

FSHD UK CHARITY

England & Wales · Charity number 1206212

Details

Other names FSHD UK

Status Registered

Legal form CIO

Registered 2023-12-14

Register [View on the Charity Commission register](#)

Contact

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London
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Activities

Objects: THE OBJECTS OF THE CIO ARE: TO PRESERVE AND PROTECT GOOD HEALTH AMONG, AND RELIEVE THE NEEDS OF, PEOPLE LIVING WITH FSHD, THEIR FAMILIES AND CARERS, IN PARTICULAR BUT NOT EXCLUSIVELY BY: (A) PROVIDING INFORMATION, HELP AND SUPPORT TO SUCH PEOPLE AND THEIR FAMILIES AND CARERS; (B) MAKING FINANCIAL DONATIONS TO SUPPORT ORGANISATIONS AND INDIVIDUALS CARRYING OUT RESEARCH INTO FSHD, THE USEFUL RESULTS OF WHICH WILL BE PUBLISHED FOR PUBLIC BENEFIT; AND (C) RAISING AWARENESS OF FSHD WITHIN THE GENERAL PUBLIC, MEDICAL AND SCIENTIFIC COMMUNITIES. (D) SUPPORT MEDICAL AND SCIENTIFIC ORGANISATIONS OR INDIVIDUALS WITH ACTIVITIES AND PROJECTS TO FURTHER THE CHARITY'S OVERALL OBJECTIVE OF HELPING TO RELIEVE THE BURDEN ON, AND IMPROVE QUALITY OF LIFE FOR, PEOPLE LIVING WITH FSHD.

Activities: To preserve and protect good health among and relieve the needs of people living with FSHD, their families and carers, in particular but not exclusively by raising awareness of FSHD within the general public, medical and scientific communities and support medical and scientific organisations or individuals with activities and projects to further the Charity's overall objectives.

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability, Other Charitable Purposes
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Charities Or Voluntary Bodies, The General Public/mankind

Geography

- Northern Ireland
- Scotland
- Throughout England

Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-05	£3,666	£2,562	-	-

Trustees

Name	Role	Appointed
Rajeshri Badiani	Chair	2023-12-14
Andrew Mcculloch Graham		2023-12-14
RUTH LEE HEREFORD		2023-12-14

FSHD UK CHARITY

England & Wales - Charity number 1206212

Accounts



Trustees' annual report (including Directors' report) for the period

From: 14/12/23

To: 5/4/25

Charity name: FSHD UK CHARITY

Charity registration number: 1206212

Company number: CE034632

Objectives and activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	To preserve and protect good health among, and relieve the needs of, people living with FSHD, their families and carers, in particular but not exclusively by: (a) providing information, help and support to such people and their families and carers; (b) making financial donations to support organisations and individuals carrying out research into FSHD, the useful results of which will be published for public benefit; and (c) raising awareness of FSHD within the general public, medical and scientific communities. (d) support medical and scientific organisations or individuals with activities and projects to further the Charity's overall objective of helping to relieve the burden on, and improve quality of life for, people living with FSHD.
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	As this is the first year of operation, the focus has been on establishing governance policies, bank accounts, and recruiting volunteers as well as setting up a website and social media accounts for beneficiaries to stay updated on FSHD research and support developments. In addition, our Chair of Trustees has continued to organise and lead a network of clinical researchers and healthcare professionals to bring more clinical trials to the UK, support trial and site readiness plus development of patient engagement and education in the UK.

Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.
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Achievements and performance

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	<p>During our first year, our achievements have been:</p> <ul style="list-style-type: none"> - Setting up the governance, risk management and financial infrastructure for the charity. - Successfully launched our website and social media accounts - Supported over 50 patients at a patient information day at UCL - Supported the development of the FSHD UK Registry and promotion to FSHD patients to register. - Secured funding to support our activities and mission.
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Financial review

Review of the charity's financial position at the end of the period	Para 1.21	Total incoming resources for the period were £3,666 of which £0 was restricted for expenditure on specific items of running costs. Total resources expended in the period were £2,562 resulting in a net movement in funds of £1,104. The fund balances at 5 April 2025 were £1,104 of which £1,104 was unrestricted and £0 was restricted
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	It is the policy of the charity that unrestricted funds which have not been designated for a specific use should be maintained at a level equivalent to between three and six month's expenditure. The trustees consider that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised. This level of reserves has been maintained throughout the period.
Amount of reserves held	Para 1.22	£500
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
The charity's principal sources of funds (including any fundraising)	Para 1.47	The principal sources of funds during this initial reporting period is unrestricted grant funding from The Healey Family Charitable Trust (HFCT) towards the core costs of FSHD UK and from individual donors. The trustees would like to acknowledge and thank the HFCT and donors for their critical support to enable the establishment of our charity and development of FSHD clinical trial infrastructure and patient engagement.
Investment policy and objectives including any social investment policy adopted	Para 1.46	Our investment objectives are to achieve growth and income. We aim to generate sustainable returns that allow us to achieve our charitable objectives while protecting the capital value of our investments. We will ensure that our charity has sufficient liquidity to meet our financial commitments, including grants and other charitable activities. We will invest in liquid assets and maintain an appropriate level of cash reserves to ensure that we can access our money when we need it. For this initial period, any interim excess funds have been held in an instant access savings account.

Structure, governance and management

Description of charity's trusts:		The charity was registered on 14/12/23 and is governed by the following Trustees: Ms. Rajeshri Badiani Mr. Andrew Graham Ms. Ruth Hereford
Type of governing document:	Para 1.25	The charity is governed by its Constitution for the Charitable Incorporated Organisation
How is the charity constituted?	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	New Trustees may be recruited to the Board at any time by the Trustees. In selecting individuals for appointment as Trustees, the Trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CID. The Trustees may, by and from their number and from time to time, elect

		such officers (chair, secretary, treasurer) as they see fit.
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Reference and administrative details

Charity name	FSHD UK CHARITY
Other name the charity uses	
Registered charity number	1206212
Charity's principal address	19 LANGLEY ROAD, LONDON SW19 3NZ

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	RAJESHRI BADIANI	CHAIR		
2	ANDREW GRAHAM	SECRETARY		
3	RUTH HEREFORD	TREASURER		
4				

Declarations

The company has taken advantage of the small companies' exemption in preparing the report above.

The trustees declare that they have approved the trustees' report (including directors' report) above.

Signed on behalf of the charity's trustees/directors

Signature(s)	<i>Rajeshri Badiani</i>	<i>RB</i>
Full name(s)	RAJESHRI BADIANI	<i>RB</i>
Position	Chair	
Date	2/2/2026	



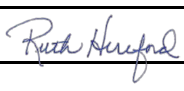
Receipts and payments accounts

For the period from	14/12/2023	To	05/04/2025
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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	644	-	-	644	-
Grants	3,000	-	-	3,000	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	3,644	-	-	3,644	-
A2 Asset and investment sales, (see table).					
Interest income	22	-	-	22	-
	-	-	-	-	-
Sub total	22	-	-	22	-
Total receipts	3,666	-	-	3,666	-
A3 Payments					
Patient engagement events	549	-	-	549	-
Insurance	561	-	-	561	-
IT and website expenses	1,038	-	-	1,038	-
Memberships	86	-	-	86	-
Printing and Stationery	18	-	-	18	-
Consultant expense	310	-	-	310	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	2,562	-	-	2,562	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	2,562	-	-	2,562	-
Net of receipts/(payments)	1,104	-	-	1,104	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	1,104	-	-	1,104	-

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	Checking	565	-	-
	Savings	539	-	-
		-	-	-
	Total cash funds	1,104	-	-
	<small>(agree balances with receipts and payments account(s))</small>	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Details	-	-	-
		-	-	-
B3 Investment assets	Details	<small>Fund to which asset belongs</small>	<small>Cost (optional)</small>	<small>Current value (optional)</small>
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	<small>Fund to which asset belongs</small>	<small>Cost (optional)</small>	<small>Current value (optional)</small>
			-	-
			-	-
			-	-
B5 Liabilities	Details	<small>Fund to which liability relates</small>	<small>Amount due (optional)</small>	<small>When due (optional)</small>
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Ruth Hereford	02/02/2026	