



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			
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.

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
<p>Summary of the main achievements of the charity during the year</p>	<p>June 2023 to May 2024</p> <p>Between June 2023 and May 2024, the LHON Society achieved several milestones to support individuals affected by Leber Hereditary Optic Neuropathy (LHON):</p> <p>Community Engagement and Events:</p> <p>Regional Gatherings: The Society organised regional events to foster community connections:</p> <p>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.</p> <p>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</p>

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****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	No (if any)
Leber's Hereditary Optic Neuropathy Society	1157206

Receipts and payments accounts

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For the period from	Period start date	To	Period end date
	6/1/2023		5/31/2024

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					
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
	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
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 asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		James Ferguson	20th March 2025	