

LEBER'S HEREDITARY OPTIC NEUROPATHY SOCIETY

England & Wales · Charity number 1157206

Details

Other names	LHON SOCIETY
Status	Registered
Legal form	CIO
Registered	2014-05-28
Register	View on the Charity Commission register

Contact

Address	Community Base 133 Queens Road Brighton East Sussex BN1 3XG
Phone	01273011969
Email	Info@LHONSociety.org
Website	http://www.LHONSociety.org/

Activities

Objects: 1. TO RELIEVE THE CHARITABLE NEEDS OF PEOPLE AFFECTED BY LEBER'S HEREDITARY OPTIC NEUROPATHY ("LHON"), THEIR FAMILIES AND CARES BY THE PROVISION OF SUPPORT, ADVOCACY, ADVICE AND INFORMATION. 2. TO CARRY OUT, OR TO PROVIDE FUNDS TO SUPPORT RESEARCH IN ALL ASPECTS OF LHON, ITS CAUSES, TREATMENT AND CURE AND PUBLISH THE USEFUL RESULTS OF SUCH RESEARCH.

Activities: We are a self-help support group for families affected by LHON across the British Isles. Through our membership we aim to identify as many affected families as possible and build a register of people willing to take part in medical research. We provide up-to-date information on LHON and current research topics.

Classification

- **How:** Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities

Geography

- Ireland
- Isle Of Man
- Northern Ireland
- Scotland

Finances

Period end	Income	Expenditure	Assets	Employees
2025-05-31	£2,265	£15,724	-	-
2024-05-31	£11,062	£2,916	-	-
2023-05-31	£4,247	£13,827	-	-
2022-05-31	£21,448	£152	-	-
2021-05-31	£1,108	£123	-	-

Trustees

Name	Role	Appointed
Charlotte Isabella McMillan		2021-09-25
Diane Louise Watson		2024-04-03
RUSSELL GEORGE WINSTON WHEELER		2014-05-25

LEBER'S HEREDITARY OPTIC NEUROPATHY SOCIETY

England & Wales - Charity number 1157206

Accounts



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	Day 01	Month 06	Year 2024		Day 31	Month 05	Year 2025

Section A Reference and administration details

Charity name

Leber's Hereditary Optic Neuropathy Society

Other names charity is known by

LHON Society

Registered charity number (if any)

1157206

Charity's principal address

Community Base
 133 Queens Road
 Brighton
Postcode BN1 3XG

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Diane Louise Watson			
2	Russell Wheeler			
3	James Ferguson		Until 30 April 2025	
4	Charlotte McMillan			
5	Andrew Mumford		Until 24 February 2025	
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Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Section B Structure, governance and management

Description of the charity’s trusts

Type of governing document (eg. trust deed, constitution)	Constitution, dated 16 Jan 2017
How the charity is constituted (eg. trust, association, company)	Charitable Incorporated Organisation – registered 28 May 2014
Trustee selection methods (eg. appointed by, elected by)	By existing trustees. Minimum of three, maximum of twelve trustees

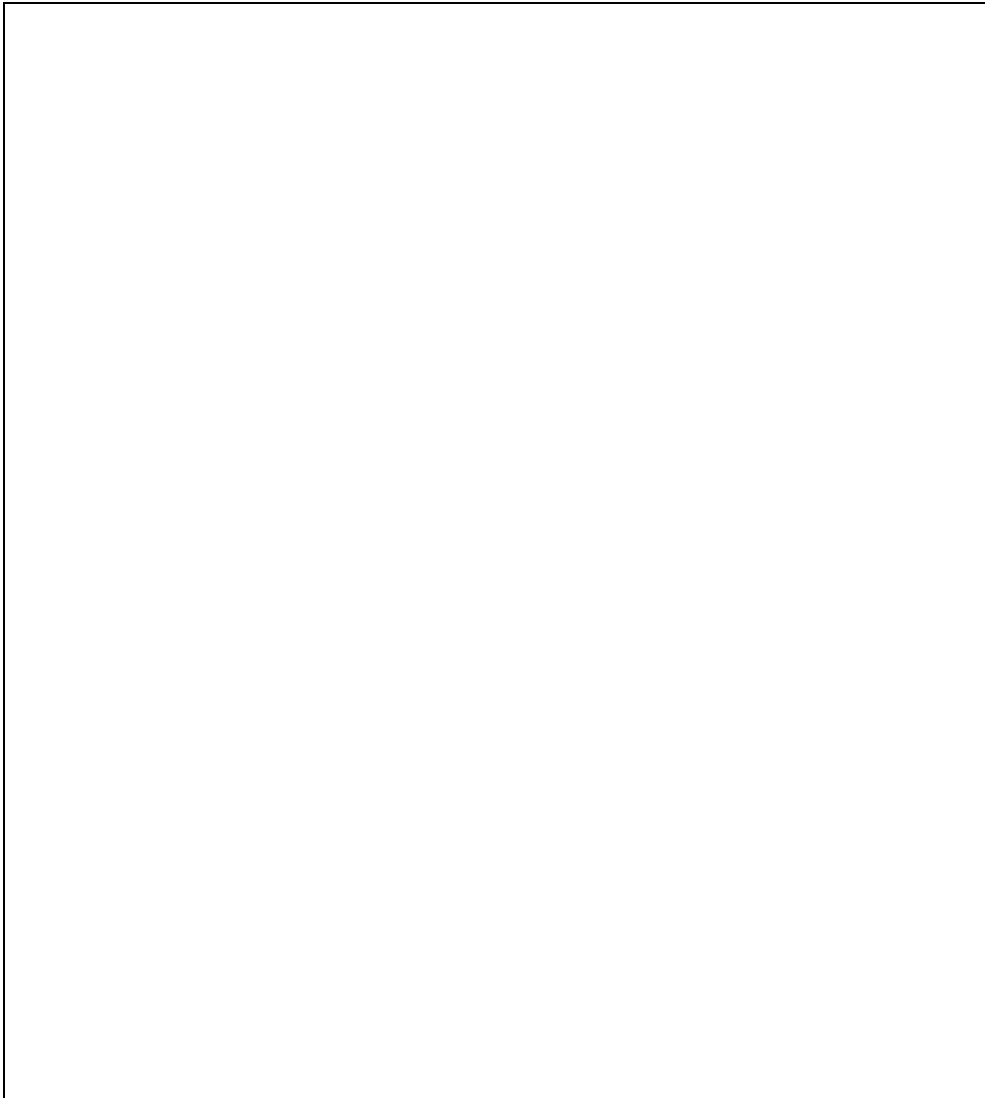
Additional governance issues (Optional information)

<p>You may choose to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> • policies and procedures adopted for the induction and training of trustees; • the charity’s organisational structure and any wider network with which the charity works; • relationship with any related parties; • trustees’ consideration of major risks and the system and procedures to manage them. 	<p>At a trustees meeting on 11 March 2025 the draft wording of a conflict of interest party was agreed and, subject to final ratification, a copy will be posted to the society’s website as soon as is practicable.</p>
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Section C Objectives and activities

<p>Summary of the objects of the charity set out in its governing document</p>	<p>Our aims: To provide support and information to those impacted by LHON; patients, their family, friends and healthcare providers. Provide guidance and representation on issues that affect the LHON community. Promote up-to-date knowledge and understanding of LHON in the welfare, medical and scientific communities. Facilitate research into understanding and seeking ways of preventing and ultimately reversing sight loss in LHON affected patients.</p>
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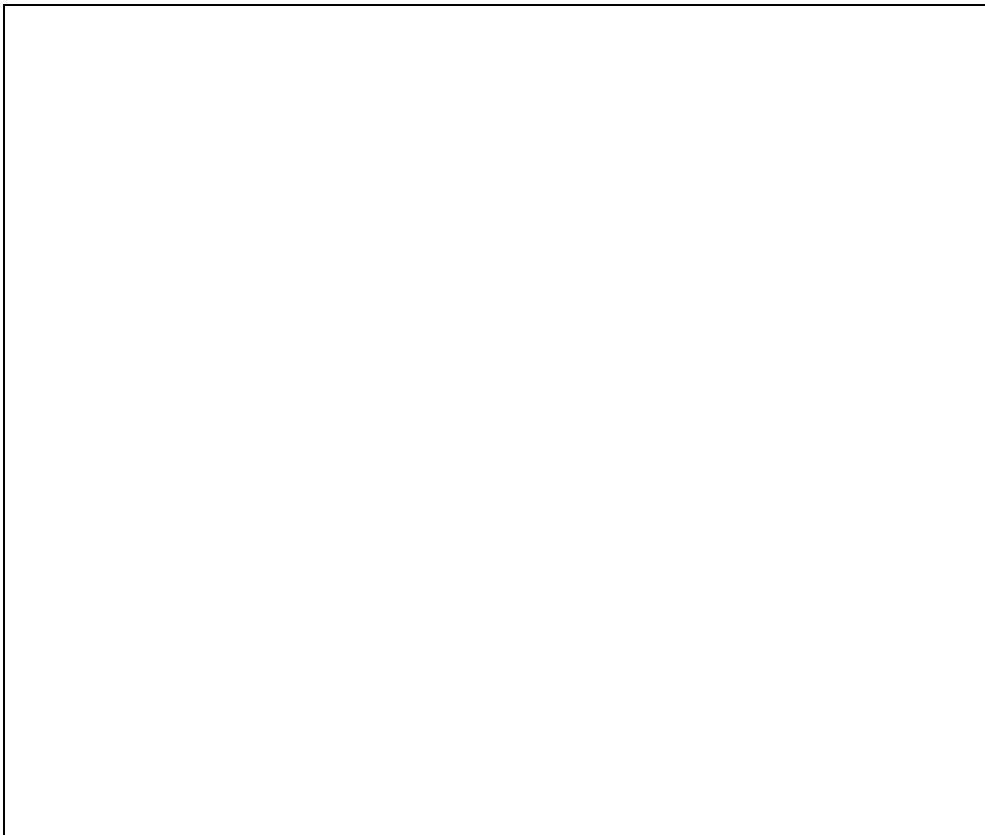
Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)



Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.



Summary of the main achievements of the charity during the year

The society once again hosted a patient and family day in July 2024, this time in Manchester, following previous similar events in the past in London, Cambridge and Birmingham. The society's policy is wherever possible to widen access to our activities and events to as large a geographic area as possible, within the resources available to us.

In the previous year we received funding from the National Lottery Community Fund which allowed us to mount a number of smaller outreach events in several regions of England and Wales, the last of these being held in June 2024 in Cambridge.

Unfortunately this year we did not receive either grant monies or the corporate sponsorship we had hoped for to support these activities and as a result the patient day in July was funded entirely from society funds, supplemented by receipts from ticket sales and contributions towards accommodation costs. This led to a substantial outflow of funds during the year, which all trustees agreed was a legitimate use of donated funds and in line with our society objectives. Hopefully we will return to our normal pattern for funding events in the future, or if that proves impossible then we will consider ways to reduce the cost of events without restricting access.

During the year under review the society made representations to NICE assessment panels, which were reviewing access to Raxone in England (it has been approved some years now in Scotland, Wales and Northern Ireland). At the time of the year end those representations were still ongoing after two applications had been rejected, but we are pleased to report that in August 2025 (ie after the end date of this report) Raxone was finally approved for prescription in England, some 10 years after its approval by the European Medicines Agency. Thanks to all those involved in this great effort on behalf of the LHON community in England.

The year has been one of considerable change for the society, with two trustees stepping down during the period, including co-founder and chairman James Ferguson, after 11 years' service and we would like to record our thanks and appreciation to James for all he has done on behalf of those affected by LHON in the UK over that time.

The remaining trustees are currently conducting a full review of the society's activities following these changes and we aim to provide an update and report on this at our next AGM in July (exact date to be confirmed).

Section E

Financial review

Brief statement of the charity's policy on reserves

Considering its relatively low levels of income and expenditure (see below), the trustees do not require any reserves to be held by the charity

Details of any funds materially in deficit

None

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

Financial Report as of 1/6/2025

Opening balance brought forward: £38,705.94

Income during the year: £2,264.96

Expenditure: £15,724.40

Closing balance: £25,243.50

Section F

Other optional information

Section G

Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Charlotte Macmillan	Russell Wheeler
Position (eg Secretary, Chair, etc)	Trustee	Trustee

Date 30 March 2026



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name Leber's Hereditary Optic Neuropathy Society	No (if any) 1157206
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CC16a

Receipts and payments accounts

For the period from	Period start date 01/06/2024	To	Period end date 31/05/2025
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Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Donations and interest	357	-	-	357	11,062
Patient Day receipts	1,874	-	-	1,874	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	2,231	-	-	2,231	11,062
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	2,231	-	-	2,231	11,062
A3 Payments					
Bank fees (net)	32	-	-	32	74
Conference attendance	-	-	-	-	617
Insurance	-	-	-	-	115
Mailchimp	146	-	-	146	177
Outreach programme	-	-	-	-	1,156
Patient day costs	14,270	-	-	14,270	28
Website expenses	1,195	-	-	1,195	749
Subscriptions	50	-	-	50	-
	-	-	-	-	-
Sub total	15,693	-	-	15,693	2,916
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	15,693	-	-	15,693	2,916
Net of receipts/(payments)	- 13,462	-	-	- 13,462	8,146
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	38,706	-	-	38,706	30,584
Cash funds this year end	25,244	-	-	25,244	38,730

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Bank Balance CAF Bank	25,244	-	-
		-	-	-
		-	-	-
	Total cash funds	25,244	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval
		Charlotte Macmillan	30th March 2026
		Russell Wheeler	30th March 2026

LEBER'S HEREDITARY OPTIC NEUROPATHY SOCIETY

England & Wales - Charity number 1157206

Accounts



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	01	06	2023		31	05	2024

Section A Reference and administration details

Charity name	Leber's Hereditary Optic Neuropathy Society
Other names charity is known by	LHON Society
Registered charity number (if any)	1157206
Charity's principal address	The Hayloft, Pury Hill Business Park, Alderton
	Northamptonshire
	Postcode NN12 7LS

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Diane Louise Watson		03 April 2024	
2	Russell Wheeler			
3	James Ferguson			
4	Charlotte McMillan			
5	Andrew Mumford			
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Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Section B Structure, governance and management

Description of the charity's trusts

Type of governing document
(eg. trust deed, constitution)

Constitution, dated 16 Jan 2017

How the charity is constituted
(eg. trust, association, company)

Charitable Incorporated Organisation – registered 28 May 2014

Trustee selection methods
(eg. appointed by, elected by)

By existing trustees. Minimum of three, maximum of twelve trustees

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

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Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

Our aims:
To provide support and information to those impacted by LHON; patients, their family, friends and healthcare providers.

Provide guidance and representation on issues that affect the LHON community.

Promote up-to-date knowledge and understanding of LHON in the welfare, medical and scientific communities.

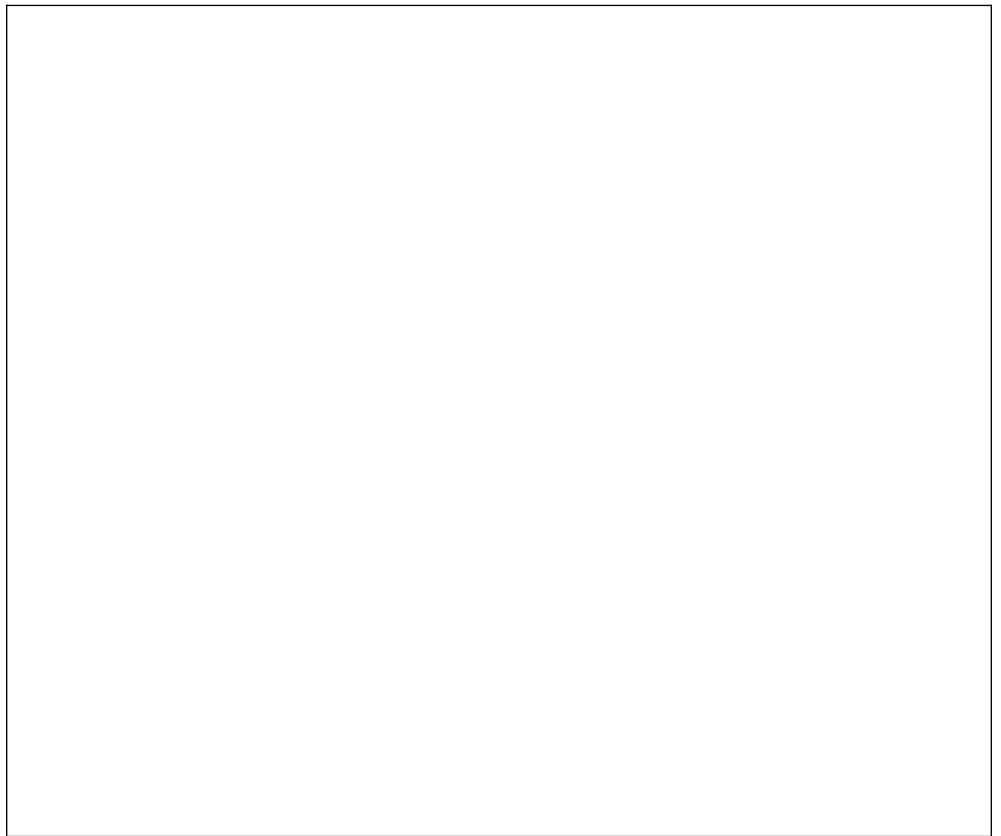
Facilitate research into understanding and seeking ways of preventing and ultimately reversing sight loss in LHON affected patients.

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.



Section D

Achievements and performance

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

June 2023 to May 2024

Between June 2023 and May 2024, the LHON Society achieved several milestones to support individuals affected by Leber Hereditary Optic Neuropathy (LHON):

Community Engagement and Events :

Regional Gatherings: The Society organised regional events to foster community connections:

Cambridge: June 24, 2023, at Chill2 Cafe

Manchester: July 1, 2023, at Cosy Club restaurant

Cardiff: November 11, 2023, at Cardiff University

A grant from the National Lottery Community Fund supported these events.

Patient and Family Day July 2024: A significant event was held on July 13, 2024, at the Hyatt Regency Hotel in Manchester. Although the date itself is outside this report's scope, planning for this patient day was well underway in 2024. The day featured presentations on the latest research and treatments, personal stories from those living with LHON

Section E

Financial review

Brief statement of the charity's policy on reserves

Considering its relatively low levels of income and expenditure (see below), the trustees do not require any reserves to be held by the charity

Details of any funds materially in deficit

None

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

Financial Report as of 1/6/2024

Opening balance brought forward: £30,584

Income during the year: £11,062

Expenditure: £2,916

Closing balance: £38,730

Section F Other optional information

Empty box for optional information.

Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	James Ferguson	
Position (eg Secretary, Chair, etc)	Chair of trustees	
Date	20 th March 2025	



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name Leber's Hereditary Optic Neuropathy Society	No (if any) 1157206
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CC16a

Receipts and payments accounts

For the period from	Period start date 6/1/2023	To	Period end date 5/31/2024
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Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Donations and interest	11,062	-	-	11,062	4,247
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	11,062	-	-	11,062	4,247
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	11,062	-	-	11,062	4,247
A3 Payments					
Bank fees	74	-	-	74	61
Conference attendance	617	-	-	617	756
Insurance	115	-	-	115	-
Mailchimp	177	-	-	177	-
Outreach programme	1,156	-	-	1,156	195
Patient day	29	-	-	29	11,777
Website expenses	749	-	-	749	1,038
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	2,916	-	-	2,916	13,827
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	2,916	-	-	2,916	13,827
Net of receipts/(payments)	8,146	-	-	8,146	- 9,580
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	30,584	-	-	30,584	30,584
Cash funds this year end	38,730	-	-	38,730	21,004

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds		-	-	-
		-	-	-
		-	-	-
	Total cash funds	38,730		-
	(agree balances with receipts and payments account(s))	OK	OK	OK

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name		Date of approval
	James Ferguson			20th March 2025

LEBER'S HEREDITARY OPTIC NEUROPATHY SOCIETY

England & Wales - Charity number 1157206

Accounts



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	01	06	2022		31	05	2023

Section A Reference and administration details

Charity name

Leber's Hereditary Optic Neuropathy Society

Other names charity is known by

LHON Society

Registered charity number (if any)

1157206

Charity's principal address

The Hayloft, Pury Hill Business Park, Alderton
Northamptonshire

Postcode **NN12 7LS**

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Mark Leverington			
2	Russell Wheeler			
3	James Ferguson			
4	Charlotte McMillan			
5	Andrew Mumford		From 18 th April 2023	
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Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Section B Structure, governance and management

Description of the charity’s trusts

Type of governing document (eg. trust deed, constitution)	Constitution, dated 16 Jan 2017
How the charity is constituted (eg. trust, association, company)	Charitable Incorporated Organisation – registered 28 May 2014
Trustee selection methods (eg. appointed by, elected by)	By existing trustees. Minimum of three, maximum of twelve trustees

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity’s organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees’ consideration of major risks and the system and procedures to manage them.

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Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

<p>Our aims: To provide support and information to those impacted by LHON; patients, their family, friends and healthcare providers.</p> <p>Provide guidance and representation on issues that affect the LHON community.</p> <p>Promote up-to-date knowledge and understanding of LHON in the welfare, medical and scientific communities.</p>

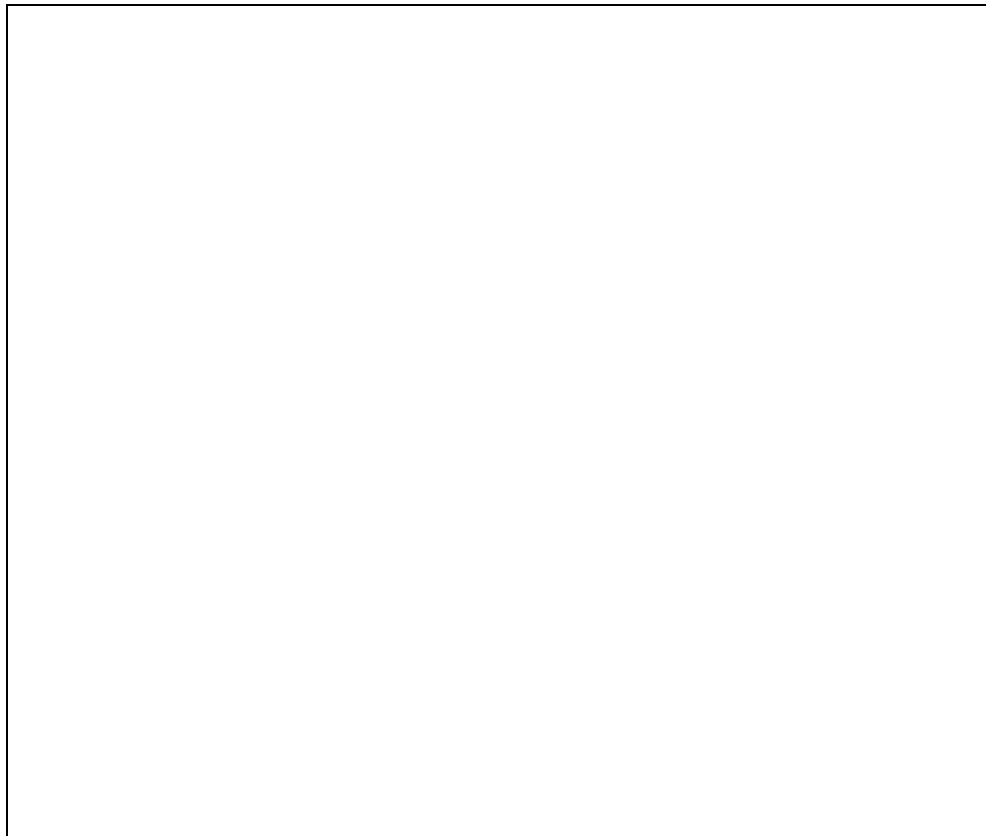
Facilitate research into understanding and seeking ways of preventing and ultimately reversing sight loss in LHON affected patients.

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.



Section D

Achievements and performance

Summary of the main achievements of the charity during the year

June 2022 to May 2023

Patient Day 2022

On the 8th of October 2022, we held a Patient & Family Engagement Event in Birmingham, drawing an audience of 40 individuals. The event featured insightful speakers, including those directly impacted by LHON, discussions on market access, an overview of qualitative research projects for LHON, and an update on gene therapy and treatment strategies for the condition. Notably, sessions from the event were recorded and are now accessible on our website, serving as a valuable resource for further reference and dissemination of knowledge.

Outreach programme

We used funding from the National Lottery's Community Fund to host five regional events in 2023. Our aim was to build stronger links within the LHON community by facilitating a series of social afternoons.

These are the details from the events;

York; Saturday 28th January 2023. We had lunch at Pizza Express and then visited the Jorvik Viking Centre, eighteen people attended

Wolverhampton, Saturday 22nd April 2023. Seven of us enjoyed lunch at The Bluebrick pub and restaurant.

Cambridge, Saturday 24th June 2023, five people had lunch at Chill2 Cafe

Manchester, 1st July 2023. Twelve enjoyed lunch at the Cosy Club in Manchester

Cardiff, 11th November 2023, ten of us had lunch at the Cosy Club in Cardiff.

The LHON Society covered the cost of each event.

Advocacy

As reported in last year's TAR the society engaged as stakeholders with NICE's early scoping work in readiness for the technology appraisal of Lumevoq®, the gene therapy developed by French company Gensight for the treatment of the ND4 (11778) mutation of LHON. This appraisal was expected to take place after the treatment had been approved by the European Medicines Agency (EMA) and whilst the MHRA were in a mutual recognition procedure as selected by the company as the route for marketing authorisation in the United Kingdom.

Unfortunately, however, in April 2023 the company met with EMA and following that meeting, they elected to withdraw their application for marketing authorisation. Given the company's decision to withdraw its marketing authorisation application, NICE confirmed that the appraisal had been suspended pending termination.

It is unknown if this product will be made available in the United Kingdom at any time soon.

Section E

Financial review

Brief statement of the charity's policy on reserves

Considering its relatively low levels of income and expenditure (see below), the trustees do not require any reserves to be held by the charity

Details of any funds materially in deficit

None

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

Financial Report as of 1/6/2023

Opening balance brought forward: £31,940

Income during the year: £4,247

Expenditure: £13,826

Closing balance: £30,583

Section F

Other optional information

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Section G

Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)



Full name(s)

Joanne Mumford

Position (eg Secretary, Chair, etc)

Secretary

Date

28th March 2024



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name Leber's Hereditary Optic Neuropathy Society	No (if any) 1157206
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CC16a

Receipts and payments accounts

For the period from	Period start date 01/06/2022	To	Period end date 31/05/2023
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Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Donations and interest	4,247	-	-	4,247	3,448
	-	-	-	-	-
	-	-	-	-	5,000
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	4,247	-	-	4,247	8,448
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	4,247	-	-	4,247	8,448
A3 Payments					
Patient day	11,777	-	-	11,777	102
Bank fees	61	-	-	61	-
Website expenses	1,038	-	-	1,038	-
Outreach programme	195	-	-	195	50
Other conference attendance	756	-	-	756	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	13,827	-	-	13,827	152
A4 Asset and investment purchases. (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	13,827	-	-	13,827	152
Net of receipts/(payments)	- 9,579	-	-	- 9,579	8,296
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	28,519	13,000	-	41,519	985
Cash funds this year end	18,940	13,000	-	31,940	9,281

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds		-	-	-
		-	-	-
		-	-	-
	Total cash funds	31,940	-	-
	(agree balances with receipts and payments account(s))	Agreement Error	Agreement Error	OK


Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
	Joanne Mumford	28th March 2024

LEBER'S HEREDITARY OPTIC NEUROPATHY SOCIETY

England & Wales - Charity number 1157206

Accounts



Trustees' Annual Report

for the period

From (start date) 0 1 0 6 2 1 to (end date) 3 1 0 5 2 2

Section A Reference and administration details

Charity name

Other names the charity is known by

Registered charity number (if any)

Charity's principal address

 Postcode

Names of the charity trustees who manage the charity

	Trustee Name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Mark Leverington			
2	Russell Wheeler			
3	James Ferguson			
4	Charlotte McMillan			
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Names of the trustees for the charity, if any (for example, any custodian trustees)

Name	Dates acted if not for whole year

Section A**Reference and administration details (continued)**

Names and addresses of advisers (optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (optional information)

Section B**Structure, governance and management**

Description of the charity's trusts

Type of governing document
(eg trust deed, constitution)

Constitution, dated 16 Jan 2017

How the charity is constituted
(eg trust, association, company)

Charitable Incorporated Organisation – registered 28 May 2014

Trustee selection methods
(eg appointed by, elected by)

By existing trustees. Minimum of three, maximum of twelve trustees

Additional governance issues (optional information)

You **may choose** to include additional
information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
 - relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

The society is a full and active member of EURORDIS, a non-governmental patient-driven alliance of patient organisations representing 724 rare disease patient organisations in 64 countries covering over 4000 diseases (www.eurordis.org). Through this membership the society aims to be kept informed of policy changes and developments throughout Europe which affect rare disease patients and in conjunction with EURORDIS to influence those policies wherever possible for the benefit of our members and rare disease patients in general.

The society continues to hold discussions with other LHON patient representatives from other countries in Europe, with a view to establishing more formal links between us in order to collaborate on research and understanding of the disease.

The society continues to participate in the European Reference Network for rare eye diseases ("ERN-EYE") a European Union initiative which brings together leading specialists from 28 different specialist ophthalmic centres from 13 different member states in order to collaborate on research and treatment of rare eye diseases.

Section C

Objectives and activities

Summary of the objects of the charity set out in its governing document

1. To relieve the charitable needs of people affected by LHON, their families and carers by the provision of support, advocacy, advice and information
2. To carry out, or to provide funds to support, research in all aspects of LHON: its causes, treatment and cure. To publish the useful results of such research

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

We are a self-help support group for families affected by LHON across the British Isles. Through our membership we aim to identify as many affected families as possible and build a register of people willing to take part in medical research. We provide up-to-date information on LHON and current research topics.

Additional details of objectives and activities (optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

The year from May 2020-21 took in the most difficult period of the pandemic and the majority of the society's plans and activities were curtailed during that time. We returned to face to face meetings with a patient day held in Birmingham in October 2022, which will be reported on in next year's report. However a substantial amount of time was spent planning for this during the year under review and sponsorship monies for hosting the event was received in the amount of £5,000 each from corporate sponsors Chiesi and Gensight, for which we are very grateful. The purpose of our events is to inform our membership of important developments in research and to help them to find ways of supporting each other, especially those new members for whom this is a strange and traumatic event in their lives.

This last year we were successful in bidding for a National Lottery grant to fund an outreach programme to support our membership. The majority of the grant will fund a series of events up and down the country so that those members who find it difficult to attend an event held centrally have more opportunity for a local meeting.

Raxone is the only approved therapy for treatment of LHON and has been available in Scotland since early 2017 and in Wales since early 2021 but has been rejected by NHS England for reimbursement on prescription in England. The active ingredient, Idebenone, is, however, readily available over the counter ("OTC") in the USA and in several other countries, leaving many patients in England to effectively "self-medicate" by purchasing their own supplies of generic Idebenone. This leaves patients to the mercy of the marketplace regarding both the cost and the purity of the treatment. The LHON Society has raised this issue several times with the appropriate authorities and will continue to do so until fairness is established.

It had been anticipated that by the time of writing this report there might have been a decision by EMA on regulatory approval in Europe for Gensight's gene therapy treatment (Lumevoq). However, due to manufacturing issues at the company's main supplier, the decision is not expected before early 2024. The LHON society has been cooperating with researchers in Cambridge under Dr Patrick Yu Wai Man in the refining of patient reported outcome measures ("PROMs") which might help in better evaluating the effectiveness of this, or indeed any other treatment for the condition.

The society has also taken part in early "scoping exercises" by the UK health technology assessment agency NICE to assist them in understanding the patient view and reaction to the prospect of Lumevoq becoming available in the UK and in support of an eventual determination by the NHS on reimbursement of this very expensive (but likely one-off) cost of this advanced therapy.

Section E**Financial review**

Brief statement of the charity's policy on reserves

Considering its relatively low levels of income and expenditure (see below), the trustees do not require any reserves to be held by the charity

Details of any funds materially in deficit

None

Further financial review details (optional information)

You **may choose** to include additional information, where relevant, about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

Financial Report as at 31/05/2022

Opening balance brought forward: £20223

Income during the year:
£21448

Expenditure:
£152

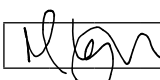
Closing balance: £41519

Section F**Other optional information****Section G****Declaration**

The trustees declare that they have approved the trustees' report above

Signed on behalf of the charity's trustees

Signature(s)



Full name(s)

Position (eg Secretary, Chair, etc)

Date

D	D	M	M	Y	Y
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Charity Name		No (if any)	
Leber's Hereditary Optic Neuropathy Society		1157206	
Receipts and payments accounts			
For the period from	Period start date	To	Period end date
	01/06/2021		31/05/2022


CC16a

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Exclusively from donations	3,448	-	-	3,448	1,108
Gensight Biologics	-	5,000	-	5,000	-
Chiesi UK	5,000	-	-	5,000	-
National Lottery Community Fund	-	8,000	-	8,000	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	8,448	13,000	-	21,448	1,108
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	8,448	13,000	-	21,448	1,108
A3 Payments					
	-	-	-	-	-
	-	-	-	-	-
Bank account fees	102	-	-	102	80
	-	-	-	-	-
EURORDIS membership fee	50	-	-	50	43
	-	-	-	-	-
	-	-	-	-	-
Sub total	152	-	-	152	123
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	152	-	-	152	123
Net of receipts/(payments)	8,296	13,000	-	21,296	985
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	20,223	-	-	20,223	-
Cash funds this year end	28,519	13,000	-	41,519	985

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds	Restricted funds	Endowment funds
		to nearest £	to nearest £	to nearest £
B1 Cash funds		-	-	-

		-	-	-
		-	-	-
	Total cash funds	28,519	13,000	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds	Restricted funds	Endowment funds
	Details	to nearest £	to nearest £	to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Mark Leverington	21/03/23	

LEBER'S HEREDITARY OPTIC NEUROPATHY SOCIETY

England & Wales - Charity number 1157206

Accounts



Trustees' Annual Report for the period

		Period start date			Period end date		
From	01	06	2020	To	31	05	2021



Charity name Leber's Hereditary Optic Neuropathy Society

Other names charity is known by LHON Society

Registered charity number (if any) 1157206

Charity's principal address

8 Hill Lane
Hockley
Essex
Postcode SS5 4HL

Names of the charity trustees who manage the charity

Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1 Mark Leverington	Secretary		
2 Russell Wheeler			
3 James Ferguson			
4 Charlotte McMillan			
5			
6			
7			
8			
9			
10			

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
Name of chief executive or names of senior staff members (Optional information)		



Description of the charity’s trusts

Type of governing document (eg. trust deed, constitution)	Constitution, dated 16 Jan 2017
How the charity is constituted (eg. trust, association, company)	Charitable Incorporated Organisation – registered 28 May 2014
Trustee selection methods (eg. appointed by, elected by)	By existing trustees. Minimum of three, maximum of twelve trustees

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity’s organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees’ consideration of major risks and the system and procedures to manage them.

<p>The society is a full and active member of EURORDIS, a non-governmental patient-driven alliance of patient organisations representing 724 rare disease patient organisations in 64 countries covering over 4000 diseases (www.eurordis.org). Through this membership the society aims to be kept informed of policy changes and developments throughout Europe which affect rare disease patients and in conjunction with EURORDIS to influence those policies wherever possible for the benefit of our members and rare disease patients in general.</p> <p>The society continues to hold discussions with other LHON patient representatives from other countries in Europe, with a view to establishing more formal links between us in order to collaborate on research and understanding of the disease.</p> <p>The society continues to participate in the European Reference Network for rare eye diseases (“ERN-EYE”) a European Union initiative which brings together leading specialists from 28 different specialist ophthalmic centres from 13 different member states in order to collaborate on research and treatment of rare eye diseases.</p>
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Summary of the objects of the charity set out in its governing document

1. To relieve the charitable needs of people affected by LHON, their families and carers by the provision of support, advocacy, advice and information
2. To carry out, or to provide funds to support, research in all aspects of LHON: its causes, treatment and cure. To publish the useful results of such research

We are a self-help support group for families affected by LHON across the British Isles. Through our membership we aim to identify as many affected families as possible and build a register of people willing to take part in medical research. We provide up-to-date information on LHON and current research topics.

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

Summary of the main achievements of the charity during the year

Last year's report of activity (to May 2020) just reached into the early days of the Covid crisis and we reported then on how some of our funding requests had been already damaged by the understandable need to divert resources to the pandemic response and unfortunately this remained a theme throughout the year, as indeed did the crisis itself. Plans for a patient meeting in the autumn were of course cancelled and all activity switched to virtual platforms. This has been a learning curve for everyone and it seems likely that such virtual platforms will remain a part of our communications armoury going forward, although hopefully supplemented by face to face meetings as and when these are possible.

Thus the society's AGM was held on 4th July as a completely virtual event over Zoom and this was well attended and surprisingly effective, with a lively discussion and in addition to the formal AGM itself we successfully held a mini version of what we might have delivered if we had been able to meet in person. We are getting better at this, and we can hopefully learn from this activity which has been forced upon us to better communicate with those who are unable to attend our in-person meetings for whatever reason.

The effects of the pandemic were felt everywhere in society and in the research area especially the vast majority of non-Covid projects were at best severely delayed and in many cases abandoned. It had been our aim to sponsor a networking event in September to bring together a wide range of researchers from different fields all over Europe who have an interest in LHON or in vision impairment generally or mitochondrial or other related disease but would not normally meet together. This is all too common in research, which develops in silos with the end result that lots of work is duplicated and lessons learned are not transferable and mistakes are repeated. Unfortunately, due to the cancellation of all face to face meetings this had to be abandoned (it was to have piggy-backed on a vision research meeting which was also cancelled) as it is impractical to kick-start such a novel approach via a virtual presentation. The concept remains every bit as attractive, if not more so, and we will resurrect this as soon as we are able to do so.

Notwithstanding the effects of the pandemic, the only approved treatment for LHON, Raxone, was assessed by the All Wales Therapeutics and Toxicology Centre (AWTTC) on behalf of the NHS in Wales and, despite an initial rejection, this was reviewed in January 2021 and following representations from LHON Society and strong testimony from some individual society members in Wales, the decision was reversed and Raxone is now available on prescription in Wales. A further review also took place in England but we were not consulted by NHS England on this (despite pushing) and in a decision that was just as opaque and difficult to understand as their initial rejection they held fast in their refusal to grant access to this treatment. As a result, England is the only country in the British Isles where Raxone is not available on prescription and, indeed, in most of Europe.

The clinical trials for gene therapy as treatment for the ND4 mutation in LHON undertaken by French biotech company Gensight came to a successful conclusion during the year and application was made to the European Medicines Agency (EMA) for approval. The review of this treatment is taking much longer than anticipated, also in part impacted by the Covid crisis, and the outcome is still unknown at the time of writing this report.

Regrettably, at the end of the transition period for the UK's departure from the EU, the four UK University hospital centres (Moorfields, Oxford, Manchester and Leeds) had to leave the European Reference Network for Rare Eye Diseases (www.ern.eye.eu) but contacts built up through this network will be maintained as closely as possible and LHON Society remains on the governing board of this important network dedicated to improving research and outcomes for all affected by rare eye diseases. The world of rare diseases is small enough already, without politics making it smaller. One of the most important projects for this network is the establishment of a Europe-wide registry for all rare eye diseases (REDgistry) which will contain data elements that allow for information to be grouped on an anonymous basis to support research and enable accelerated progress towards better understanding of diseases and development of novel treatments. This is not the same as a specific disease registry, which remains our ultimate goal, where the specific data for LHON is captured and available for analysis, but it is a vital element in building the right foundations for a LHON registry that is truly compatible internationally – right now there are LHON registries in some European countries (not in the UK) but it is not possible to aggregate information and their reporting is inconsistent. In such a rare disease, the benefits of a small national register are very limited and we must be able to scale this up to extract the full benefits.

The information generated by a strong disease registry and natural history study both form part of what in the jargon is termed Real World Data or RWD. This in turn forms part of Real World Evidence (RWE) which is increasingly being recognised by regulators and payers worldwide as an important element in determining the efficacy, safety and, ultimately, value of a medical treatment for any given disease. An over-reliance on clinical trial data in the past has been a major cause of delays and setbacks in the development of treatments for rare disease and we welcome this more enlightened approach to supplementing and, in some cases, even replacing clinical trial data.

The emergence of new techniques and tools for analysing data (so-called Artificial Intelligence and Machine Learning) makes all of this much more possible now, together with plummeting costs of computing power. LHON Society is supporting EMA in their efforts to move in this direction through membership of their Advisory Group on Raw Data and we are in discussion with several researchers seeking to use these tools in order to identify new treatment options, especially amongst those already approved for other diseases. Raxone itself is a repurposed drug that was developed for another disease but the pathway to its use in LHON took several years and these efforts are aimed at finding even better compounds in a much shorter time frame. Although the details are confidential, some compounds have already been identified and are under examination as a result of this approach.

Given the potential value of these techniques to the LHON community and the importance of high quality data in order to fuel their application, you can expect to hear a lot more about our need for developing that data in the coming years.

Brief statement of the charity's policy on reserves

Considering its relatively low levels of income and expenditure (see below), the trustees do not require any reserves to be held by the charity

Details of any funds materially in deficit

None

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

Financial Report as at 31/05/2021

Opening balance brought forward: £19238

Income during the year:

£1108 – exclusively from fundraising and donations

Expenditure:

£80 - charity bank account fees

£43 - EURORDIS membership fee

Closing Balance at 31/05/2019: £20223

Section F Other optional information

[Empty box for optional information]

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)



Full name(s)

Mark Leverington

Position (eg Secretary, Chair, etc)

Trustee & Secretary



Date 17th March 2022



Charity Name		No (if any)	
Leber's Hereditary Optic Neuropathy Society		1157206	
Receipts and payments accounts			
For the period from	Period start date	To	Period end date
	01/06/2020		31/05/2021

CC16a

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Exclusively from donations	1,108	-	-	1,108	8,499
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	1,108	-	-	1,108	8,499
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	1,108	-	-	1,108	8,499
A3 Payments					
	-	-	-	-	-
	-	-	-	-	-
Bank account fees	80	-	-	80	60
Genetic Alliance UK membership fee	-	-	-	-	50
Mailchimp account fees	-	-	-	-	17
EURORDIS membership fee	43	-	-	43	43
	-	-	-	-	-
	-	-	-	-	-
Sub total	123	-	-	123	170
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	123	-	-	123	170
Net of receipts/(payments)	985	-	-	985	8,329
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	19,238	-	-	19,238	-
Cash funds this year end	20,223	-	-	20,223	8,329

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds	Restricted funds	Endowment funds
		to nearest £	to nearest £	to nearest £
B1 Cash funds		-	-	-

