



Trustees' Annual Report for the period

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

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.

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.

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.

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)

Position (eg Secretary, Chair, etc)

Date

Charlotte Macmillan	Russell Wheeler
Trustee	Trustee

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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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
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets				
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use				
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
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	