



# 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 Leber's Hereditary Optic Neuropathy Society

Other names the charity is known by LHON Society

Registered charity number (if any) 1 1 5 7 2 0 6

Charity's principal address  
 8 Hill Lane  
 Hockley  
 Essex  
 Postcode S S 5 4 H L

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](http://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

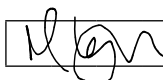
Closing balance: £41519

**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)		CC16a
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	

## 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 £
<b>A1 Receipts</b>					
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
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
<b>Total receipts</b>	<b>8,448</b>	<b>13,000</b>	<b>-</b>	<b>21,448</b>	<b>1,108</b>
<b>A3 Payments</b>					
	-	-	-	-	-
	-	-	-	-	-
Bank account fees	102	-	-	102	80
	-	-	-	-	-
EURORDIS membership fee	50	-	-	50	43
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	152	-	-	152	123
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
<b>Total payments</b>	<b>152</b>	<b>-</b>	<b>-</b>	<b>152</b>	<b>123</b>
<b>Net of receipts/(payments)</b>	<b>8,296</b>	<b>13,000</b>	<b>-</b>	<b>21,296</b>	<b>985</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>20,223</b>	<b>-</b>	<b>-</b>	<b>20,223</b>	<b>-</b>
<b>Cash funds this year end</b>	<b>28,519</b>	<b>13,000</b>	<b>-</b>	<b>41,519</b>	<b>985</b>

## 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 £
<b>B1 Cash funds</b>		-	-	-

		-	-	-
		-	-	-
	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