



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From 31 Oct 2020 Period start date To 30 Oct 2021 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; iv. 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">- Metreleptin approved by NICE for NHS funding- Patient pathways survey for clinicians-- Patient support activities online- Raising awareness (World Lipodystrophy Day, conferences, publications, social media)- Fatigue project green lighted
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	
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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"> 1) Instrumental in NICE HST appraisal success - Metreleptin approved for all eligible Lipodystrophy patients! 2) Publication including patient perspective of living with Lipodystrophy (Gomes, A., et al. Experiences and Perspectives of Patients with Non-HIV-Associated Lipodystrophies and Their Caregivers: A Qualitative Study. Patient 14, 673–685 (2021). https://doi.org/10.1007/s40271-021-00511-5) 3) Published interview with Pharmaphorum 4) Ongoing virtual support for community through COVID - live chats, community check-ins, etc. 5) Considering volunteer positions to assist Board (Social Media Executive and Fundraising Officer) 6) Creating Patient Pathways survey for patients/carers to compliment clinicians survey - aim to produce set of best practice guidelines 7) New website delayed by lack of copy and requirement for a PO box so as not to use personal address for 'place of business operation' contact details - being resolved 8) Fatigue project (in collaboration with the Patient Lead Research Hub, PLRH, and Addenbrookes Hospital) funding decision delayed due to COVID. Now back on track, funding approved, focus group re: data capture questions complete, developing project plans/questionnaire resource 9) Ongoing relationship with National Centre of Excellence in Lipodystrophy (Addenbrookes Hospital) 10) Ongoing patient representative on ECLip Board 11) Ongoing relationship with the Centre of Appearance Research (CAR) 12) Note: several activities delayed/postponed due to COVID
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Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	Ongoing objectives to 1) raise awareness of Lipodystrophy conditions; 2) provide 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
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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 exclusively from fundraising activities
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. Considering recruiting a volunteer Fundraising Officer.
Other		

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document (trust deed, royal charter)	Para 1.25	Constitution
How is the charity constituted? (e.g unincorporated association, 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 Genetic Disorders UK for fundraising, and 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 - although being phased out
Registered charity number	1175462

Charity's principal address	29 Collington Way, Kingston Bagpuize, Abingdon OX13 5GP
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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	Rachel Sanders	Treasurer	N/A	Rebecca Sanders (Founder)
3	Becky Smith	N/A	N/A	Board majority vote
4	Siobhan Dunn	N/A	N/A	Board majority vote
5	Claire Adams	N/A	N/A	Board majority vote
6				
7				
8				
9				
10				
11				
12				
13				
14				
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
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N/A		

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

N/A

Exemptions from disclosure

Reason for non-disclosure of key personnel details

N/A

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)

	
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Full name(s)

Rebecca Sanders	
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Position (eg
Secretary, Chair, etc)

Chair	
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Date

30/01/2022



Receipts and payments accounts

For the period
from

Period start date

Oct-20

To

Period end date

Oct-21

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds
	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts				
Donations	781	-	-	781
Refunds	127	-	-	127
Other	32	-	-	32
	- 0	-	-	-
	- 0	-	-	-
	- 0	-	-	-
	- 0	-	-	-
	- 0	-	-	-
Sub total (Gross income for AR)	941	-	-	941
A2 Asset and investment sales, (see table).				
	- 0	- 0	- 0	-
	- 0	- 0	- 0	-
Sub total	- 0	- 0	- 0	-
Total receipts	941	- 0	- 0	941
A3 Payments				
Insurance	185	-	-	185
Invoices	91	-	-	91
	- 0	-	-	-
	- 0	-	-	-
	- 0	-	-	-
	- 0	-	-	-
	- 0	-	-	-
	- 0	-	-	-
	- 0	-	-	-
Sub total	276	-	-	276
A4 Asset and investment purchases, (see table)				
	- 0	- 0	- 0	-
	- 0	- 0	- 0	-
Sub total	- 0	- 0	- 0	-
Total payments	276	- 0	- 0	276
Net of receipts/(payments)	665	-	-	665
A5 Transfers between funds	- 0	-	-	-
A6 Cash funds last year end	6,881	-	-	6,881
Cash funds this year end	7,546	-	-	7,546

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds	Restricted funds
		to nearest £	to nearest £
B1 Cash funds	Bank Account	7,387	-
		-	-

		-	-
	Total cash funds	7,387	-
	(agree balances with receipts and payments account(s))	Agreement Error	OK
		Unrestricted funds	Restricted funds
	Details	to nearest £	to nearest £
B2 Other monetary assets		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
	Details	Fund to which asset belongs	Cost (optional)
B3 Investment assets			-
			-
			-
			-
			-
	Details	Fund to which asset belongs	Cost (optional)
B4 Assets retained for the charity's own use			-
			-
			-
			-
			-
			-
			-
			-
			-
	Details	Fund to which liability relates	Amount due (optional)
B5 Liabilities			-
			-
			-
			-
			-
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	
	Rachel Sanders	Rachel Sanders	

CC16a
Last year
to the nearest £
-
-
-
-
-
-
-
-
-
-
- 0
- 0
- 0
-
-
-
-
-
-
-
-
-
-
- 0
- 0
-
-
-
-
Endowment funds
to nearest £
-
-

-
-
OK
Endowment funds
to nearest £
-
-
-
-
-
-
Current value (optional)
-
-
-
-
-
Current value (optional)
-
-
-
-
-
-
-
-
-
When due (optional)
Date of approval
12/11/21