

# Return of Organization Exempt From Income Tax

# 2025

Department of the Treasury  
Internal Revenue Service

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

Do not enter social security numbers on this form as it may be made public.

Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

Open to Public Inspection

### A For the 2025 calendar year, or tax year beginning and ending

|  |  |  |   |
|--|--|--|---|
| <b>B</b> Check if applicable:<br><input type="checkbox"/> Address change<br><input type="checkbox"/> Name change<br><input type="checkbox"/> Initial return<br><input type="checkbox"/> Final return/terminated<br><input type="checkbox"/> Amended return<br><input type="checkbox"/> Application pending | <b>C</b> Name of organization<br><b>F</b> Name and address of principal officer:                                   |  | <b>D</b> Employer identification number   |
|  | FSHD SOCIETY<br>Doing business as  |  | 52-1762747  |
|  | Number and street (or P.O. box if mail is not delivered to street address) Room/suite<br>75 NORTH MAIN STREET 1073 |  | <b>E</b> Telephone number<br>781-301-6060   |
|  | City or town, state or province, country, and ZIP or foreign postal code<br>RANDOLPH, MA 02368                     |  | <b>G</b> Gross receipts \$ 5,858,691.   |
|  | MARK A. STONE<br>SAME AS C ABOVE   |  | <b>H(a)</b> Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No<br><b>H(b)</b> Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No<br>If "No," attach a list. See instructions<br><b>H(c)</b> Group exemption number |

**I** Tax-exempt status:  501(c)(3)  501(c) ( ) (insert no.)  4947(a)(1) or  527

**J** Website: WWW.FSHDSOCIETY.ORG

**K** Form of organization:  Corporation  Trust  Association  Other

**L** Year of formation: 1991 **M** State of legal domicile: DC

### Part I Summary

|   |  |                           |              |
|---|--|---------------------------|--------------|
| <b>Activities &amp; Governance</b>  | <b>1</b> Briefly describe the organization's mission or most significant activities: <u>FIND TREATMENTS AND A CURE FOR FSHD WHILE EMPOWERING OUR FAMILIES.</u> |                           |              |
|   | <b>2</b> Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.               |                           |              |
|   | <b>3</b> Number of voting members of the governing body (Part VI, line 1a)   | <b>3</b>                  | 16           |
|   | <b>4</b> Number of independent voting members of the governing body (Part VI, line 1b)   | <b>4</b>                  | 16           |
|   | <b>5</b> Total number of individuals employed in calendar year 2025 (Part V, line 2a)  | <b>5</b>                  | 23           |
|   | <b>6</b> Total number of volunteers (estimate if necessary)  | <b>6</b>                  | 150          |
|   | <b>7a</b> Total unrelated business revenue from Part VIII, column (C), line 12   | <b>7a</b>                 | 0.           |
| <b>b</b> Net unrelated business taxable income from Form 990-T, Part I, line 11 | <b>7b</b>  | 0.                        |              |
| <b>Revenue</b>  | <b>8</b> Contributions and grants (Part VIII, line 1h)   | Prior Year                | Current Year |
|   | <b>9</b> Program service revenue (Part VIII, line 2g)  | 4,438,901.                | 5,394,709.   |
|   | <b>10</b> Investment income (Part VIII, column (A), lines 3, 4, and 7d)  | 302,974.                  | 318,071.     |
|   | <b>11</b> Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)   | 122,391.                  | 66,371.      |
|   | <b>12</b> Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)   | 78,305.                   | 2,703.       |
| <b>Expenses</b>   | <b>13</b> Grants and similar amounts paid (Part IX, column (A), lines 1-3)   | 4,942,571.                | 5,781,854.   |
|   | <b>14</b> Benefits paid to or for members (Part IX, column (A), line 4)  | 278,084.                  | 497,280.     |
|   | <b>15</b> Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)  | 0.                        | 0.           |
|   | <b>16a</b> Professional fundraising fees (Part IX, column (A), line 11e)   | 2,701,795.                | 3,033,956.   |
|   | <b>b</b> Total fundraising expenses (Part IX, column (D), line 25)   | 0.                        | 0.           |
|   | <b>17</b> Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)   | 709,637.                  |              |
|   | <b>18</b> Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)  | 2,495,397.                | 3,082,623.   |
| <b>19</b> Revenue less expenses. Subtract line 18 from line 12                  | 5,475,276.   | 6,613,859.                |              |
| <b>Net Assets or Fund Balances</b>  | <b>20</b> Total assets (Part X, line 16)   | -532,705.                 | -832,005.    |
|   | <b>21</b> Total liabilities (Part X, line 26)  | Beginning of Current Year | End of Year  |
|   | <b>22</b> Net assets or fund balances. Subtract line 21 from line 20   | 5,592,191.                | 5,533,752.   |
|   |  | 893,399.                  | 1,415,624.   |
|   | 4,698,792.   | 4,118,128.                |              |

### Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

|                                 |                                  |                       |           |   |           |
|---------------------------------|----------------------------------|-----------------------|-----------|---|-----------|
| <b>Sign Here</b>                | Signature of officer             |                       | Date      |   |           |
|                                 | MARK A. STONE, CEO & PRESIDENT   |                       |           |   |           |
| <b>Paid Preparer Use Only</b>   | Preparer's name                  | Preparer's signature  | Date      | Check if self-employed <input type="checkbox"/> | PTIN      |
|                                 | SAM A. LAZZARA                   | <i>SAM A. LAZZARA</i> | 4/30/2026 |   | P01342929 |
| <b>Firm's</b>                   | Firm's name                      | Firm's EIN            |           | Phone no. (813) 875-7774                        |           |
|                                 | RIVERO, GORDIMER & COMPANY, P.A. | 59-3040705            |           |   |           |
| Firm's address                  |                                  |                       |           |   |           |
| 201 N. FRANKLIN ST., SUITE 2200 |                                  |                       |           |   |           |
| TAMPA, FL 33602                 |                                  |                       |           |   |           |

May the IRS discuss this return with the preparer shown above? See instructions  Yes  No

Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response or note to any line in this Part III [X]

1 Briefly describe the organization's mission: TO FIND TREATMENTS AND A CURE FOR FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY (FSHD) WHILE EMPOWERING OUR FAMILIES.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? [ ] Yes [X] No

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? [ ] Yes [X] No

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses.

4a (Code: ) (Expenses \$ 2,368,097. including grants of \$ 497,280. ) (Revenue \$ 318,071. ) RESEARCH: THE SOCIETY SEEKS TO ACCELERATE RESEARCH TO EXPEDITE TREATMENTS AND A CURE FOR FSHD MUSCULAR DYSTROPHY. WE BRING TOGETHER PATIENTS, SCIENTISTS, AND INDUSTRY LEADERS TO DRIVE PROGRESS FASTER. THE FSHD SOCIETY DRIVES GLOBAL RESEARCH EFFORTS TO ACCELERATE BREAKTHROUGHS IN UNDERSTANDING, TREATING, AND ULTIMATELY CURING FSHD THROUGH THE FOLLOWING:

THERAPEUTIC ACCELERATOR: BREAKING DOWN BARRIERS TO SUCCESSFUL CLINICAL TRIALS AND TREATMENT APPROVALS.

CLINICAL TRIAL READINESS: INVESTING IN RESEARCH NETWORKS AND TRIAL-READY PATIENT COMMUNITIES. (CONTINUED ON SCHEDULE O)

4b (Code: ) (Expenses \$ 2,842,075. including grants of \$ ) (Revenue \$ ) THE SOCIETY EQUIPS INDIVIDUALS AND FAMILIES WITH KNOWLEDGE, SUPPORT, AND A POWERFUL VOICE.

EDUCATION & RESOURCES: PROVIDING TRUSTED RESOURCES THROUGH INITIATIVES LIKE BETTERLIFE FSHD, FSHD NAVIGATOR, EXPERT WEBINARS, AND REGIONAL CONFERENCES.

SUPPORT NETWORKS: CONNECTING PEOPLE THROUGH OUR CHAPTER PROGRAM, THE GATHERING PLACE, AND OTHER ONLINE COMMUNITIES.

ADVOCACY & POLICY: ENGAGING WITH POLICYMAKERS, THE NIH, AND THE FDA TO INFLUENCE LEGISLATION AND FUNDING.

4c (Code: ) (Expenses \$ including grants of \$ ) (Revenue \$ )

4d Other program services (Describe on Schedule O.) (Expenses \$ including grants of \$ ) (Revenue \$ )

4e Total program service expenses 5,210,172.

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Yes, No. Rows include questions 1 through 21 regarding organizational requirements, with 'X' marks in the Yes/No columns.

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question number, Yes, No. Rows 22-38 detailing various organizational requirements and compliance checks.

Part V Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response or note to any line in this Part V

Table with 3 columns: Question number, Yes, No. Rows 1a-1c regarding Form 1096, Forms W-2G, and backup withholding rules.

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

Table with columns for question number, question text, and Yes/No columns. Includes questions 2a through 17 regarding employee reporting, tax returns, unrelated business income, foreign accounts, prohibited transactions, and charitable contributions.

Part VI Governance, Management, and Disclosure. For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on Schedule O. See instructions.

Check if Schedule O contains a response or note to any line in this Part VI [X]

Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members of the governing body at the end of the tax year (16); 1b Enter the number of voting members included on line 1a, above, who are independent (16); 2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee? (X); 3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person? (X); 4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? (X); 5 Did the organization become aware during the year of a significant diversion of the organization's assets? (X); 6 Did the organization have members or stockholders? (X); 7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body? (X); 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? (X); 8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: a The governing body? (X); b Each committee with authority to act on behalf of the governing body? (X); 9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses on Schedule O (X).

Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.)

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters, branches, or affiliates? (X); 10b If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?; 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? (X); 11b Describe on Schedule O the process, if any, used by the organization to review this Form 990.; 12a Did the organization have a written conflict of interest policy? If "No," go to line 13 (X); 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? (X); 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe on Schedule O how this was done (X); 13 Did the organization have a written whistleblower policy? (X); 14 Did the organization have a written document retention and destruction policy? (X); 15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? a The organization's CEO, Executive Director, or top management official (X); b Other officers or key employees of the organization (X); If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions.; 16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? (X); 16b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?

Section C. Disclosure

Table with 2 columns: Question, Answer. Rows include: 17 List the states with which a copy of this Form 990 is required to be filed (NONE); 18 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply. [X] Own website [X] Another's website [X] Upon request [ ] Other (explain on Schedule O); 19 Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.; 20 State the name, address, and telephone number of the person who possesses the organization's books and records (THE ORGANIZATION - 781-301-6060, 75 NORTH MAIN STREET 1073, RANDOLPH, MA 02368).

**Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors**

Check if Schedule O contains a response or note to any line in this Part VII

**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees**

**1a** Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
  - List all of the organization's **current** key employees, if any. See the instructions for definition of "key employee."
  - List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (box 5 of Form W-2, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.
  - List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
  - List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.
- See the instructions for the order in which to list the persons above.

Check this box if neither the organization nor any related organization compensated any current officer, director, or trustee.

| (A)<br>Name and title  | (B)<br>Average hours per week (list any hours for related organizations below line) | (C)<br>Position (do not check more than one box, unless person is both an officer and a director/trustee) |                       |         |              |                              |        | (D)<br>Reportable compensation from the organization (W-2/1099-MISC/1099-NEC) | (E)<br>Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC) | (F)<br>Estimated amount of other compensation from the organization and related organizations |
|--|---|---|-----------------------|---------|--------------|------------------------------|--------|---|--|---|
|  |   | Individual trustee or director  | Institutional trustee | Officer | Key employee | Highest compensated employee | Former |   |  |   |
| (1) MARK STONE<br>CEO & PRESIDENT                            | 40.00   |   |                       | X       |              |                              |        | 240,615.  | 0.   | 36,383.   |
| (2) AGNES M. MESTRICH<br>CHIEF FINANCIAL OFFICER             | 40.00   |   |                       | X       |              |                              |        | 178,435.  | 0.   | 28,958.   |
| (3) KENNETH KAHTAVA<br>CHIEF OPERATING OFFICER               | 40.00   |   |                       |         |              | X                            |        | 139,336.  | 0.   | 23,139.   |
| (4) ELIZABETH JOHNSTON<br>CHIEF COMMUNITY ENGAGEMENT OFFICER | 40.00   |   |                       |         |              | X                            |        | 153,537.  | 0.   | 7,956.  |
| (5) AMANDA HILL<br>SENIOR DIRECTOR OF RESEARCH AND CARE      | 40.00   |   |                       |         |              | X                            |        | 132,447.  | 0.   | 25,979.   |
| (6) ANNA GILMORE<br>CHIEF PROGRAMS OFFICER                   | 40.00   |   |                       |         |              | X                            |        | 116,883.  | 0.   | 34,490.   |
| (7) AMANDA RICKARD<br>MANAGING DIRECTOR                      | 40.00   |   |                       |         |              | X                            |        | 108,097.  | 0.   | 3,061.  |
| (8) JAMES A. CHIN SR.<br>BOARD CHAIR                         | 10.00   | X   |                       | X       |              |                              |        | 0.  | 0.   | 0.  |
| (9) AMY BEKIER<br>VICE CHAIR                                 | 10.00   | X   |                       | X       |              |                              |        | 0.  | 0.   | 0.  |
| (10) GEORGE POLLOCK JR.<br>TREASURER                         | 10.00   | X   |                       | X       |              |                              |        | 0.  | 0.   | 0.  |
| (11) WILLIAM SARRAILLE<br>SECRETARY                          | 10.00   | X   |                       | X       |              |                              |        | 0.  | 0.   | 0.  |
| (12) JACK GERBLICK<br>BOARD MEMBER                           | 1.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (13) MEL HAYES<br>BOARD MEMBER                               | 1.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (14) BOB HUMPHREYS JR<br>BOARD MEMBER                        | 1.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (15) FRANK KOLAKOWSKI<br>BOARD MEMBER                        | 1.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (16) STEWART LAI<br>BOARD MEMBER                             | 1.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |
| (17) BILL LEWIS III<br>BOARD MEMBER                          | 1.00  | X   |                       |         |              |                              |        | 0.  | 0.   | 0.  |

**Part VII** Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees (continued)

| (A)<br>Name and title  | (B)<br>Average hours per week (list any hours for related organizations below line) | (C)<br>Position (do not check more than one box, unless person is both an officer and a director/trustee) |                       |         |              |                              |            | (D)<br>Reportable compensation from the organization (W-2/1099-MISC/1099-NEC) | (E)<br>Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC) | (F)<br>Estimated amount of other compensation from the organization and related organizations |
|--|---|---|-----------------------|---------|--------------|------------------------------|------------|---|--|---|
|  |   | Individual trustee or director  | Institutional trustee | Officer | Key employee | Highest compensated employee | Former     |   |  |   |
| (18) CHRIS MANCILL<br>BOARD MEMBER                                   | 1.00  | X   |                       |         |              |                              |            | 0.  | 0.   | 0.  |
| (19) BRUCE RYSKAMP<br>BOARD MEMBER                                   | 1.00  | X   |                       |         |              |                              |            | 0.  | 0.   | 0.  |
| (20) JASON SHI<br>BOARD MEMBER                                       | 1.00  | X   |                       |         |              |                              |            | 0.  | 0.   | 0.  |
| (21) NEIL SOLOMON<br>BOARD MEMBER                                    | 1.00  | X   |                       |         |              |                              |            | 0.  | 0.   | 0.  |
| (22) LINDA LAURELLO<br>BOARD MEMBER                                  | 1.00  | X   |                       |         |              |                              |            | 0.  | 0.   | 0.  |
| (23) HOWARD CHABNER<br>BOARD MEMBER                                  | 1.00  | X   |                       |         |              |                              |            | 0.  | 0.   | 0.  |
| <b>1b Subtotal</b> .....   |   |   |                       |         |              |                              | 1,069,350. | 0.  | 159,966.   |   |
| <b>c Total from continuation sheets to Part VII, Section A</b> ..... |   |   |                       |         |              |                              | 0.         | 0.  | 0.   |   |
| <b>d Total (add lines 1b and 1c)</b> .....                           |   |   |                       |         |              |                              | 1,069,350. | 0.  | 159,966.   |   |

**2** Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization 7

|   | Yes | No |
|---|-----|----|
| <b>3</b> Did the organization list any <b>former</b> officer, director, trustee, key employee, or highest compensated employee on line 1a? If "Yes," complete Schedule J for such individual .....  |     | X  |
| <b>4</b> For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? If "Yes," complete Schedule J for such individual ..... | X   |    |
| <b>5</b> Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person .....                       |     | X  |

**Section B. Independent Contractors**

**1** Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

| (A)<br>Name and business address | (B)<br>Description of services | (C)<br>Compensation |
|----------------------------------|--------------------------------|---------------------|
| NONE                             |                                |                     |
|                                  |                                |                     |
|                                  |                                |                     |
|                                  |                                |                     |
|                                  |                                |                     |

**2** Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization 0

**Part VIII Statement of Revenue**

Check if Schedule O contains a response or note to any line in this Part VIII

|  |   |  | (A)                     | (B)                                | (C)                        | (D)  |
|--|---|--|-------------------------|------------------------------------|----------------------------|--|
|  |   |  | Total revenue           | Related or exempt function revenue | Unrelated business revenue | Revenue excluded from tax under sections 512 - 514 |
| Contributions, Gifts, Grants and Other Similar Amounts | 1 a   | Federated campaigns  | 1a                      |                                    |                            |  |
|  | b   | Membership dues  | 1b                      |                                    |                            |  |
|  | c   | Fundraising events   | 1c                      | 1,048,948.                         |                            |  |
|  | d   | Related organizations  | 1d                      |                                    |                            |  |
|  | e   | Government grants (contributions)  | 1e                      |                                    |                            |  |
|  | f   | All other contributions, gifts, grants, and similar amounts not included above | 1f                      | 4,345,761.                         |                            |  |
|  | g   | Noncash contributions included in lines 1a-1f                                  | 1g                      | \$ 955,000.                        |                            |  |
|  | h   | <b>Total.</b> Add lines 1a-1f  |                         | 5,394,709.                         |                            |  |
| Program Service Revenue                                | 2 a   | DATA SAMPLE ACCESS   | Business Code<br>900099 | 231,807.                           | 231,807.                   |  |
|  | b   | PROGRAM REGISTRATIONS  | 900099                  | 86,264.                            | 86,264.                    |  |
|  | c   |  |                         |                                    |                            |  |
|  | d   |  |                         |                                    |                            |  |
|  | e   |  |                         |                                    |                            |  |
|  | f   | All other program service revenue  |                         |                                    |                            |  |
|  | g   | <b>Total.</b> Add lines 2a-2f  |                         | 318,071.                           |                            |  |
| Other Revenue  | 3   | Investment income (including dividends, interest, and other similar amounts)   |                         | 66,371.                            |                            | 66,371.  |
|  | 4   | Income from investment of tax-exempt bond proceeds                             |                         |                                    |                            |  |
|  | 5   | Royalties  |                         |                                    |                            |  |
|  | 6 a   | Gross rents  | (i) Real                |                                    |                            |  |
|  |   |  | (ii) Personal           |                                    |                            |  |
|  |   |  |                         |                                    |                            |  |
|  | b   | Less: rental expenses  |                         |                                    |                            |  |
|  | c   | Rental income or (loss)  |                         |                                    |                            |  |
|  | d   | Net rental income or (loss)  |                         |                                    |                            |  |
|  | 7 a   | Gross amount from sales of assets other than inventory                         | (i) Securities          |                                    |                            |  |
|  |   |  | (ii) Other              |                                    |                            |  |
|  |   |  |                         |                                    |                            |  |
|  |   |  |                         |                                    |                            |  |
|  | b   | Less: cost or other basis and sales expenses                                   |                         |                                    |                            |  |
| c  | Gain or (loss)  |  |                         |                                    |                            |  |
| d  | Net gain or (loss)  |  |                         |                                    |                            |  |
| 8 a  | Gross income from fundraising events (not including \$ 1,048,948. of contributions reported on line 1c). See Part IV, line 18 |  | 76,837.                 |                                    |                            |  |
|  |   |  | 76,837.                 |                                    |                            |  |
|  |   |  |                         |                                    |                            |  |
| b  | Less: direct expenses   |  |                         |                                    |                            |  |
| c  | Net income or (loss) from fundraising events  |  | 0.                      |                                    |                            |  |
| 9 a  | Gross income from gaming activities. See Part IV, line 19   |  |                         |                                    |                            |  |
|  |   |  |                         |                                    |                            |  |
|  |   |  |                         |                                    |                            |  |
| b  | Less: direct expenses   |  |                         |                                    |                            |  |
| c  | Net income or (loss) from gaming activities   |  |                         |                                    |                            |  |
| 10 a   | Gross sales of inventory, less returns and allowances   |  |                         |                                    |                            |  |
|  |   |  |                         |                                    |                            |  |
|  |   |  |                         |                                    |                            |  |
| b  | Less: cost of goods sold  |  |                         |                                    |                            |  |
| c  | Net income or (loss) from sales of inventory  |  |                         |                                    |                            |  |
| Miscellaneous Revenue                                  | 11 a  | OTHER INCOME   | Business Code<br>900099 | 2,703.                             | 2,703.                     |  |
|  | b   |  |                         |                                    |                            |  |
|  | c   |  |                         |                                    |                            |  |
|  | d   | All other revenue  |                         |                                    |                            |  |
|  | e   | <b>Total.</b> Add lines 11a-11d  |                         | 2,703.                             |                            |  |
| 12   | <b>Total revenue.</b> See instructions  |  | 5,781,854.              | 320,774.                           | 0.                         | 66,371.  |

**Part IX Statement of Functional Expenses**

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

Check if Schedule O contains a response or note to any line in this Part IX  X

| Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.   | (A)<br>Total expenses | (B)<br>Program service expenses | (C)<br>Management and general expenses | (D)<br>Fundraising expenses |
|--|-----------------------|---------------------------------|--|-----------------------------|
| 1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21   | 232,071.              | 232,071.                        |  |                             |
| 2 Grants and other assistance to domestic individuals. See Part IV, line 22  |                       |                                 |  |                             |
| 3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16   | 265,209.              | 265,209.                        |  |                             |
| 4 Benefits paid to or for members  |                       |                                 |  |                             |
| 5 Compensation of current officers, directors, trustees, and key employees   | 419,049.              | 288,155.                        | 67,251.                                | 63,643.                     |
| 6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)   |                       |                                 |  |                             |
| 7 Other salaries and wages   | 1,997,437.            | 1,373,515.                      | 320,560.                               | 303,362.                    |
| 8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)   | 79,990.               | 55,004.                         | 12,837.                                | 12,149.                     |
| 9 Other employee benefits  | 341,021.              | 234,499.                        | 54,729.                                | 51,793.                     |
| 10 Payroll taxes   | 196,459.              | 135,093.                        | 31,529.                                | 29,837.                     |
| 11 Fees for services (nonemployees):   |                       |                                 |  |                             |
| a Management   |                       |                                 |  |                             |
| b Legal  | 76,697.               | 72,957.                         | 3,740.                                 |                             |
| c Accounting   | 43,896.               |                                 | 43,896.                                |                             |
| d Lobbying   |                       |                                 |  |                             |
| e Professional fundraising services. See Part IV, line 17  |                       |                                 |  |                             |
| f Investment management fees   |                       |                                 |  |                             |
| g Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Sch O.)   | 1,081,960.            | 1,070,953.                      | 11,007.                                |                             |
| 12 Advertising and promotion   |                       |                                 |  |                             |
| 13 Office expenses   | 114,005.              | 66,824.                         | 28,448.                                | 18,733.                     |
| 14 Information technology  | 375,144.              | 292,849.                        | 41,958.                                | 40,337.                     |
| 15 Royalties   |                       |                                 |  |                             |
| 16 Occupancy   |                       |                                 |  |                             |
| 17 Travel  | 427,285.              | 375,395.                        | 10,670.                                | 41,220.                     |
| 18 Payments of travel or entertainment expenses for any federal, state, or local public officials  |                       |                                 |  |                             |
| 19 Conferences, conventions, and meetings  | 282,162.              | 281,662.                        |  | 500.                        |
| 20 Interest  |                       |                                 |  |                             |
| 21 Payments to affiliates  |                       |                                 |  |                             |
| 22 Depreciation, depletion, and amortization   | 230,720.              | 230,720.                        |  |                             |
| 23 Insurance   | 12,926.               | 2,408.                          | 10,518.                                |                             |
| 24 Other expenses. Itemize expenses not covered above. (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A), amount, list line 24e expenses on Schedule O.)   |                       |                                 |  |                             |
| a <b>BANK SERVICE CHARGES</b>  | 130,127.              | 39,857.                         | 19,141.                                | 71,129.                     |
| b <b>PUBLIC AWARENESS</b>  | 110,703.              | 109,853.                        |  | 850.                        |
| c <b>PRINTING</b>  | 107,820.              | 79,481.                         | 159.                                   | 28,180.                     |
| d <b>DONOR SOFTWARE AND DONO</b>   | 47,863.               |                                 |  | 47,863.                     |
| e All other expenses   | 41,315.               | 3,667.                          | 37,607.                                | 41.                         |
| 25 <b>Total functional expenses.</b> Add lines 1 through 24e   | 6,613,859.            | 5,210,172.                      | 694,050.                               | 709,637.                    |
| 26 <b>Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720) |                       |                                 |  |                             |

**Part X Balance Sheet**

Check if Schedule O contains a response or note to any line in this Part X

|   |  | (A)<br>Beginning of year |            | (B)<br>End of year |
|---|--|--------------------------|------------|--------------------|
| <b>Assets</b>   | <b>1</b> Cash - non-interest-bearing .....   | 15,976.                  | <b>1</b>   | 5,460.             |
|   | <b>2</b> Savings and temporary cash investments .....  | 1,080,178.               | <b>2</b>   | 128,996.           |
|   | <b>3</b> Pledges and grants receivable, net .....  | 84,086.                  | <b>3</b>   |                    |
|   | <b>4</b> Accounts receivable, net .....  | 175,000.                 | <b>4</b>   | 75,000.            |
|   | <b>5</b> Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons ..... |                          | <b>5</b>   |                    |
|   | <b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B) .....   |                          | <b>6</b>   |                    |
|   | <b>7</b> Notes and loans receivable, net .....   |                          | <b>7</b>   |                    |
|   | <b>8</b> Inventories for sale or use .....   |                          | <b>8</b>   |                    |
|   | <b>9</b> Prepaid expenses and deferred charges .....   | 337,028.                 | <b>9</b>   | 216,430.           |
|   | <b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D .....   | <b>10a</b>               |            |                    |
|   | <b>b</b> Less: accumulated depreciation .....  | <b>10b</b>               | <b>10c</b> |                    |
|   | <b>11</b> Investments - publicly traded securities .....   | 2,316,091.               | <b>11</b>  | 2,048,373.         |
|   | <b>12</b> Investments - other securities. See Part IV, line 11 .....   |                          | <b>12</b>  |                    |
|   | <b>13</b> Investments - program-related. See Part IV, line 11 .....  | 150,000.                 | <b>13</b>  | 150,000.           |
|   | <b>14</b> Intangible assets .....  | 1,433,832.               | <b>14</b>  | 2,909,493.         |
|   | <b>15</b> Other assets. See Part IV, line 11 .....   |                          | <b>15</b>  |                    |
| <b>16 Total assets.</b> Add lines 1 through 15 (must equal line 33) ..... | 5,592,191.   | <b>16</b>                | 5,533,752. |                    |
| <b>Liabilities</b>  | <b>17</b> Accounts payable and accrued expenses .....  | 343,126.                 | <b>17</b>  | 778,225.           |
|   | <b>18</b> Grants payable .....   | 407,660.                 | <b>18</b>  | 402,355.           |
|   | <b>19</b> Deferred revenue .....   |                          | <b>19</b>  |                    |
|   | <b>20</b> Tax-exempt bond liabilities .....  |                          | <b>20</b>  |                    |
|   | <b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D .....  |                          | <b>21</b>  |                    |
|   | <b>22</b> Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons .....     |                          | <b>22</b>  |                    |
|   | <b>23</b> Secured mortgages and notes payable to unrelated third parties .....   |                          | <b>23</b>  |                    |
|   | <b>24</b> Unsecured notes and loans payable to unrelated third parties .....   |                          | <b>24</b>  | 50,000.            |
|   | <b>25</b> Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D .....  | 142,613.                 | <b>25</b>  | 185,044.           |
|   | <b>26 Total liabilities.</b> Add lines 17 through 25 .....   | 893,399.                 | <b>26</b>  | 1,415,624.         |
| <b>Net Assets or Fund Balances</b>  | <b>Organizations that follow FASB ASC 958, check here</b> <input checked="" type="checkbox"/> <b>and complete lines 27, 28, 32, and 33.</b>  |                          |            |                    |
|   | <b>27</b> Net assets without donor restrictions .....  | 4,583,881.               | <b>27</b>  | 3,934,966.         |
|   | <b>28</b> Net assets with donor restrictions .....   | 114,911.                 | <b>28</b>  | 183,162.           |
|   | <b>Organizations that do not follow FASB ASC 958, check here</b> <input type="checkbox"/> <b>and complete lines 29 through 33.</b>   |                          |            |                    |
|   | <b>29</b> Capital stock or trust principal, or current funds .....   |                          | <b>29</b>  |                    |
|   | <b>30</b> Paid-in or capital surplus, or land, building, or equipment fund .....   |                          | <b>30</b>  |                    |
|   | <b>31</b> Retained earnings, endowment, accumulated income, or other funds .....   |                          | <b>31</b>  |                    |
|   | <b>32</b> Total net assets or fund balances .....  | 4,698,792.               | <b>32</b>  | 4,118,128.         |
| <b>33</b> Total liabilities and net assets/fund balances .....            | 5,592,191.   | <b>33</b>                | 5,533,752. |                    |

**Part XI Reconciliation of Net Assets**

Check if Schedule O contains a response or note to any line in this Part XI

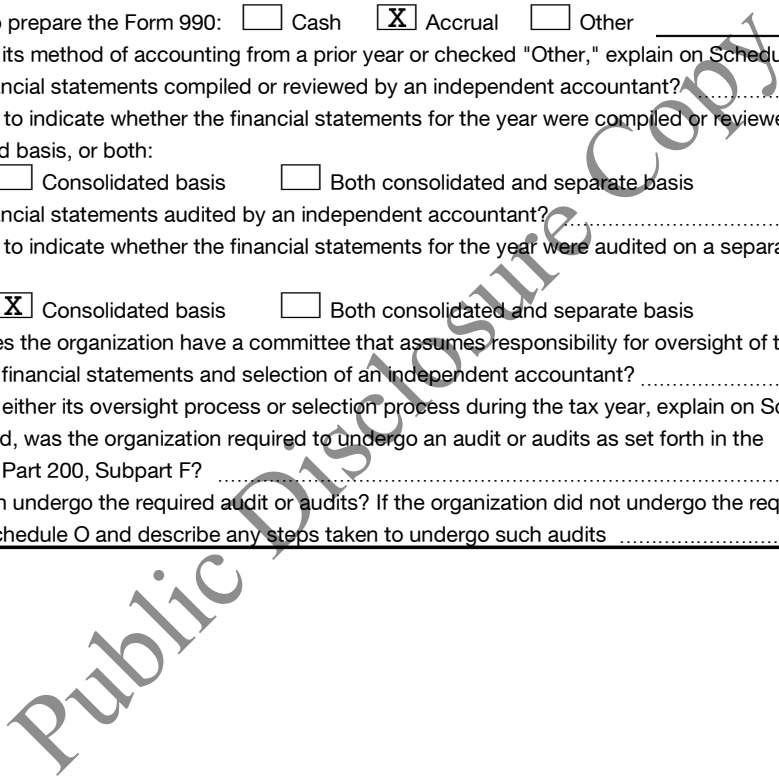
|           |  |           |            |
|-----------|--|-----------|------------|
| <b>1</b>  | Total revenue (must equal Part VIII, column (A), line 12)  | <b>1</b>  | 5,781,854. |
| <b>2</b>  | Total expenses (must equal Part IX, column (A), line 25)   | <b>2</b>  | 6,613,859. |
| <b>3</b>  | Revenue less expenses. Subtract line 2 from line 1   | <b>3</b>  | -832,005.  |
| <b>4</b>  | Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))                      | <b>4</b>  | 4,698,792. |
| <b>5</b>  | Net unrealized gains (losses) on investments   | <b>5</b>  | 251,341.   |
| <b>6</b>  | Donated services and use of facilities   | <b>6</b>  |            |
| <b>7</b>  | Investment expenses  | <b>7</b>  |            |
| <b>8</b>  | Prior period adjustments   | <b>8</b>  |            |
| <b>9</b>  | Other changes in net assets or fund balances (explain on Schedule O)   | <b>9</b>  | 0.         |
| <b>10</b> | Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B)) | <b>10</b> | 4,118,128. |

**Part XII Financial Statements and Reporting**

Check if Schedule O contains a response or note to any line in this Part XII

|   | Yes | No |
|---|-----|----|
| <b>1</b> Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____<br>If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.  |     |    |
| <b>2a</b> Were the organization's financial statements compiled or reviewed by an independent accountant?<br>If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both:<br><input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis |     | X  |
| <b>b</b> Were the organization's financial statements audited by an independent accountant?<br>If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both:<br><input type="checkbox"/> Separate basis <input checked="" type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis                 | X   |    |
| <b>c</b> If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant?<br>If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.  |     | X  |
| <b>3a</b> As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Uniform Guidance, 2 C.F.R. Part 200, Subpart F?   |     | X  |
| <b>b</b> If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits   |     |    |

Form 990 (2025)





**Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)**

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

**Section A. Public Support**

| Calendar year (or fiscal year beginning in)  | (a) 2021 | (b) 2022 | (c) 2023 | (d) 2024 | (e) 2025 | (f) Total |
|--|----------|----------|----------|----------|----------|-----------|
| <b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....  | 4546323. | 2930776. | 4106175. | 4438901. | 5646709. | 21668884. |
| <b>2</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf .....   |          |          |          |          |          |           |
| <b>3</b> The value of services or facilities furnished by a governmental unit to the organization without charge .....   |          |          |          |          |          |           |
| <b>4 Total.</b> Add lines 1 through 3 .....  | 4546323. | 2930776. | 4106175. | 4438901. | 5646709. | 21668884. |
| <b>5</b> The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f) ..... |          |          |          |          |          | 449,061.  |
| <b>6 Public support.</b> Subtract line 5 from line 4.  |          |          |          |          |          | 21219823. |

**Section B. Total Support**

| Calendar year (or fiscal year beginning in)   | (a) 2021 | (b) 2022 | (c) 2023 | (d) 2024 | (e) 2025 | (f) Total                |
|---|----------|----------|----------|----------|----------|--------------------------|
| <b>7</b> Amounts from line 4 .....  | 4546323. | 2930776. | 4106175. | 4438901. | 5646709. | 21668884.                |
| <b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources .....  | 122,027. | 98,205.  | 154,284. | 122,391. | 66,371.  | 563,278.                 |
| <b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on .....   |          |          | 39,986.  | 78,305.  |          | 118,291.                 |
| <b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) .....   | 348,700. | 139,774. | 2,638.   |          | 2,703.   | 493,815.                 |
| <b>11 Total support.</b> Add lines 7 through 10   |          |          |          |          |          | 22844268.                |
| <b>12</b> Gross receipts from related activities, etc. (see instructions) .....   |          |          |          |          | 12       |                          |
| <b>13 First 5 years.</b> If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and <b>stop here</b> ..... |          |          |          |          |          | <input type="checkbox"/> |

**Section C. Computation of Public Support Percentage**

|   |           |                                     |
|---|-----------|-------------------------------------|
| <b>14</b> Public support percentage for 2025 (line 6, column (f), divided by line 11, column (f)) .....   | <b>14</b> | 92.89 %                             |
| <b>15</b> Public support percentage from 2024 Schedule A, Part II, line 14 .....  | <b>15</b> | 83.10 %                             |
| <b>16a 33 1/3% support test - 2025.</b> If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and <b>stop here.</b> The organization qualifies as a publicly supported organization .....  |           | <input checked="" type="checkbox"/> |
| <b>b 33 1/3% support test - 2024.</b> If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and <b>stop here.</b> The organization qualifies as a publicly supported organization .....   |           | <input type="checkbox"/>            |
| <b>17a 10% -facts-and-circumstances test - 2025.</b> If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and <b>stop here.</b> Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization .....    |           | <input type="checkbox"/>            |
| <b>b 10% -facts-and-circumstances test - 2024.</b> If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and <b>stop here.</b> Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization ..... |           | <input type="checkbox"/>            |
| <b>18 Private foundation.</b> If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions .....  |           | <input type="checkbox"/>            |

Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Table with 7 columns: (a) 2021, (b) 2022, (c) 2023, (d) 2024, (e) 2025, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Gross receipts from admissions; 3 Gross receipts from activities that are not an unrelated trade or business; 4 Tax revenues levied for the organization's benefit; 5 The value of services or facilities furnished by a governmental unit; 6 Total. Add lines 1 through 5; 7a Amounts included on lines 1, 2, and 3 received from disqualified persons; 7b Amounts included on lines 2 and 3 received from other than disqualified persons; 8 Public support. (Subtract line 7c from line 6.)

Section B. Total Support

Table with 7 columns: (a) 2021, (b) 2022, (c) 2023, (d) 2024, (e) 2025, (f) Total. Rows include: 9 Amounts from line 6; 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources; 10b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975; 10c Add lines 10a and 10b; 11 Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on; 12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.); 13 Total support. (Add lines 9, 10c, 11, and 12.)

14 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here

Section C. Computation of Public Support Percentage

Table with 2 columns: Line number, Percentage. Row 15: Public support percentage for 2025 (line 8, column (f), divided by line 13, column (f)) 15 %; Row 16: Public support percentage from 2024 Schedule A, Part III, line 15 16 %

Section D. Computation of Investment Income Percentage

Table with 2 columns: Line number, Percentage. Row 17: Investment income percentage for 2025 (line 10c, column (f), divided by line 13, column (f)) 17 %; Row 18: Investment income percentage from 2024 Schedule A, Part III, line 17 18 %

19a 33 1/3% support tests - 2025. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization; 19b 33 1/3% support tests - 2024. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization; 20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions

**Part IV Supporting Organizations**

(Complete only if you checked a box on line 12 of Part I. If you checked box 12a, Part I, complete Sections A and B. If you checked box 12b, Part I, complete Sections A and C. If you checked box 12c, Part I, complete Sections A, D, and E. If you checked box 12d, Part I, complete Sections A and D, and complete Part V.)

**Section A. All Supporting Organizations**

|  | Yes | No |
|--|-----|----|
| <b>1</b> Are all of the organization's supported organizations listed by name in the organization's governing documents? <i>If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.</i>  |     |    |
| <b>2</b> Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>   |     |    |
| <b>3a</b> Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer lines 3b and 3c below.</i>   |     |    |
| <b>b</b> Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? <i>If "Yes," describe in Part VI when and how the organization made the determination.</i>   |     |    |
| <b>c</b> Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in Part VI what controls the organization put in place to ensure such use.</i>  |     |    |
| <b>4a</b> Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.</i>  |     |    |
| <b>b</b> Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.</i>  |     |    |
| <b>c</b> Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? <i>If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.</i>   |     |    |
| <b>5a</b> Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).</i> |     |    |
| <b>b Type I or Type II only.</b> Was any added or substituted supported organization part of a class already designated in the organization's organizing document?   |     |    |
| <b>c Substitutions only.</b> Was the substitution the result of an event beyond the organization's control?  |     |    |
| <b>6</b> Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? <i>If "Yes," provide detail in Part VI.</i>  |     |    |
| <b>7</b> Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? <i>If "Yes," complete Part I of Schedule L (Form 990).</i>  |     |    |
| <b>8</b> Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? <i>If "Yes," complete Part I of Schedule L (Form 990).</i>  |     |    |
| <b>9a</b> Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? <i>If "Yes," provide detail in Part VI.</i>   |     |    |
| <b>b</b> Did one or more disqualified persons (as defined on line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? <i>If "Yes," provide detail in Part VI.</i>  |     |    |
| <b>c</b> Did a disqualified person (as defined on line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? <i>If "Yes," provide detail in Part VI.</i>   |     |    |
| <b>10a</b> Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? <i>If "Yes," answer line 10b below.</i>  |     |    |
| <b>b</b> Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i>   |     |    |

**Part IV Supporting Organizations** (continued)

|  | Yes | No |
|--|-----|----|
| <b>11</b> Has the organization accepted a gift or contribution from any of the following persons?  |     |    |
| <b>a</b> A person who directly or indirectly controls, either alone or together with persons described on lines 11b and 11c below, the governing body of a supported organization? |     |    |
| <b>b</b> A family member of a person described on line 11a above?  |     |    |
| <b>c</b> A 35% controlled entity of a person described on line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide detail in <b>Part VI</b> .                             |     |    |
| <b>11a</b>   |     |    |
| <b>11b</b>   |     |    |
| <b>11c</b>   |     |    |

**Section B. Type I Supporting Organizations**

|   | Yes | No |
|---|-----|----|
| <b>1</b> Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, directors, or trustees at all times during the tax year? If "No," describe in <b>Part VI</b> how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove officers, directors, or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year. |     |    |
| <b>2</b> Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in <b>Part VI</b> how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.   |     |    |
| <b>1</b>  |     |    |
| <b>2</b>  |     |    |

**Section C. Type II Supporting Organizations**

|  | Yes | No |
|--|-----|----|
| <b>1</b> Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? If "No," describe in <b>Part VI</b> how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s). |     |    |
| <b>1</b>   |     |    |

**Section D. All Type III Supporting Organizations**

|   | Yes | No |
|---|-----|----|
| <b>1</b> Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided? |     |    |
| <b>2</b> Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in <b>Part VI</b> how the organization maintained a close and continuous working relationship with the supported organization(s).   |     |    |
| <b>3</b> By reason of the relationship described on line 2, above, did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? If "Yes," describe in <b>Part VI</b> the role the organization's supported organizations played in this regard.  |     |    |
| <b>1</b>  |     |    |
| <b>2</b>  |     |    |
| <b>3</b>  |     |    |

**Section E. Type III Functionally Integrated Supporting Organizations**

|  |  |     |    |
|--|--|-----|----|
| <b>1</b> Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).   |  |     |    |
| <b>a</b> <input type="checkbox"/> The organization satisfied the Activities Test. Complete <b>line 2</b> below.  |  |     |    |
| <b>b</b> <input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete <b>line 3</b> below.   |  |     |    |
| <b>c</b> <input type="checkbox"/> The organization supported a governmental supported organization. Describe in <b>Part VI</b> how you supported a governmental supported organization (see instructions).   |  |     |    |
| <b>2</b> Activities Test. Answer lines 2a and 2b below.  |  |     |    |
| <b>a</b> Did substantially all of the organization's activities during the tax year directly further the exempt purposes of its supported organization(s)? If "Yes," then in <b>Part VI</b> identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to each of its supported organizations, and how the organization determined that these activities constituted substantially all of its activities. |  | Yes | No |
| <b>b</b> Did the activities described on line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in <b>Part VI</b> the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.   |  |     |    |
| <b>3</b> Parent of Supported Organizations. Answer lines 3a, 3b, and 3c below.   |  |     |    |
| <b>a</b> Are the organization and its supported organization(s) part of an integrated system (for example, a hospital system)? If "Yes," provide details in <b>Part VI</b> .   |  |     |    |
| <b>b</b> Did the organization direct the policies, programs, and activities of each of its supported organizations? If "Yes," describe in <b>Part VI</b> the role played by the organization in this regard.   |  |     |    |
| <b>c</b> Did the organization have the power to regularly appoint or elect (and remove) a majority of the officers, directors, or trustees of each of the supported organizations? If "Yes" or "No," provide details in <b>Part VI</b> .   |  |     |    |
| <b>2a</b>  |  |     |    |
| <b>2b</b>  |  |     |    |
| <b>3a</b>  |  |     |    |
| <b>3b</b>  |  |     |    |
| <b>3c</b>  |  |     |    |

**Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations**

1  Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (*explain in Part VI*). See instructions. All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

| Section A - Adjusted Net Income |  | (A) Prior Year | (B) Current Year (optional) |
|---------------------------------|--|----------------|-----------------------------|
| 1                               | Net short-term capital gain  | 1              |                             |
| 2                               | Recoveries of prior-year distributions   | 2              |                             |
| 3                               | Other gross income (see instructions)  | 3              |                             |
| 4                               | Add lines 1 through 3.   | 4              |                             |
| 5                               | Depreciation and depletion   | 5              |                             |
| 6                               | Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions) | 6              |                             |
| 7                               | Other expenses (see instructions)  | 7              |                             |
| 8                               | <b>Adjusted Net Income</b> (subtract lines 5, 6, and 7 from line 4)  | 8              |                             |

| Section B - Minimum Asset Amount |   | (A) Prior Year | (B) Current Year (optional) |
|----------------------------------|---|----------------|-----------------------------|
| 1                                | Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year): |                |                             |
| a                                | Average monthly value of securities   | 1a             |                             |
| b                                | Average monthly cash balances   | 1b             |                             |
| c                                | Fair market value of other non-exempt-use assets  | 1c             |                             |
| d                                | <b>Total</b> (add lines 1a, 1b, and 1c)   | 1d             |                             |
| e                                | <b>Discount</b> claimed for blockage or other factors ( <i>explain in detail in Part VI</i> ):                                  |                |                             |
| 2                                | Acquisition indebtedness applicable to non-exempt-use assets  | 2              |                             |
| 3                                | Subtract line 2 from line 1d.   | 3              |                             |
| 4                                | Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).                                  | 4              |                             |
| 5                                | Net value of non-exempt-use assets (subtract line 4 from line 3)  | 5              |                             |
| 6                                | Multiply line 5 by 0.035.   | 6              |                             |
| 7                                | Recoveries of prior-year distributions  | 7              |                             |
| 8                                | <b>Minimum Asset Amount</b> (add line 7 to line 6)  | 8              |                             |

| Section C - Distributable Amount |   |   | Current Year |
|----------------------------------|---|---|--------------|
| 1                                | Adjusted net income for prior year (from Section A, line 8, column A)   | 1 |              |
| 2                                | Enter 0.85 of line 1.   | 2 |              |
| 3                                | Minimum asset amount for prior year (from Section B, line 8, column A)  | 3 |              |
| 4                                | Enter greater of line 2 or line 3.  | 4 |              |
| 5                                | Income tax imposed in prior year  | 5 |              |
| 6                                | <b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).   | 6 |              |
| 7                                | <input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions). |   |              |

**Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations** (continued)

| <b>Section D - Distributions</b> |  | <b>Current Year</b> |
|----------------------------------|--|---------------------|
| <b>1</b>                         | Amounts paid to supported organizations to accomplish exempt purposes  | <b>1</b>            |
| <b>2</b>                         | Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity      | <b>2</b>            |
| <b>3</b>                         | Administrative expenses paid to accomplish exempt purposes of supported organizations  | <b>3</b>            |
| <b>4</b>                         | Amounts paid to acquire exempt-use assets  | <b>4</b>            |
| <b>5</b>                         | Qualified set-aside amounts (prior IRS approval required - provide details in Part VI)   | <b>5</b>            |
| <b>6</b>                         | <b>Total annual distributions.</b> Add lines 1 through 5.  | <b>6</b>            |
| <b>7</b>                         | Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions. | <b>7</b>            |
| <b>8</b>                         | Distributable amount for 2025 from Section C, line 6   | <b>8</b>            |
| <b>9</b>                         | Line 7 amount divided by line 8 amount   | <b>9</b>            |

| <b>Section E - Distribution Allocations</b> (see instructions)   | <b>(i)<br/>Excess Distributions</b> | <b>(ii)<br/>Underdistributions<br/>Pre-2025</b> | <b>(iii)<br/>Distributable<br/>Amount for 2025</b> |
|--|-------------------------------------|---|--|
| <b>1</b> Distributable amount for 2025 from Section C, line 6  |                                     |   |  |
| <b>2</b> Underdistributions, if any, for years prior to 2025 (reasonable cause required - explain in Part VI). See instructions.   |                                     |   |  |
| <b>3</b> Excess distributions carryover, if any, to 2025   |                                     |   |  |
| <b>a</b> From 2020   |                                     |   |  |
| <b>b</b> From 2021   |                                     |   |  |
| <b>c</b> From 2022   |                                     |   |  |
| <b>d</b> From 2023   |                                     |   |  |
| <b>e</b> From 2024   |                                     |   |  |
| <b>f</b> <b>Total</b> of lines 3a through 3e   |                                     |   |  |
| <b>g</b> Applied to under distributions of prior years   |                                     |   |  |
| <b>h</b> Applied to 2025 distributable amount  |                                     |   |  |
| <b>i</b> Carryover from 2020 not applied (see instructions)  |                                     |   |  |
| <b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from line 3f.  |                                     |   |  |
| <b>4</b> Distributions for 2025 from Section D, line 6: \$   |                                     |   |  |
| <b>a</b> Applied to underdistributions of prior years  |                                     |   |  |
| <b>b</b> Applied to 2025 distributable amount  |                                     |   |  |
| <b>c</b> Remainder. Subtract lines 4a and 4b from line 4.  |                                     |   |  |
| <b>5</b> Remaining underdistributions for years prior to 2025, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI. See instructions. |                                     |   |  |
| <b>6</b> Remaining underdistributions for 2025. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.                        |                                     |   |  |
| <b>7</b> <b>Excess distributions carryover to 2026.</b> Add lines 3j and 4c.   |                                     |   |  |
| <b>8</b> Breakdown of line 7:  |                                     |   |  |
| <b>a</b> Excess from 2021  |                                     |   |  |
| <b>b</b> Excess from 2022  |                                     |   |  |
| <b>c</b> Excess from 2023  |                                     |   |  |
| <b>d</b> Excess from 2024  |                                     |   |  |
| <b>e</b> Excess from 2025  |                                     |   |  |

**Part VI** **Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a, 3b, and 3c; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5 and 7; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions.)

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**Schedule B  
(Form 990)**

(Rev. December 2024)  
Department of the Treasury  
Internal Revenue Service

**Schedule of Contributors**

Attach to Form 990, 990-EZ, or 990-PF.  
Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

Name of the organization

**FSHD SOCIETY**

Employer identification number

**52-1762747**

Organization type (check one):

**Filers of:**

**Section:**

Form 990 or 990-EZ

501(c)( 3 ) (enter number) organization

4947(a)(1) nonexempt charitable trust **not** treated as a private foundation

527 political organization

Form 990-PF

501(c)(3) exempt private foundation

4947(a)(1) nonexempt charitable trust treated as a private foundation

501(c)(3) taxable private foundation

Check if your organization is covered by the **General Rule** or a **Special Rule**.

**Note:** Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

**General Rule**

For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

**Special Rules**

For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of **(1)** \$5,000; or **(2)** 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II.

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 *exclusively* for religious, charitable, scientific, literary, or educational purposes; or for the prevention of cruelty to children or animals. Complete Parts I (entering "N/A" in column (b) instead of the contributor name and address), II, and III.

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions *exclusively* for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc., purpose. Don't complete any of the parts unless the **General Rule** applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions totaling \$5,000 or more during the year ..... \$ \_\_\_\_\_

**Caution:** An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990), but it **must** answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990-PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990).

For Paperwork Reduction Act Notice, see the instructions for Form 990, 990-EZ, or 990-PF.

Schedule B (Form 990) (Rev. 12-2024)

|   |   |
|---|---|
| Name of organization<br><br><b>FSHD SOCIETY</b> | Employer identification number<br><br><b>52-1762747</b> |
|---|---|

**Part I Contributors** (see instructions). Use duplicate copies of Part I if additional space is needed.

| (a)<br>No. | (b)<br>Name, address, and ZIP + 4 | (c)<br>Total contributions | (d)<br>Type of contribution   |
|------------|-----------------------------------|----------------------------|---|
| 1          | <br><hr/><br><hr/><br><hr/>       | \$ <u>129,120.</u>         | Person <input checked="" type="checkbox"/><br>Payroll <input type="checkbox"/><br>Noncash <input type="checkbox"/><br>(Complete Part II for noncash contributions.) |
| 2          | <br><hr/><br><hr/><br><hr/>       | \$ <u>122,715.</u>         | Person <input checked="" type="checkbox"/><br>Payroll <input type="checkbox"/><br>Noncash <input type="checkbox"/><br>(Complete Part II for noncash contributions.) |
| 3          | <br><hr/><br><hr/><br><hr/>       | \$ <u>329,320.</u>         | Person <input checked="" type="checkbox"/><br>Payroll <input type="checkbox"/><br>Noncash <input type="checkbox"/><br>(Complete Part II for noncash contributions.) |
| 4          | <br><hr/><br><hr/><br><hr/>       | \$ <u>232,000.</u>         | Person <input checked="" type="checkbox"/><br>Payroll <input type="checkbox"/><br>Noncash <input type="checkbox"/><br>(Complete Part II for noncash contributions.) |
| 5          | <br><hr/><br><hr/><br><hr/>       | \$ <u>190,000.</u>         | Person <input checked="" type="checkbox"/><br>Payroll <input type="checkbox"/><br>Noncash <input type="checkbox"/><br>(Complete Part II for noncash contributions.) |
| 6          | <br><hr/><br><hr/><br><hr/>       | \$ <u>186,375.</u>         | Person <input checked="" type="checkbox"/><br>Payroll <input type="checkbox"/><br>Noncash <input type="checkbox"/><br>(Complete Part II for noncash contributions.) |

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|   |   |
|---|---|
| Name of organization<br><br><b>FSHD SOCIETY</b> | Employer identification number<br><br><b>52-1762747</b> |
|---|---|

**Part I Contributors** (see instructions). Use duplicate copies of Part I if additional space is needed.

| (a)<br>No.              | (b)<br>Name, address, and ZIP + 4 | (c)<br>Total contributions | (d)<br>Type of contribution   |
|-------------------------|-----------------------------------|----------------------------|---|
| 7                       | <hr/> <hr/> <hr/> <hr/>           | \$ 150,000.                | Person <input checked="" type="checkbox"/><br>Payroll <input type="checkbox"/><br>Noncash <input type="checkbox"/><br>(Complete Part II for noncash contributions.) |
| 8                       | <hr/> <hr/> <hr/> <hr/>           | \$ 955,000.                | Person <input type="checkbox"/><br>Payroll <input type="checkbox"/><br>Noncash <input checked="" type="checkbox"/><br>(Complete Part II for noncash contributions.) |
| <hr/> <hr/> <hr/> <hr/> | <hr/> <hr/> <hr/> <hr/>           | \$ _____                   | Person <input type="checkbox"/><br>Payroll <input type="checkbox"/><br>Noncash <input type="checkbox"/><br>(Complete Part II for noncash contributions.)            |
| <hr/> <hr/> <hr/> <hr/> | <hr/> <hr/> <hr/> <hr/>           | \$ _____                   | Person <input type="checkbox"/><br>Payroll <input type="checkbox"/><br>Noncash <input type="checkbox"/><br>(Complete Part II for noncash contributions.)            |
| <hr/> <hr/> <hr/> <hr/> | <hr/> <hr/> <hr/> <hr/>           | \$ _____                   | Person <input type="checkbox"/><br>Payroll <input type="checkbox"/><br>Noncash <input type="checkbox"/><br>(Complete Part II for noncash contributions.)            |
| <hr/> <hr/> <hr/> <hr/> | <hr/> <hr/> <hr/> <hr/>           | \$ _____                   | Person <input type="checkbox"/><br>Payroll <input type="checkbox"/><br>Noncash <input type="checkbox"/><br>(Complete Part II for noncash contributions.)            |
| <hr/> <hr/> <hr/> <hr/> | <hr/> <hr/> <hr/> <hr/>           | \$ _____                   | Person <input type="checkbox"/><br>Payroll <input type="checkbox"/><br>Noncash <input type="checkbox"/><br>(Complete Part II for noncash contributions.)            |

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|   |   |
|---|---|
| Name of organization<br><b>FSHD SOCIETY</b> | Employer identification number<br><b>52-1762747</b> |
|---|---|

**Part II Noncash Property** (see instructions). Use duplicate copies of Part II if additional space is needed.

| (a)<br>No.<br>from<br>Part I | (b)<br>Description of noncash property given     | (c)<br>FMV (or estimate)<br>(See instructions.) | (d)<br>Date received |
|------------------------------|--|---|----------------------|
| 8                            | INTELLECTUAL PROPERTY<br>_____<br>_____<br>_____ | \$ 955,000.                                     | 12/31/25             |
| _____                        | _____<br>_____<br>_____                          | \$ _____  | _____                |
| _____                        | _____<br>_____<br>_____                          | \$ _____  | _____                |
| _____                        | _____<br>_____<br>_____                          | \$ _____  | _____                |
| _____                        | _____<br>_____<br>_____                          | \$ _____  | _____                |
| _____                        | _____<br>_____<br>_____                          | \$ _____  | _____                |
| _____                        | _____<br>_____<br>_____                          | \$ _____  | _____                |

Public Disclosure Copy

|   |   |
|---|---|
| Name of organization<br><b>FSHD SOCIETY</b> | Employer identification number<br><b>52-1762747</b> |
|---|---|

**Part III** Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of exclusively religious, charitable, etc., contributions of \$1,000 or less for the year. (Enter this info. once.) \$ \_\_\_\_\_  
Use duplicate copies of Part III if additional space is needed.

| (a) No. from Part I                     | (b) Purpose of gift | (c) Use of gift                          | (d) Description of how gift is held |
|---|---------------------|--|-------------------------------------|
|   |                     |  |                                     |
| <b>(e) Transfer of gift</b>             |                     |  |                                     |
| Transferee's name, address, and ZIP + 4 |                     | Relationship of transferor to transferee |                                     |
|   |                     |  |                                     |
|   |                     |  |                                     |
| <b>(e) Transfer of gift</b>             |                     |  |                                     |
| Transferee's name, address, and ZIP + 4 |                     | Relationship of transferor to transferee |                                     |
|   |                     |  |                                     |
|   |                     |  |                                     |
| <b>(e) Transfer of gift</b>             |                     |  |                                     |
| Transferee's name, address, and ZIP + 4 |                     | Relationship of transferor to transferee |                                     |
|   |                     |  |                                     |
|   |                     |  |                                     |
| <b>(e) Transfer of gift</b>             |                     |  |                                     |
| Transferee's name, address, and ZIP + 4 |                     | Relationship of transferor to transferee |                                     |
|   |                     |  |                                     |
|   |                     |  |                                     |
| <b>(e) Transfer of gift</b>             |                     |  |                                     |
| Transferee's name, address, and ZIP + 4 |                     | Relationship of transferor to transferee |                                     |
|   |                     |  |                                     |
|   |                     |  |                                     |
| <b>(e) Transfer of gift</b>             |                     |  |                                     |
| Transferee's name, address, and ZIP + 4 |                     | Relationship of transferor to transferee |                                     |
|   |                     |  |                                     |
|   |                     |  |                                     |

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**SCHEDULE D**  
**(Form 990)**

(Rev. December 2024)  
Department of the Treasury  
Internal Revenue Service

**Supplemental Financial Statements**

Complete if the organization answered "Yes" on Form 990,  
Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.  
Attach to Form 990.

Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**Open to Public  
Inspection**

Name of the organization

**FSHD SOCIETY**

Employer identification number

**52-1762747**

**Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.** Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

|   | (a) Donor advised funds | (b) Funds and other accounts                             |
|---|-------------------------|--|
| 1 Total number at end of year .....   |                         |  |
| 2 Aggregate value of contributions to (during year) .....   |                         |  |
| 3 Aggregate value of grants from (during year) .....  |                         |  |
| 4 Aggregate value at end of year .....  |                         |  |
| 5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? .....  |                         | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? ..... |                         | <input type="checkbox"/> Yes <input type="checkbox"/> No |

**Part II Conservation Easements.** Complete if the organization answered "Yes" on Form 990, Part IV, line 7.

1 Purpose(s) of conservation easements held by the organization (check all that apply).

Preservation of land for public use (for example, recreation or education)  Preservation of a historically important land area

Protection of natural habitat  Preservation of a certified historic structure

Preservation of open space

2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.

|  | Held at the End of the Tax Year |
|--|---------------------------------|
| a Total number of conservation easements .....   | 2a                              |
| b Total acreage restricted by conservation easements .....   | 2b                              |
| c Number of conservation easements on a certified historic structure included on line 2a .....   | 2c                              |
| d Number of conservation easements included on line 2c acquired after July 25, 2006, and not on a historic structure listed in the National Register ..... | 2d                              |

3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year \_\_\_\_\_

4 Number of states where property subject to conservation easement is located \_\_\_\_\_

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? .....

Yes  No

6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year \_\_\_\_\_

7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year \_\_\_\_\_

8 Does each conservation easement reported on line 2d above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? .....

Yes  No

9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.

**Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

1a If the organization elected, as permitted under FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide in Part XIII the text of the footnote to its financial statements that describes these items.

b If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items.

(i) Revenue included on Form 990, Part VIII, line 1 ..... \$ \_\_\_\_\_

(ii) Assets included in Form 990, Part X ..... \$ \_\_\_\_\_

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items:

a Revenue included on Form 990, Part VIII, line 1 ..... \$ \_\_\_\_\_

b Assets included in Form 990, Part X ..... \$ \_\_\_\_\_

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule D (Form 990) (Rev. 12-2024)

LHA 532051 04-01-25

**Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets** (continued)

- 3** Using the organization's acquisition, accession, and other records, check any of the following that make significant use of its collection items (check all that apply).
- a**  Public exhibition
  - b**  Scholarly research
  - c**  Preservation for future generations
  - d**  Loan or exchange program
  - e**  Other \_\_\_\_\_
- 4** Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5** During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?  Yes  No

**Part IV Escrow and Custodial Arrangements** Complete if the organization answered "Yes" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

- 1a** Is the organization an agent, trustee, custodian, or other intermediary for contributions or other assets not included on Form 990, Part X?  Yes  No
- b** If "Yes," explain the arrangement in Part XIII and complete the following table:
- |  | Amount    |
|--|-----------|
| <b>c</b> Beginning balance             | <b>1c</b> |
| <b>d</b> Additions during the year     | <b>1d</b> |
| <b>e</b> Distributions during the year | <b>1e</b> |
| <b>f</b> Ending balance                | <b>1f</b> |
- 2a** Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability?  Yes  No
- b** If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII

**Part V Endowment Funds** Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

|   | (a) Current year | (b) Prior year | (c) Two years back | (d) Three years back | (e) Four years back |
|---|------------------|----------------|--------------------|----------------------|---------------------|
| <b>1a</b> Beginning of year balance                     |                  |                |                    |                      |                     |
| <b>b</b> Contributions                                  |                  |                |                    |                      |                     |
| <b>c</b> Net investment earnings, gains, and losses     |                  |                |                    |                      |                     |
| <b>d</b> Grants or scholarships                         |                  |                |                    |                      |                     |
| <b>e</b> Other expenditures for facilities and programs |                  |                |                    |                      |                     |
| <b>f</b> Administrative expenses                        |                  |                |                    |                      |                     |
| <b>g</b> End of year balance                            |                  |                |                    |                      |                     |

- 2** Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a** Board designated or quasi-endowment \_\_\_\_\_ %
  - b** Permanent endowment \_\_\_\_\_ %
  - c** Term endowment \_\_\_\_\_ %
- The percentages on lines 2a, 2b, and 2c should equal 100%.
- 3a** Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- |   | Yes           | No |
|---|---------------|----|
| <b>(i)</b> Unrelated organizations?   | <b>3a(i)</b>  |    |
| <b>(ii)</b> Related organizations?  | <b>3a(ii)</b> |    |
| <b>b</b> If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R? | <b>3b</b>     |    |
- 4** Describe in Part XIII the intended uses of the organization's endowment funds.

**Part VI Land, Buildings, and Equipment**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

| Description of property   | (a) Cost or other basis (investment) | (b) Cost or other basis (other) | (c) Accumulated depreciation | (d) Book value |
|---|--------------------------------------|---------------------------------|------------------------------|----------------|
| <b>1a</b> Land  |                                      |                                 |                              |                |
| <b>b</b> Buildings  |                                      |                                 |                              |                |
| <b>c</b> Leasehold improvements   |                                      |                                 |                              |                |
| <b>d</b> Equipment  |                                      |                                 |                              |                |
| <b>e</b> Other  |                                      |                                 |                              |                |
| <b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, line 10c, column (B)) |                                      |                                 |                              | 0.             |

**Part VII Investments - Other Securities**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

| (a) Description of security or category (including name of security)    | (b) Book value | (c) Method of valuation: Cost or end-of-year market value |
|---|----------------|---|
| (1) Financial derivatives .....   |                |   |
| (2) Closely held equity interests .....                                 |                |   |
| (3) Other .....   |                |   |
| (A)   |                |   |
| (B)   |                |   |
| (C)   |                |   |
| (D)   |                |   |
| (E)   |                |   |
| (F)   |                |   |
| (G)   |                |   |
| (H)   |                |   |
| <b>Total.</b> (Col. (b) must equal Form 990, Part X, line 12, col. (B)) |                |   |

**Part VIII Investments - Program Related.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

| (a) Description of investment   | (b) Book value | (c) Method of valuation: Cost or end-of-year market value |
|---|----------------|---|
| (1)   |                |   |
| (2)   |                |   |
| (3)   |                |   |
| (4)   |                |   |
| (5)   |                |   |
| (6)   |                |   |
| (7)   |                |   |
| (8)   |                |   |
| (9)   |                |   |
| <b>Total.</b> (Col. (b) must equal Form 990, Part X, line 13, col. (B)) |                |   |

**Part IX Other Assets**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

| (a) Description   | (b) Book value |
|---|----------------|
| (1)   |                |
| (2)   |                |
| (3)   |                |
| (4)   |                |
| (5)   |                |
| (6)   |                |
| (7)   |                |
| (8)   |                |
| (9)   |                |
| <b>Total.</b> (Column (b) must equal Form 990, Part X, line 15, col. (B)) |                |

**Part X Other Liabilities**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

| 1. (a) Description of liability   | (b) Book value  |
|---|-----------------|
| (1) Federal income taxes  |                 |
| (2) <b>DEFERRED COMPENSATION LIABILITY</b>                                | <b>185,044.</b> |
| (3)   |                 |
| (4)   |                 |
| (5)   |                 |
| (6)   |                 |
| (7)   |                 |
| (8)   |                 |
| (9)   |                 |
| <b>Total.</b> (Column (b) must equal Form 990, Part X, line 25, col. (B)) |                 |

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII...



**SCHEDULE F  
(Form 990)**

(Rev. December 2024)  
Department of the Treasury  
Internal Revenue Service

**Statement of Activities Outside the United States**

Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.

Attach to Form 990.

Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

Open to Public Inspection

|   |   |
|---|---|
| Name of the organization<br><b>FSHD SOCIETY</b> | Employer identification number<br><b>52-1762747</b> |
|---|---|

**Part I General Information on Activities Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 14b.

- For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? .....  **Yes**  **No**
- For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.
- Activities per Region. (The following Part I, line 3 table can be duplicated if additional space is needed.)

| (a) Region  | (b) Number of offices in the region | (c) Number of employees, agents, and independent contractors in the region | (d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region) | (e) If activity listed in (d) is a program service, describe specific type of service(s) in the region | (f) Total expenditures for and investments in the region |
|---|-------------------------------------|--|--|--|--|
| EUROPE  | 0                                   | 0  | GRANTS   | N/A  | 181,222.   |
| MIDDLE EAST AND NORTH AFRICA                            | 0                                   | 0  | GRANTS   | N/A  | 34,940.  |
| AUSTRALIA   | 0                                   | 0  | GRANTS   | N/A  | 29,547.  |
| SOUTH AMERICA   | 0                                   | 0  | GRANTS   | N/A  | 14,500.  |
|   |                                     |  |  |  |  |
|   |                                     |  |  |  |  |
|   |                                     |  |  |  |  |
|   |                                     |  |  |  |  |
|   |                                     |  |  |  |  |
| <b>3 a</b> Subtotal .....                               | 0                                   | 0  |  |  | 260,209.   |
| <b>b</b> Total from continuation sheets to Part I ..... | 0                                   | 0  |  |  | 0.   |
| <b>c Totals</b> (add lines 3a and 3b) .....             | 0                                   | 0  |  |  | 260,209.   |

**Part II** Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

| 1<br>(a) Name of organization | (b) IRS code section and EIN (if applicable) | (c) Region                   | (d) Purpose of grant   | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of noncash assistance | (h) Description of noncash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
|-------------------------------|--|------------------------------|--|--------------------------|---------------------------------|----------------------------------|---------------------------------------|---|
|                               |  | EUROPE                       | GENETIC CAUSES AND MODIFIERS OF FSHD   | 55,500.                  | WIRE TRANSFER                   | 0.                               | N/A                                   | BOOK  |
|                               |  | EUROPE                       | A NOVEL THERAPEUTIC PERSPECTIVE FOR FSHD MUSCULAR DYSTROPHY; IMMUNOPATHOGENESIS OF | 77,097.                  | WIRE TRANSFER                   | 0.                               | N/A                                   | BOOK  |
|                               |  | EUROPE                       | A NOVEL BIOMARKER CANDIDATE FOR DUX4-INDUCED TOXICITY IN FSHD                      | 25,000.                  | WIRE TRANSFER                   | 0.                               | N/A                                   | BOOK  |
|                               |  | EUROPE                       | PHARMACOLOGICAL PREVENTION DUX4-MEDIATED MYONECROSIS IN VITRO                      | 23,625.                  | WIRE TRANSFER                   | 0.                               | N/A                                   | BOOK  |
|                               |  | AUSTRALIA                    | INVESTIGATING SMCHD1 FUNCTION TO DEVELOP A THERAPEUTIC STRATEGY FOR FSHD           | 29,547.                  | WIRE TRANSFER                   | 0.                               | N/A                                   | BOOK  |
|                               |  | MIDDLE EAST AND NORTH AFRICA | VERIFIED ALL-ATOM STRUCTURES OF THE DUX4-P300 AND DUX-SIX1 INTERACTION             | 34,940.                  | WIRE TRANSFER                   | 0.                               | N/A                                   | BOOK  |
|                               |  | SOUTH AMERICA                | COREGULATORY ROLE OF DUX4 ON THE HUMAN ESTROGEN NUCLEAR RECEPTORS                  | 14,500.                  | WIRE TRANSFER                   | 0.                               | N/A                                   | BOOK  |
|                               |  | NORTH AMERICA                | FSHD MOUSE TEST ON SILPHION COMPOUND   | 5,000.                   |                                 | 0.                               |                                       |   |

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as a tax exempt 501(c)(3) organization by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter ..... 7

3 Enter total number of other organizations or entities .....

SEE PART V FOR COLUMN (D) DESCRIPTIONS



**Part IV Foreign Forms**

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see the Instructions for Form 926)* .....  Yes  No
  
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see the Instructions for Forms 3520 and 3520-A; don't file with Form 990)* .....  Yes  No
  
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Corporations (see the Instructions for Form 5471)* .....  Yes  No
  
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see the Instructions for Form 8621)* .....  Yes  No
  
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see the Instructions for Form 8865)* .....  Yes  No
  
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see the Instructions for Form 5713; don't file with Form 990)* .....  Yes  No

Schedule F (Form 990) (Rev. 12-2024)

Public Disclosure Copy

**Part V Supplemental Information**

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.

**PART I, LINE 2:**

THE FSHD SOCIETY MONITORS GRANTS AND ASSISTANCE PROVIDED TO INSTITUTIONS OR INDIVIDUALS OUTSIDE THE UNITED STATES THROUGH FORMAL GRANT AGREEMENTS THAT OUTLINE REPORTING REQUIREMENTS, MILESTONES, AND ALLOWABLE EXPENSES. GRANTEES ARE REQUIRED TO SUBMIT PERIODIC FINANCIAL AND NARRATIVE REPORTS DETAILING PROGRESS AND USE OF FUNDS. THE SOCIETY REVIEWS THESE SUBMISSIONS FOR COMPLIANCE AND ALIGNMENT WITH THE GRANT'S PURPOSE. FOR LARGER OR MULTI-YEAR GRANTS, PAYMENTS ARE DISBURSED IN STAGES BASED ON SATISFACTORY REPORTING AND MILESTONE COMPLETION. FURTHER, GRANTEES ARE REQUIRED TO PRESENT THEIR WORK AT THE FSHD SOCIETY'S INTERNATIONAL RESEARCH CONFERENCE (IRC), WHICH SERVES AS AN ADDITIONAL MECHANISM FOR OVERSIGHT AND DISSEMINATION OF OUTCOMES. ALL RECORDS ARE MAINTAINED TO SUBSTANTIATE SELECTION CRITERIA, ELIGIBILITY, AND OVERSIGHT PROCEDURES.

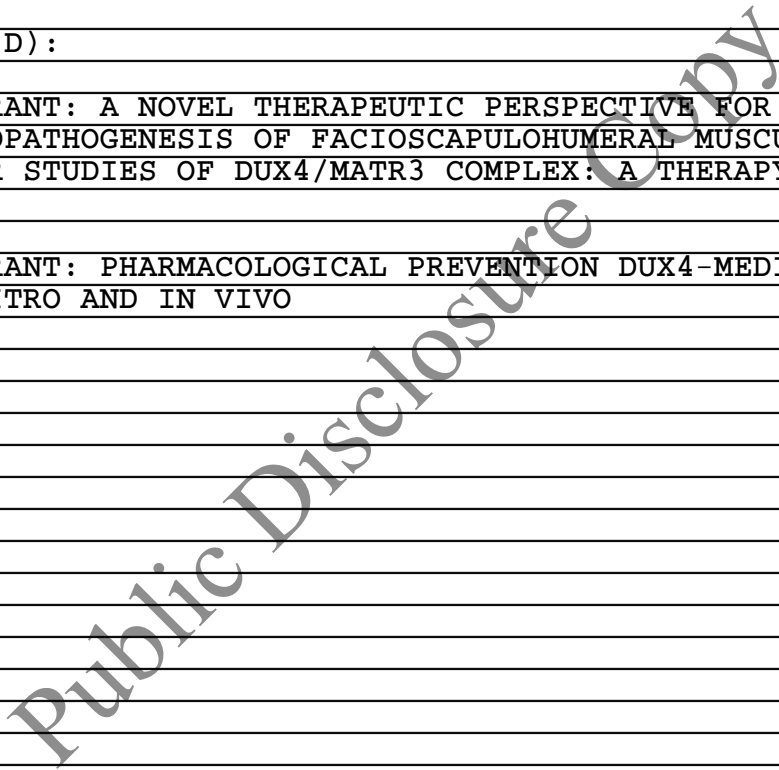
**PART II, COLUMN (D):**

REGION: EUROPE

(D) PURPOSE OF GRANT: A NOVEL THERAPEUTIC PERSPECTIVE FOR FSHD MUSCULAR DYSTROPHY; IMMUNOPATHOGENESIS OF FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY (FSHD); MOLECULAR STUDIES OF DUX4/MATR3 COMPLEX: A THERAPY AGAINST FSHD

REGION: EUROPE

(D) PURPOSE OF GRANT: PHARMACOLOGICAL PREVENTION DUX4-MEDIATED MYONECROSIS IN VITRO AND IN VIVO





**Part II Fundraising Events.** Complete if the organization answered "Yes" on Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

|                 |  | (a) Event #1  | (b) Event #2                 | (c) Other events       | (d) Total events<br>(add col. (a) through<br>col. (c)) |
|-----------------|--|---|------------------------------|------------------------|--|
|                 |  | PEER TO PEER<br>EVENTS<br>(event type)                      | OTHER EVENTS<br>(event type) | NONE<br>(total number) |  |
| Revenue         | 1  | Gross receipts  | 1,118,031.                   | 7,754.                 | 1,125,785.   |
|                 | 2  | Less: Contributions   | 1,041,194.                   | 7,754.                 | 1,048,948.   |
|                 | 3  | Gross income (line 1 minus line 2)                          | 76,837.                      |                        | 76,837.  |
| Direct Expenses | 4  | Cash prizes   | 39,999.                      |                        | 39,999.  |
|                 | 5  | Noncash prizes  |                              |                        |  |
|                 | 6  | Rent/facility costs   | 13,111.                      |                        | 13,111.  |
|                 | 7  | Food and beverages  | 7,107.                       |                        | 7,107.   |
|                 | 8  | Entertainment   | 1,335.                       |                        | 1,335.   |
|                 | 9  | Other direct expenses                                       | 15,285.                      |                        | 15,285.  |
|                 | 10   | Direct expense summary. Add lines 4 through 9 in column (d) |                              |                        | 76,837.  |
| 11              | Net income summary. Subtract line 10 from line 3, column (d) |   |                              | 0.                     |  |

**Part III Gaming.** Complete if the organization answered "Yes" on Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

|                 |   | (a) Bingo  | (b) Pull tabs/instant<br>bingo/progressive bingo                    | (c) Other gaming  | (d) Total gaming (add<br>col. (a) through col. (c))                 |
|-----------------|---|--|---|---|---|
|                 |   |  |   |   |   |
| Revenue         | 1 | Gross revenue  |   |   |   |
| Direct Expenses | 2 | Cash prizes  |   |   |   |
|                 | 3 | Noncash prizes   |   |   |   |
|                 | 4 | Rent/facility costs  |   |   |   |
|                 | 5 | Other direct expenses  |   |   |   |
|                 | 6 | Volunteer labor  | <input type="checkbox"/> Yes _____ %<br><input type="checkbox"/> No | <input type="checkbox"/> Yes _____ %<br><input type="checkbox"/> No | <input type="checkbox"/> Yes _____ %<br><input type="checkbox"/> No |
|                 | 7 | Direct expense summary. Add lines 2 through 5 in column (d)        |   |   |   |
|                 | 8 | Net gaming income summary. Subtract line 7 from line 1, column (d) |   |   |   |

9 Enter the state(s) in which the organization conducts gaming activities: \_\_\_\_\_  
 a Is the organization licensed to conduct gaming activities in each of these states?  Yes  No  
 b If "No," explain: \_\_\_\_\_

10a Were any of the organization's gaming licenses revoked, suspended, or terminated during the tax year?  Yes  No  
 b If "Yes," explain: \_\_\_\_\_



**Part IV** Supplemental Information (continued)

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**SCHEDULE I  
(Form 990)**

(Rev. December 2024)  
Department of the Treasury  
Internal Revenue Service

**Grants and Other Assistance to Organizations,  
Governments, and Individuals in the United States**  
Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.  
Attach to Form 990.  
Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**Open to Public  
Inspection**

Name of the organization **FSHD SOCIETY** Employer identification number **52-1762747**

**Part I General Information on Grants and Assistance**

- 1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?  Yes  No
- 2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

**Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments.** Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

| 1 (a) Name and address of organization or government | (b) EIN    | (c) IRC section (if applicable) | (d) Amount of cash grant | (e) Amount of noncash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of noncash assistance | (h) Purpose of grant or assistance   |
|--|------------|---------------------------------|--------------------------|----------------------------------|---|---------------------------------------|--|
| BAYLOR COLLEGE OF MEDICINE                           | 74-1613878 | 501(C)(3)                       | 42,054.                  | 0.                               | BOOK  | N/A                                   | THE FIBRO-ADIPOGENIC PROGENITORS, THE EXOSOMES, AND THE FSHD MYOPATHY/BAYLOR/SERRA                 |
| UNIVERSITY OF COLORADO DENVER                        | 84-6000555 | 170(C)(1)                       | 25,000.                  | 0.                               | BOOK  | N/A                                   | ROLE OF MISSPLICING AND NEOANTIGEN PRODUCTION IN IMMUNE ACTIVATION IN FSHD-PRAGYAN SINGH           |
| YALE UNIVERSITY                                      | 06-0646973 | 501(C)(3)                       | 31,212.                  | 0.                               | BOOK  | N/A                                   | CHARACTERIZATION OF DUX4-INDUCED METABOLIC AND HYPOXIC CHANGES IN FSHD, YALE UNIVERSITY,           |
| ARVINAS OPERATIONS                                   | 46-3139663 | C-CORP                          | 127,500.                 | 0.                               |   |                                       | LIGAND IDENTIFICATION FOR DUX4 BINDERS TO ENABLE PROTAC DEGRADER DESIGN AS A POTENTIAL THERAPEUTIC |
| UNIVERSITY OF ROCHESTER                              | 16-0743209 | 170(C)(1)                       | 6,305.                   | 0.                               |   |                                       | BIOLOGICAL RESOURCES AVAILABLE THROUGH THE CTRN  |

2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table ..... **2.**

3 Enter total number of other organizations listed in the line 1 table .....

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule I (Form 990) (Rev. 12-2024)

SEE PART IV FOR COLUMN (H) DESCRIPTIONS

**Part III Grants and Other Assistance to Domestic Individuals.** Complete if the organization answered "Yes" on Form 990, Part IV, line 22.  
Part III can be duplicated if additional space is needed.

| (a) Type of grant or assistance | (b) Number of recipients | (c) Amount of cash grant | (d) Amount of non-cash assistance | (e) Method of valuation (book, FMV, appraisal, other) | (f) Description of noncash assistance |
|---------------------------------|--------------------------|--------------------------|-----------------------------------|---|---------------------------------------|
|                                 |                          |                          |                                   |   |                                       |
|                                 |                          |                          |                                   |   |                                       |
|                                 |                          |                          |                                   |   |                                       |
|                                 |                          |                          |                                   |   |                                       |
|                                 |                          |                          |                                   |   |                                       |
|                                 |                          |                          |                                   |   |                                       |

DISCLOSURE COPY

**Part IV Supplemental Information.** Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

**PART I, LINE 2:**

THE FSHD SOCIETY MONITORS GRANTS AND ASSISTANCE PROVIDED TO INSTITUTIONS OR INDIVIDUALS IN THE UNITED STATES THROUGH FORMAL GRANT AGREEMENTS THAT OUTLINE REPORTING REQUIREMENTS, MILESTONES, AND ALLOWABLE EXPENSES. GRANTEES ARE REQUIRED TO SUBMIT PERIODIC FINANCIAL AND NARRATIVE REPORTS DETAILING PROGRESS AND USE OF FUNDS. THE SOCIETY REVIEWS THESE SUBMISSIONS FOR COMPLIANCE AND ALIGNMENT WITH THE GRANT'S PURPOSE. FOR LARGER OR MULTI-YEAR GRANTS, PAYMENTS ARE DISBURSED IN STAGES BASED ON SATISFACTORY REPORTING AND MILESTONE COMPLETION. FURTHER, GRANTEES ARE REQUIRED TO PRESENT THEIR WORK AT THE FSHD SOCIETY'S INTERNATIONAL RESEARCH CONFERENCE (IRC), WHICH SERVES AS AN ADDITIONAL MECHANISM FOR OVERSIGHT AND DISSEMINATION OF OUTCOMES. ALL RECORDS ARE MAINTAINED TO SUBSTANTIATE SELECTION CRITERIA, ELIGIBILITY, AND OVERSIGHT PROCEDURES.

**PART II, LINE 1, COLUMN (H):**

NAME OF ORGANIZATION OR GOVERNMENT: YALE UNIVERSITY  
(H) PURPOSE OF GRANT OR ASSISTANCE: CHARACTERIZATION OF DUX4-INDUCED METABOLIC AND HYPOXIC CHANGES IN FSHD, YALE UNIVERSITY, LEK

**Part IV Supplemental Information**

NAME OF ORGANIZATION OR GOVERNMENT: ARVINAS OPERATIONS  
(H) PURPOSE OF GRANT OR ASSISTANCE: LIGAND IDENTIFICATION FOR DUX4 BINDERS TO ENABLE PROTAC DEGRADER DESIGN AS A POTENTIAL THERAPEUTIC APPROACH TO FSHD DEVELOPMENT PROGRAM

Public Disclosure Copy

**SCHEDULE J  
(Form 990)**

(Rev. December 2024)  
Department of the Treasury  
Internal Revenue Service

**Compensation Information**

For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees  
Complete if the organization answered "Yes" on Form 990, Part IV, line 23.  
Attach to Form 990.  
Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

Open to Public Inspection

Name of the organization **FSHD SOCIETY** Employer identification number **52-1762747**

**Part I Questions Regarding Compensation**

**1a** Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.

- |  |  |
|--|--|
| <input type="checkbox"/> First-class or charter travel             | <input type="checkbox"/> Housing allowance or residence for personal use   |
| <input type="checkbox"/> Travel for companions                     | <input type="checkbox"/> Payments for business use of personal residence   |
| <input type="checkbox"/> Tax indemnification and gross-up payments | <input type="checkbox"/> Health or social club dues or initiation fees     |
| <input type="checkbox"/> Discretionary spending account            | <input type="checkbox"/> Personal services (such as maid, chauffeur, chef) |

**b** If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain

**2** Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a?

**3** Indicate which, if any, of the following the organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III.

- |   |   |
|---|---|
| <input type="checkbox"/> Compensation committee                     | <input type="checkbox"/> Written employment contract                                |
| <input type="checkbox"/> Independent compensation consultant        | <input checked="" type="checkbox"/> Compensation survey or study                    |
| <input checked="" type="checkbox"/> Form 990 of other organizations | <input checked="" type="checkbox"/> Approval by the board or compensation committee |

**4** During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:

- a** Receive a severance payment or change-of-control payment? **4a**  Yes  No
- b** Participate in or receive payment from a supplemental nonqualified retirement plan? **4b**  Yes  No
- c** Participate in or receive payment from an equity-based compensation arrangement? **4c**  Yes  No
- If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.

**Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.**

**5** For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of:

- a** The organization? **5a**  Yes  No
- b** Any related organization? **5b**  Yes  No
- If "Yes" on line 5a or 5b, describe in Part III.

**6** For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of:

- a** The organization? **6a**  Yes  No
- b** Any related organization? **6b**  Yes  No
- If "Yes" on line 6a or 6b, describe in Part III.

**7** For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described on lines 5 and 6? If "Yes," describe in Part III **7**  Yes  No

**8** Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III **8**  Yes  No

**9** If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)? **9**  Yes  No

|           | Yes                                 | No                                  |
|-----------|-------------------------------------|-------------------------------------|
| <b>1b</b> |                                     |                                     |
| <b>2</b>  |                                     |                                     |
| <b>4a</b> |                                     | <input checked="" type="checkbox"/> |
| <b>4b</b> | <input checked="" type="checkbox"/> |                                     |
| <b>4c</b> |                                     | <input checked="" type="checkbox"/> |
| <b>5a</b> | <input checked="" type="checkbox"/> |                                     |
| <b>5b</b> |                                     | <input checked="" type="checkbox"/> |
| <b>6a</b> |                                     | <input checked="" type="checkbox"/> |
| <b>6b</b> |                                     | <input checked="" type="checkbox"/> |
| <b>7</b>  |                                     | <input checked="" type="checkbox"/> |
| <b>8</b>  |                                     | <input checked="" type="checkbox"/> |
| <b>9</b>  |                                     | <input checked="" type="checkbox"/> |

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule J (Form 990) (Rev. 12-2024)

**Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees.** Use duplicate copies if additional space is needed.

For each individual whose compensation must be reported on Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii). Do not list any individuals that aren't listed on Form 990, Part VII.

**Note:** The sum of columns (B)(i)-(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

| (A) Name and Title   |      | (B) Breakdown of W-2 and/or 1099-MISC and/or 1099-NEC compensation |                                     |                                     | (C) Retirement and other deferred compensation | (D) Nontaxable benefits | (E) Total of columns (B)(i)-(D) | (F) Compensation in column (B) reported as deferred on prior Form 990 |
|--|------|--|-------------------------------------|-------------------------------------|--|-------------------------|---------------------------------|---|
|  |      | (i) Base compensation  | (ii) Bonus & incentive compensation | (iii) Other reportable compensation |  |                         |                                 |   |
| (1) MARK STONE<br>CEO & PRESIDENT                            | (i)  | 240,615.   | 0.                                  | 0.                                  | 34,740.  | 1,643.                  | 276,998.                        | 0.  |
|  | (ii) | 0.   | 0.                                  | 0.                                  | 0.   | 0.                      | 0.                              | 0.  |
| (2) AGNES M. MESTRICH<br>CHIEF FINANCIAL OFFICER             | (i)  | 178,435.   | 0.                                  | 0.                                  | 7,897.   | 21,061.                 | 207,393.                        | 0.  |
|  | (ii) | 0.   | 0.                                  | 0.                                  | 0.   | 0.                      | 0.                              | 0.  |
| (3) KENNETH KAHTAVA<br>CHIEF OPERATING OFFICER               | (i)  | 139,336.   | 0.                                  | 0.                                  | 6,591.   | 16,548.                 | 162,475.                        | 0.  |
|  | (ii) | 0.   | 0.                                  | 0.                                  | 0.   | 0.                      | 0.                              | 0.  |
| (4) ELIZABETH JOHNSTON<br>CHIEF COMMUNITY ENGAGEMENT OFFICER | (i)  | 153,537.   | 0.                                  | 0.                                  | 6,678.   | 1,278.                  | 161,493.                        | 0.  |
|  | (ii) | 0.   | 0.                                  | 0.                                  | 0.   | 0.                      | 0.                              | 0.  |
| (5) AMANDA HILL<br>SENIOR DIRECTOR OF RESEARCH AND CARE      | (i)  | 132,447.   | 0.                                  | 0.                                  | 5,608.   | 20,371.                 | 158,426.                        | 0.  |
|  | (ii) | 0.   | 0.                                  | 0.                                  | 0.   | 0.                      | 0.                              | 0.  |
| (6) ANNA GILMORE<br>CHIEF PROGRAMS OFFICER                   | (i)  | 116,883.   | 0.                                  | 0.                                  | 4,887.   | 29,603.                 | 151,373.                        | 0.  |
|  | (ii) | 0.   | 0.                                  | 0.                                  | 0.   | 0.                      | 0.                              | 0.  |
|  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|  | (ii) |  |                                     |                                     |  |                         |                                 |   |
|  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|  | (ii) |  |                                     |                                     |  |                         |                                 |   |
|  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|  | (ii) |  |                                     |                                     |  |                         |                                 |   |
|  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|  | (ii) |  |                                     |                                     |  |                         |                                 |   |
|  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|  | (ii) |  |                                     |                                     |  |                         |                                 |   |
|  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|  | (ii) |  |                                     |                                     |  |                         |                                 |   |
|  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|  | (ii) |  |                                     |                                     |  |                         |                                 |   |

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**SCHEDULE M  
(Form 990)**

**Noncash Contributions**

OMB No. 1545-0047

**2025**

Open to Public Inspection

Department of the Treasury  
Internal Revenue Service

Complete if the organizations answered "Yes" on Form 990, Part IV, line 29 or 30.  
Attach to Form 990.

Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

Name of the organization: **FSHD SOCIETY** Employer identification number: **52-1762747**

**Part I Types of Property**

|  | (a)<br>Check if applicable | (b)<br>Number of contributions or items contributed | (c)<br>Noncash contribution amounts reported on Form 990, Part VIII, line 1g | (d)<br>Method of determining noncash contribution amounts |
|--|----------------------------|---|--|---|
| 1 Art - Works of art   |                            |   |  |   |
| 2 Art - Historical treasures                                 |                            |   |  |   |
| 3 Art - Fractional interests                                 |                            |   |  |   |
| 4 Books and publications                                     |                            |   |  |   |
| 5 Clothing and household goods                               |                            |   |  |   |
| 6 Cars and other vehicles                                    |                            |   |  |   |
| 7 Boats and planes   |                            |   |  |   |
| 8 Intellectual property                                      | X                          | 1   | 955,000.FMV  |   |
| 9 Securities - Publicly traded                               |                            |   |  |   |
| 10 Securities - Closely held stock                           |                            |   |  |   |
| 11 Securities - Partnership, LLC, or trust interests         |                            |   |  |   |
| 12 Securities - Miscellaneous                                |                            |   |  |   |
| 13 Qualified conservation contribution - Historic structures |                            |   |  |   |
| 14 Qualified conservation contribution - Other               |                            |   |  |   |
| 15 Real estate - Residential                                 |                            |   |  |   |
| 16 Real estate - Commercial                                  |                            |   |  |   |
| 17 Real estate - Other                                       |                            |   |  |   |
| 18 Collectibles  |                            |   |  |   |
| 19 Food inventory  |                            |   |  |   |
| 20 Drugs and medical supplies                                |                            |   |  |   |
| 21 Taxidermy   |                            |   |  |   |
| 22 Historical artifacts                                      |                            |   |  |   |
| 23 Scientific specimens                                      |                            |   |  |   |
| 24 Archeological artifacts                                   |                            |   |  |   |
| 25 Other ( )   |                            |   |  |   |
| 26 Other ( )   |                            |   |  |   |
| 27 Other ( )   |                            |   |  |   |
| 28 Other ( )   |                            |   |  |   |

29 Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part V, Donee Acknowledgment **29**

|   | Yes | No |
|---|-----|----|
| 30a During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least 3 years from the date of the initial contribution, and which isn't required to be used for exempt purposes for the entire holding period? |     | X  |
| b If "Yes," describe the arrangement in Part II.  |     |    |
| 31 Does the organization have a gift acceptance policy that requires the review of any nonstandard contributions?   |     | X  |
| 32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?  |     | X  |
| b If "Yes," describe in Part II.  |     |    |
| 33 If the organization didn't report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II.   |     |    |

For Paperwork Reduction Act Notice, see the Instructions for Form 990. Schedule M (Form 990) 2025 Created 12/29/25

**Part II** **Supplemental Information.** Provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also, complete this part for any additional information.

Lined area for supplemental information.

Public Disclosure Copy

**SCHEDULE O  
(Form 990)**

(Rev. December 2024)  
Department of the Treasury  
Internal Revenue Service

**Supplemental Information to Form 990 or 990-EZ**

Complete to provide information for responses to specific questions on  
Form 990 or 990-EZ or to provide any additional information.  
Attach to Form 990 or Form 990-EZ.  
Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

Open to Public  
Inspection

|   |   |
|---|---|
| Name of the organization<br><b>FSHD SOCIETY</b> | Employer identification number<br><b>52-1762747</b> |
|---|---|

**FORM 990, PART III, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:**

NO ONE SHOULD FACE FSHD ALONE. THE FSHD SOCIETY IS DEDICATED TO ACCELERATING RESEARCH TOWARD TREATMENTS AND A CURE WHILE SUPPORTING INDIVIDUALS AND FAMILIES EVERY DAY. THIS VITAL WORK IS MADE POSSIBLE THROUGH THE GENEROSITY OF OUR COMMUNITY - PATIENTS, FAMILIES, VOLUNTEERS, AND DONORS WHO SHARE OUR VISION OF A WORLD WITHOUT FSHD.

**FORM 990, PART III, LINE 4A, PROGRAM SERVICE ACCOMPLISHMENTS:**

**FUNDING RESEARCH: SUPPORTING GROUNDBREAKING STUDIES THAT MOVE TREATMENTS FROM THE LAB TO REAL LIFE.**

**INTERNATIONAL COLLABORATION: CONVENING GLOBAL EXPERTS TO SHARE DISCOVERIES AND SET RESEARCH PRIORITIES.**

**FORM 990, PART VI, SECTION B, LINE 11B:  
THE BOARD OF DIRECTORS REVIEWS THE FORM 990 PRIOR TO ITS FILING. THE FORM 990 IS THEN AUTHORIZED AND SIGNED BY THE SOCIETY'S PRESIDENT & CEO.**

**FORM 990, PART VI, SECTION B, LINE 12C:  
THE ORGANIZATION MAINTAINS A WRITTEN CONFLICT OF INTEREST POLICY APPLICABLE TO OFFICERS, DIRECTORS, AND KEY EMPLOYEES. ON AN ANNUAL BASIS, COVERED INDIVIDUALS ARE REQUIRED TO COMPLETE A WRITTEN DISCLOSURE IDENTIFYING ANY ACTUAL OR POTENTIAL CONFLICTS OF INTEREST. DISCLOSURES ARE REVIEWED BY MANAGEMENT AND/OR THE GOVERNING BODY, AS APPROPRIATE. WHEN A POTENTIAL OR ACTUAL CONFLICT IS IDENTIFIED, THE INDIVIDUAL IS REQUIRED TO RECUSE THEMSELVES FROM ANY DISCUSSION OR VOTE RELATED TO THE MATTER, AND THE GOVERNING BODY DETERMINES WHETHER THE TRANSACTION OR ARRANGEMENT IS FAIR, REASONABLE, AND IN THE BEST INTERESTS OF THE ORGANIZATION. COMPLIANCE WITH THE POLICY IS MONITORED THROUGHOUT THE YEAR.**

**FORM 990, PART VI, SECTION B, LINE 15:  
THE ORGANIZATION'S BOARD OF DIRECTORS REVIEWS AND APPROVES THE COMPENSATION OF THE OFFICERS. THE BOARD IS RESPONSIBLE FOR ESTABLISHING AND MAINTAINING A COMPETITIVE COMPENSATION PROGRAM FOR THE KEY EXECUTIVES OF THE ORGANIZATION. THE BOARD MEETS AS NEEDED TO REVIEW THE COMPENSATION POGRAM AND MAKES RECOMENDATIONS FOR ANY CHANGES. THE REVIEW PROCESS INCLUDES CONSIDERATION OF COMPARABILITY DATA, SUCH AS COMPENSATION SURVEYS OR DATA FROM SIMILARLY SITUATED ORGANIZATIONS. THE GOVERNING BODY DOCUMENTS THE BASIS FOR ITS DECISIONS AT THE TIME COMPENSATION IS APPROVED.**

**FORM 990, PART VI, SECTION C, LINE 18:  
THE FORM 990 IS AVAILABLE ON THE SOCIETY'S WEBSITE, UPON REQUEST, AND ON THIRD PARTY WEBSITES.**

**FORM 990, PART VI, SECTION C, LINE 19:  
GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY, AND FINANCIAL STATEMENTS ARE AVAILABLE UPON REQUEST.**

**FORM 990, PART IX, LINE 11G, OTHER FEES:  
CONSULTANTS :**

For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule O (Form 990) (Rev. 12-2024)

LHA 532211 04-01-25

|  |              |                                |            |
|--|--------------|--------------------------------|------------|
| Name of the organization                               | FSHD SOCIETY | Employer identification number | 52-1762747 |
| PROGRAM SERVICE EXPENSES                               |              |                                | 1,070,953. |
| MANAGEMENT AND GENERAL EXPENSES                        |              |                                | 11,007.    |
| FUNDRAISING EXPENSES                                   |              |                                | 0.         |
| TOTAL EXPENSES   |              |                                | 1,081,960. |
| TOTAL OTHER FEES ON FORM 990, PART IX, LINE 11G, COL A |              |                                | 1,081,960. |

Public Disclosure Copy

**SCHEDULE R  
(Form 990)**

(Rev. January 2025)

Department of the Treasury  
Internal Revenue Service

**Related Organizations and Unrelated Partnerships**  
Complete if the organization answered "Yes" on Form 990, Part IV, line 33, 34, 35b, 36, or 37.  
Attach to Form 990.

Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**Open to Public  
Inspection**

Name of the organization **FSDH SOCIETY** Employer identification number **52-1762747**

**Part I Identification of Disregarded Entities.** Complete if the organization answered "Yes" on Form 990, Part IV, line 33.

| (a)<br>Name, address, and EIN (if applicable)<br>of disregarded entity                             | (b)<br>Primary activity | (c)<br>Legal domicile (state or<br>foreign country) | (d)<br>Total income | (e)<br>End-of-year assets | (f)<br>Direct controlling<br>entity |
|--|-------------------------|---|---------------------|---------------------------|-------------------------------------|
| FSDH GLOBAL INNOVATION HUB, LLC - 99-5019057<br>75 N. MAIN STREET SUITE 1073<br>RANDOLPH, MA 02368 | CLINICAL TRIAL CAPACITY | MASSACHUSETTS                                       | 231,807.            | 337,262.                  | FSDH SOCIETY                        |
|  |                         |   |                     |                           |                                     |
|  |                         |   |                     |                           |                                     |
|  |                         |   |                     |                           |                                     |
|  |                         |   |                     |                           |                                     |
|  |                         |   |                     |                           |                                     |
|  |                         |   |                     |                           |                                     |
|  |                         |   |                     |                           |                                     |
|  |                         |   |                     |                           |                                     |
|  |                         |   |                     |                           |                                     |

**Part II Identification of Related Tax-Exempt Organizations.** Complete if the organization answered "Yes" on Form 990, Part IV, line 34, because it had one or more related tax-exempt organizations during the tax year.

| (a)<br>Name, address, and EIN<br>of related organization | (b)<br>Primary activity | (c)<br>Legal domicile (state or<br>foreign country) | (d)<br>Exempt Code<br>section | (e)<br>Public charity<br>status (if section<br>501(c)(3)) | (f)<br>Direct controlling<br>entity | (g)<br>Section 512(b)(13)<br>controlled<br>entity? |    |
|--|-------------------------|---|-------------------------------|---|-------------------------------------|--|----|
|  |                         |   |                               |   |                                     | Yes  | No |
|  |                         |   |                               |   |                                     |  |    |
|  |                         |   |                               |   |                                     |  |    |
|  |                         |   |                               |   |                                     |  |    |
|  |                         |   |                               |   |                                     |  |    |
|  |                         |   |                               |   |                                     |  |    |
|  |                         |   |                               |   |                                     |  |    |
|  |                         |   |                               |   |                                     |  |    |
|  |                         |   |                               |   |                                     |  |    |
|  |                         |   |                               |   |                                     |  |    |
|  |                         |   |                               |   |                                     |  |    |

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule R (Form 990) (Rev. 1-2025)



**Part V Transactions With Related Organizations.** Complete if the organization answered "Yes" on Form 990, Part IV, line 34, 35b, or 36.

**Note:** Complete line 1 if any entity is listed in Parts II, III, or IV of this schedule.

**1** During the tax year, did the organization engage in any of the following transactions with one or more related organizations listed in Parts II-IV?

|  | Yes       | No |
|--|-----------|----|
| <b>a</b> Receipt of <b>(i)</b> interest, <b>(ii)</b> annuities, <b>(iii)</b> royalties, or <b>(iv)</b> rent from a controlled entity ..... | <b>1a</b> |    |
| <b>b</b> Gift, grant, or capital contribution to related organization(s) .....   | <b>1b</b> |    |
| <b>c</b> Gift, grant, or capital contribution from related organization(s) .....   | <b>1c</b> |    |
| <b>d</b> Loans or loan guarantees to or for related organization(s) .....  | <b>1d</b> |    |
| <b>e</b> Loans or loan guarantees by related organization(s) .....   | <b>1e</b> |    |
| <b>f</b> Dividends from related organization(s) .....  | <b>1f</b> |    |
| <b>g</b> Sale of assets to related organization(s) .....   | <b>1g</b> |    |
| <b>h</b> Purchase of assets from related organization(s) .....   | <b>1h</b> |    |
| <b>i</b> Exchange of assets with related organization(s) .....   | <b>1i</b> |    |
| <b>j</b> Lease of facilities, equipment, or other assets to related organization(s) .....  | <b>1j</b> |    |
| <b>k</b> Lease of facilities, equipment, or other assets from related organization(s) .....  | <b>1k</b> |    |
| <b>l</b> Performance of services or membership or fundraising solicitations for related organization(s) .....                              | <b>1l</b> |    |
| <b>m</b> Performance of services or membership or fundraising solicitations by related organization(s) .....                               | <b>1m</b> |    |
| <b>n</b> Sharing of facilities, equipment, mailing lists, or other assets with related organization(s) .....                               | <b>1n</b> |    |
| <b>o</b> Sharing of paid employees with related organization(s) .....  | <b>1o</b> |    |
| <b>p</b> Reimbursement paid to related organization(s) for expenses .....  | <b>1p</b> |    |
| <b>q</b> Reimbursement paid by related organization(s) for expenses .....  | <b>1q</b> |    |
| <b>r</b> Other transfer of cash or property to related organization(s) .....   | <b>1r</b> |    |
| <b>s</b> Other transfer of cash or property from related organization(s) .....   | <b>1s</b> |    |

**2** If the answer to any of the above is "Yes," see the instructions for information on who must complete this line, including covered relationships and transaction thresholds.

|     | (a)<br>Name of related organization | (b)<br>Transaction type (a-s) | (c)<br>Amount involved | (d)<br>Method of determining amount involved |
|-----|-------------------------------------|-------------------------------|------------------------|--|
| (1) |                                     |                               |                        |  |
| (2) |                                     |                               |                        |  |
| (3) |                                     |                               |                        |  |
| (4) |                                     |                               |                        |  |
| (5) |                                     |                               |                        |  |
| (6) |                                     |                               |                        |  |





**Application for Extension of Time To File an Exempt Organization  
Return or Excise Taxes Related to Employee Benefit Plans**

Department of the Treasury  
Internal Revenue Service

File a separate application for each return.  
Go to [www.irs.gov/Form8868](http://www.irs.gov/Form8868) for the latest information.

**Electronic filing (e-file).** You can electronically file Form 8868 to request up to a 6-month extension of time to file any of the forms listed below except for Form 8870, Information Return for Transfers Associated With Certain Personal Benefit Contracts. An extension request for Form 8870 must be sent to the IRS in a paper format (see instructions). For more details on the electronic filing of Form 8868, visit [www.irs.gov/e-file-providers/e-file-for-charities-and-non-profits](http://www.irs.gov/e-file-providers/e-file-for-charities-and-non-profits).

**Caution:** If you are going to make an electronic funds withdrawal (direct debit) with this Form 8868, see Form 8453-TE and Form 8879-TE for payment instructions.

All corporations required to file an income tax return other than Form 990-T (including 1120-C filers), partnerships, REMICs, and trusts must use Form 7004 to request an extension of time to file income tax returns.

**Part I - Identification**

|  |   |   |
|--|---|---|
| <b>Type or Print</b>   | Name of exempt organization, employer, or other filer, see instructions.<br><b>FSHD SOCIETY</b>                       | Taxpayer identification number (TIN)<br><b>52-1762747</b> |
| File by the due date for filing your return. See instructions. | Number, street, and room or suite no. If a P.O. box, see instructions.<br><b>75 NORTH MAIN STREET 1073</b>            |   |
|  | City, town or post office, state, and ZIP code. For a foreign address, see instructions.<br><b>RANDOLPH, MA 02368</b> |   |

Enter the Return Code for the return that this application is for (file a separate application for each return) 01

| Application Is For                       | Return Code | Application Is For                 | Return Code |
|--|-------------|------------------------------------|-------------|
| Form 990 or Form 990-EZ                  | 01          | Form 4720 (other than individual)  | 09          |
| Form 4720 (individual)                   | 03          | Form 5227                          | 10          |
| Form 990-PF                              | 04          | Form 6069                          | 11          |
| Form 990-T (sec. 401(a) or 408(a) trust) | 05          | Form 8870                          | 12          |
| Form 990-T (trust other than above)      | 06          | Form 5330 (individual)             | 13          |
| Form 990-T (corporation)                 | 07          | Form 5330 (other than individual)  | 14          |
| Form 1041-A                              | 08          | Form 990-T (governmental entities) | 15          |

• After you enter your Return Code, complete either Part II or Part III. Part III, including signature, is applicable only for an extension of time to file Form 5330.

• If this application is for an extension of time to file Form 5330, you must enter the following information.

Plan Name \_\_\_\_\_  
Plan Number \_\_\_\_\_  
Plan Year Ending (MM/DD/YYYY) \_\_\_\_\_

**Part II - Automatic Extension of Time To File for Exempt Organizations (see instructions)**

The books are in the care of **THE ORGANIZATION**  
**75 NORTH MAIN STREET 1073 - RANDOLPH, MA 02368**

Telephone No. **781-301-6060** Fax No. \_\_\_\_\_

- If the organization does not have an office or place of business in the United States, check this box
- If this is for a Group Return, enter the organization's four-digit Group Exemption Number (GEN) \_\_\_\_\_. If this is for the whole group, check this box . If it is for part of the group, check this box  and attach a list with the names and TINs of all members the extension is for.

**1** I request an automatic 6-month extension of time until **NOVEMBER 15**, 20 **26**, to file the exempt organization return for the organization named above. The extension is for the organization's return for:  
 calendar year 20 **25** or  
 tax year beginning \_\_\_\_\_, 20 \_\_\_\_\_, and ending \_\_\_\_\_, 20 \_\_\_\_\_

**2** If the tax year entered in line 1 is for less than 12 months, check reason:  Initial return  Final return  
 Change in accounting period

|   |           |    |    |
|---|-----------|----|----|
| <b>3a</b> If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less any nonrefundable credits. See instructions.   | <b>3a</b> | \$ | 0. |
| <b>b</b> If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit. | <b>3b</b> | \$ | 0. |
| <b>c Balance due.</b> Subtract line 3b from line 3a. Include your payment with this form, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions.              | <b>3c</b> | \$ | 0. |

**For Privacy Act and Paperwork Reduction Act Notice, see instructions.**