)*

Year ended 30 June 2021

PLANS FOR FUTURE PERIODS

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

With the Lottery Grant the Lowe Syndrome Trust now has additional resources allocated to support Lowe Syndrome Families. The charity is planning to develop a chatbot for the website, as well as to provide advice and create leaflets for families and medical professionals which will outline and explain the available support from the government and other authorities, including help for applying for lasting power of attorney (LPA), UK social services support for Special Educational Needs (SEN), Personal Independence Payment (PIP), Employment and Support Allowance (ESA), Disabled Badges, Carer's Allowance, Care Plans and Direct Payments.

The Charity is also planning to work with the Lowe Syndrome Association and Sanford Research Coordination of Rare Diseases at Sanford (CoRDS) in USA to establish a medical research data base specifically for Lowe syndrome for families to record their details and history of the disease.

CONCLUDING REMARKS

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

Andrew Thomas, CEO
Lowe Syndrome Trust

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

Mr. A. Thomas
CEO / Charity Secretary

The Lowe Syndrome Trust

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

Year ended 30 June 2021

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 2021.

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

The Lowe Syndrome Trust
Statement of Financial Activities
Year ended 30 June 2021

		2021	2021		2020
	Note	Unrestricted funds £	Restricted funds £	Total funds £	Total funds £
Income and endowments					
Donations and legacies	4	25,593	31,966	57,559	42,820
Investment income	5	23	-	23	328
Total income		<u>25,616</u>	<u>31,966</u>	<u>57,582</u>	<u>43,148</u>
Expenditure					
Expenditure on charitable activities	6,7	30,795	25,927	56,722	75,520
Total expenditure		<u>30,795</u>	<u>25,927</u>	<u>56,722</u>	<u>75,520</u>
Net expenditure		<u>(5,179)</u>	<u>6,039</u>	<u>860</u>	<u>(32,372)</u>
Other recognised gains and losses					
Net movement in funds		<u>(5,179)</u>	<u>6,039</u>	<u>860</u>	<u>(32,372)</u>
Reconciliation of funds					
Total funds brought forward		146,361	27,356	173,717	206,089
Total funds carried forward		<u>141,182</u>	<u>33,395</u>	<u>174,577</u>	<u>173,717</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 10 to 15 form part of these financial statements.

The Lowe Syndrome Trust

Statement of Financial Position

30 June 2021

	Note	2021 £	£	2020 £
Current assets				
Debtors	12	–		43
Cash at bank and in hand		<u>175,777</u>		<u>176,074</u>
		<u>175,777</u>		<u>176,117</u>
Creditors: amounts falling due within one year	13	<u>(1,200)</u>		<u>(2,400)</u>
Net current assets			<u>174,577</u>	<u>173,717</u>
Total assets less current liabilities			<u>174,577</u>	<u>173,717</u>
Net assets			<u>174,577</u>	<u>173,717</u>
Funds of the charity				
Restricted funds			<u>33,395</u>	<u>27,356</u>
Unrestricted funds			<u>141,182</u>	<u>146,361</u>
Total charity funds	14		<u>174,577</u>	<u>173,717</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 10 to 15 form part of these financial statements.

The Lowe Syndrome Trust

Notes to the Financial Statements

Year ended 30 June 2021

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.

The Lowe Syndrome Trust

Notes to the Financial Statements *(continued)*

Year ended 30 June 2021

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

The Lowe Syndrome Trust

Notes to the Financial Statements *(continued)*

Year ended 30 June 2021

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 2021 £
<i>Current year</i>			
Donations			
Miscellaneous donations	5,320	–	5,320
Major donors	20,000	–	20,000
Grants			
Lottery Grant	–	31,966	31,966
Just Giving.com	273	–	273
	<u>25,593</u>	<u>31,966</u>	<u>57,559</u>
<i>Prior year</i>			
Donations			
Miscellaneous donations	8,045	–	8,045
Major donors	5,800	–	5,800
Grants			
Lottery Grant	–	28,659	28,659
Just Giving.com	316	–	361
	<u>14,161</u>	<u>28,659</u>	<u>42,820</u>

5. Investment income

	Unrestricted Funds £	Total Funds 2021 £	Unrestricted Funds £	Total Funds 2020 £
Bank interest receivable	<u>23</u>	<u>23</u>	<u>328</u>	<u>328</u>

The Lowe Syndrome Trust

Notes to the Financial Statements *(continued)*

Year ended 30 June 2021

6. Expenditure on charitable activities by fund type

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
<i>Current year</i>			
Grants payable	29,115	–	29,115
Support costs	1,680	25,927	27,607
	<u>30,795</u>	<u>25,927</u>	<u>56,722</u>
	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
<i>Prior year</i>			
Grants payable	47,541	–	47,541
Support costs	1,200	26,779	27,979
	<u>48,741</u>	<u>26,779</u>	<u>75,520</u>

7. Expenditure on charitable activities by activity type

	Activities undertaken directly £	Support costs £	Total funds 2021 £	Total fund 2020 £
Principal activity	–	25,927	25,927	26,779
Grants payable	29,115	–	29,115	47,541
Governance costs	–	1,680	1,680	1,200
	<u>29,115</u>	<u>27,607</u>	<u>56,722</u>	<u>75,520</u>

8. Independent examination fees

	2021 £	2020 £
Fees payable to the independent examiner for: Independent examination of the financial statements	<u>1,680</u>	<u>1,200</u>

9. Staff costs

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

	2021 £	2020 £
Wages and salaries	<u>16,426</u>	<u>12,532</u>

The average head count of employees during the year was 1 (2020: 1).

No employee received employee benefits of more than £60,000 during the year (2020: 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.

The Lowe Syndrome Trust

Notes to the Financial Statements *(continued)*

Year ended 30 June 2021

11. Tangible fixed assets

	Equipment £	Total £
Cost		
At 1 July 2020 and 30 June 2021	16,917	16,917
Depreciation		
At 1 July 2020 and 30 June 2021	16,917	16,917
Carrying amount		
At 30 June 2021	-	-
At 30 June 2020	-	-

12. Debtors

	2021 £	2020 £
Prepayments and accrued income	-	43

13. Creditors: amounts falling due within one year

	2021 £	2020 £
Accruals and deferred income	1,200	2,400

14. Analysis of charitable funds

Unrestricted funds

	At 1 Jul 2020 £	Income £	Expenditure £	Transfers £	At 30 Jun 2021 £
Current year					
General Funds	46,361	25,616	(1,680)	(29,115)	41,182
Designated Fund - Grants Payable	50,000	-	(29,115)	29,115	50,000
Designated Fund - General office administration	50,000	-	-	-	50,000
	<u>146,361</u>	<u>25,616</u>	<u>(30,795)</u>	<u>-</u>	<u>141,182</u>
Prior year					
General Funds	70,613	14,489	(1,200)	(37,541)	46,361
Designated Fund - Grants Payable	60,000	-	(47,541)	37,541	50,000
Designated Fund - General office administration	50,000	-	-	-	50,000
	<u>180,613</u>	<u>14,489</u>	<u>(48,741)</u>	<u>-</u>	<u>146,361</u>

The Lowe Syndrome Trust

Notes to the Financial Statements *(continued)*

Year ended 30 June 2021

14. Analysis of charitable funds *(continued)*

Restricted funds

	At 1 Jul 2020	Income	Expenditure	Transfers	At 30 Jun 2021
	£	£	£	£	£
<i>Current year</i>					
Big Lottery Fund	27,356	<u>31,966</u>	<u>(25,927)</u>	<u>—</u>	<u>33,395</u>
<i>Prior year</i>					
Big Lottery Fund	25,476	<u>28,659</u>	<u>(26,779)</u>	<u>—</u>	<u>27,356</u>

15. Analysis of net assets between funds

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Current assets	<u>141,182</u>	<u>33,395</u>	<u>174,577</u>
<i>Prior year</i>			
Current assets	<u>146,361</u>	<u>27,356</u>	<u>173,717</u>

The Lowe Syndrome Trust

Management Information

Year ended 30 June 2021

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

The Lowe Syndrome Trust
Detailed Statement of Financial Activities
Year ended 30 June 2021

	2021 £	2020 £
Income and endowments		
Donations and legacies		
Miscellaneous donations	5,320	8,045
Major donors	20,000	5,800
Lottery Grant	31,966	28,659
Just Giving.com and CAF	273	316
	<u>57,559</u>	<u>42,820</u>
 Investment income		
Bank interest receivable	23	328
	<u>23</u>	<u>328</u>
 Total income	<u><u>57,582</u></u>	<u><u>43,148</u></u>
 Expenditure		
Expenditure on charitable activities		
Wages and salaries	16,426	12,532
Rent	4,160	8,148
Repairs and maintenance	-	-
Insurance	1,473	1,235
Travel costs	1,390	2,091
Legal and professional fees	1,680	1,200
Telephone	2,238	2,423
Other office costs	240	112
Grants payable	29,115	47,541
Computer and website costs	-	238
	<u>56,722</u>	<u>75,520</u>
 Total expenditure	<u><u>56,722</u></u>	<u><u>75,520</u></u>
 NET INCOME / (EXPENDITURE)	<u><u>860</u></u>	<u><u>(32,372)</u></u>

The Lowe Syndrome Trust

Notes to the Detailed Statement of Financial Activities

Year ended 30 June 2021

	2021 £	2020 £
Expenditure on charitable activities		
Principal activity		
Support costs		
Wages and salaries	16,426	12,532
Rent and security	4,160	8,148
Repairs & renewals	-	-
Insurance	1,473	1,235
Travel costs	1,390	2,091
Telephone	2,238	2,423
Office costs	240	112
Computer & website costs	-	238
	<u>25,927</u>	<u>26,779</u>
Grants payable		
Activities undertaken directly		
Grants payable	29,115	47,541
Governance costs		
Governance costs - accountancy fees	1,680	1,200
Governance costs - costs of trustees' meetings	-	10
	<u>1,680</u>	<u>1,210</u>
Expenditure on charitable activities	<u><u>56,722</u></u>	<u><u>75,520</u></u>