



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	
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.

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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

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

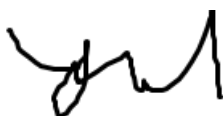
Section G

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

CC16a


Receipts and payments accounts

For the period from	Period start date	To	Period end date
	01/06/2022		31/05/2023

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
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities		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	
		Joanne Mumford	28th March 2024	