



CHARITY COMMISSION
FOR ENGLAND AND WALES

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 | <p>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:</p> <p>(a) providing information, help and support to such people and their families and carers;</p> <p>(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</p> <p>(c) raising awareness of FSHD within the general public, medical and scientific communities.</p> <p>(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.</p> |
| 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 | <p>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.</p> <p>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.</p> |

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| 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

| | | |
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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 | <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

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| 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 |

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| 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 |

| | | |
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| | | 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

CC16a

For the period
from

14/12/2023


To

05/04/2025

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 | - | - |
| | (agree balances with receipts and payments account(s)) | OK | OK | OK |
| B2 Other monetary assets | Details | Unrestricted funds to nearest £ | Restricted funds to nearest £ | Endowment funds to nearest £ |
| | | - | - | - |
| | | - | - | - |
| 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 asset belongs | Cost (optional) | Current value (optional) |
| | | | - | - |
| | | | - | - |
| | | | - | - |
| B5 Liabilities | 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 | |
| |  | Ruth Hereford | 02/02/2026 | |
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