



**CHARITY COMMISSION**  
FOR ENGLAND AND WALES

## Trustees' Annual Report for the period

From **31 Oct 2024** Period start date To **30 Oct 2025** Period end date

Charity name: **Lipodystrophy UK**

Charity registration number: 1175462

## Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	The objects of the CIO are: i. To raise awareness of Lipodystrophy conditions, both within the medical profession and the general public; ii. To provide information and support to people with Lipodystrophy and those affected by it; iii. To advocate for excellent care and improved treatment options for people with Lipodystrophy; To encourage research addressing the concerns of people with Lipodystrophy
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	<ul style="list-style-type: none"><li>- Patient support activities online</li><li>- Raising awareness (World Lipodystrophy Day, conferences, publications, social media, focus groups)</li><li>- Advocacy (Part of Global Patient Leaders group, Patient resources, Clinician discussions and relationship building)</li></ul>
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	All trustees have had regard to the Charity Commission's guidance on public benefit.

## Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	Lipodystrophy UK does not have a policy on grant making, since we don't currently offer grants
Policy on social investment including program related investment	Para 1.38	Lipodystrophy UK does not have a policy on social investment

Contribution made by volunteers	Para 1.38	Lipodystrophy UK does not have a policy on contributions made by volunteers
Other		

## Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	<ol style="list-style-type: none"> <li>1) Fully funded Patient Support Day for WLD 2025. An in-person, all day event with a full agenda of speakers to help educate, raise awareness, provide information and resources and opportunities for social networking. This event was the highlight of the year, hugely successful with fantastic feedback from delegates. We funded food, transport and accommodation to make the event accessible for all.</li> <li>2) New Trustees joined the Board (Vanessa Kill, Catherine Ellison)</li> <li>3) Patient resources being developed as part of Global Patient Leaders group in collaboration with Amryt Pharma.</li> <li>4) Ongoing awareness activities – World Lipodystrophy Day, Rare Disease Day</li> <li>5) Collaboration with Physicians, Pharma and other Patient Group Leaders (Global Patient Leaders group) on development of new resources.</li> <li>6) Several new resources added to our website, including patient story videos</li> <li>7) Chair gave several awareness talks at different conferences and participated in focus groups with stakeholders</li> <li>8) Ongoing individual patient support, ad hoc</li> <li>9) Ongoing relationship with National Centre of Excellence in Lipodystrophy (Addenbrookes Hospital)</li> <li>10) Ongoing patient representative on ECLip Board (re-elected). Stepped down in October 2025 after more than 5-years.</li> <li>11) Ongoing relationship with the Centre of Appearance Research (CAR)</li> </ol>

### Additional information (optional)

You may choose to include further statements where relevant about:

		Ongoing objectives to 1) raise awareness of Lipodystrophy conditions; 2) provide
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Achievements against objectives set	Para 1.41	information and support to people affected by Lipodystrophy; advocate for excellent care and improved treatment options; encourage research addressing the concerns of people with Lipodystrophy
Performance of fundraising activities against objectives set	Para 1.41	N/A
Investment performance against objectives	Para 1.41	N/A
Other		

## Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	Low fundraising income, although sufficient to cover charity expenditure
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	Lipodystrophy UK does not have a reserves policy
Amount of reserves held	Para 1.22	N/A
Reasons for holding zero reserves	Para 1.22	N/A
Details of fund materially in deficit	Para 1.24	N/A
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	N/A

### Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	Funds from fundraising activities and expert consultancy fees
Investment policy and objectives including any social investment policy adopted	Para 1.46	Lipodystrophy UK does not have an investments policy
A description of the principal risks facing the charity	Para 1.46	More fundraising activities will be needed to fund more ambitious projects in the future. Actively recruiting additional volunteers
Other		

## Structure, Governance and Management

Description of charity's trusts:		
Type of governing document ( <a href="#">trust deed</a> , <a href="#">royal charter</a> )	Para 1.25	Constitution
How is the charity constituted? (e.g <a href="#">unincorporated association</a> , CIO)	Para 1.25	Charitable Incorporated Organisation
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Apart from the first charity trustees, every trustee must be appointed by a resolution passed at a properly convened meeting of the charity trustees

### Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	N/A
The charity's organisational structure and any wider network with which the charity works	Para 1.51	N/A
Relationship with any related parties	Para 1.51	Working in partnership with The Centre for Appearance Research (CAR) as a member of the Appearance Collective (AC) - supporting people living with visible differences.
Other		

## Reference and Administrative details

Charity name	Lipodystrophy UK
Other name the charity uses	LDUK - mostly phased out
Registered charity number	1175462
Charity's principal address	29 Collington Way, Kingston Bagpuize, Abingdon OX13 5GP

**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	Rebecca Sanders	Chair	N/A	Rebecca Sanders (Founder)
2	Siobhan Dunn	N/A	N/A	Board majority vote
3	Anna Greenaway	N/A	N/A	Board majority vote
4	Vanessa Kill	N/A	November 2024	Board majority vote
5	Catherine Ellison	N/A	Oct 2025	Board majority vote
6				
7				
8				
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11				
12				
13				
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15				
16				
17				
18				
19				
20				

**Corporate trustees – names of the directors at the date the report was approved**

Director name		
N/A		

**Name of trustees holding title to property belonging to the charity**

Trustee name	Dates acted if not for whole year	
N/A		

## Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	N/A
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	N/A
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	N/A

### Additional information (optional)

#### Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
N/A		

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

N/A
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## Exemptions from disclosure

#### Reason for non-disclosure of key personnel details

N/A
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## Other optional information

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## Declarations

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

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Rebecca Sanders	
Position (eg Secretary, Chair, etc)	Chair	
Date	04/01/2026	





CHARITY COMMISSION  
FOR ENGLAND AND WALES

Lipodystrophy UK

1175462

## Receipts and payments accounts

CC16a

For the period  
from

Period start date  
Oct-24


To

Period end date  
Oct-25

### 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 £
<b>A1 Receipts</b>					
Donations	2 953	-	-	2 953	-
Consultancy Fee	3 360	-	-	3 360	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>6 313</b>	<b>-</b>	<b>-</b>	<b>6 313</b>	<b>-</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>6 313</b>	<b>-</b>	<b>-</b>	<b>6 313</b>	<b>-</b>
<b>A3 Payments</b>					
Insurance	185	-	-	185	-
Invoice	25 384	-	-	25 384	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>25 569</b>	<b>-</b>	<b>-</b>	<b>25 569</b>	<b>-</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>25 569</b>	<b>-</b>	<b>-</b>	<b>25 569</b>	<b>-</b>
<b>Net of receipts/(payments)</b>	<b>- 19 255</b>	<b>-</b>	<b>-</b>	<b>- 19 255</b>	<b>-</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>35 965</b>	<b>-</b>	<b>-</b>	<b>35 965</b>	<b>-</b>
<b>Cash funds this year end</b>	<b>16 709</b>	<b>-</b>	<b>-</b>	<b>16 709</b>	<b>-</b>

## 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 £
<b>B1 Cash funds</b>	Bank account	16 709	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>16 709</b>	<b>-</b>	<b>-</b>
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B5 Liabilities</b>	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
			REBECCA SANDERS	04/01/2026