

Form **990**Department of the Treasury
Internal Revenue Service**Return of Organization Exempt From Income Tax**
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 for instructions and the latest information.

OMB No. 1545-0047

2020**Open to Public
Inspection****A For the 2020 calendar year, or tax year beginning and ending****B** Check if applicable:

- ☒ Address change
☐ Name change
☐ Initial return
☐ Final return/terminated
☐ Amended return
☐ Application pending

C Name of organization**F**SHD SOCIETY

Doing business as

Number and street (or P.O. box if mail is not delivered to street address)

75 NORTH MAIN STREET

Room/suite
1073

City or town, state or province, country, and ZIP or foreign postal code

RANDOLPH, MA 02368

F Name and address of principal officer: **MARK A. STONE**
SAME AS C ABOVE**D** Employer identification number

52-1762747

E Telephone number
(781) 301-6060**G** Gross receipts \$ 3,763,348.**H(a)** Is this a group returnfor subordinates? ☐ Yes ☒ No**H(b)** Are all subordinates included? ☐ Yes ☐ No

If "No," attach a list. See instructions

H(c) 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**

Activities & Governance	1 Briefly describe the organization's mission or most significant activities: INCREASE AWARENESS OF & CONDUCT RESEARCH ON FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY.		
	2 Check this box ☐ if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	3 Number of voting members of the governing body (Part VI, line 1a)	3	17
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	17
	5 Total number of individuals employed in calendar year 2020 (Part V, line 2a)	5	14
	6 Total number of volunteers (estimate if necessary)	6	99
	7a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0.
b Net unrelated business taxable income from Form 990-T, Part I, line 11	7b	0.	
Revenue	8 Contributions and grants (Part VIII, line 1h)	Prior Year 4,942,896.	Current Year 2,272,171.
	9 Program service revenue (Part VIII, line 2g)	202,448.	158,395.
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	116,332.	196,112.
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	6,840.	527.
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	5,268,516.	2,627,205.
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	974,862.	625,018.
	14 Benefits paid to or for members (Part IX, column (A), line 4)	0.	0.
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	1,446,749.	1,622,282.
	16a Professional fundraising fees (Part IX, column (A), line 11e)	0.	0.
	b Total fundraising expenses (Part IX, column (D), line 25) ▶ 439,375.		
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	818,749.	617,504.	
18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	3,240,360.	2,864,804.	
19 Revenue less expenses. Subtract line 18 from line 12	2,028,156.	-237,599.	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year 6,492,466.	End of Year 5,835,495.
	21 Total liabilities (Part X, line 26)	775,028.	301,823.
	22 Net assets or fund balances. Subtract line 21 from line 20	5,717,438.	5,533,672.

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.

Sign Here	<i>Mark Stone</i> Signature of officer	03/29/2021 Date			
	MARK A. STONE, CEO & PRESIDENT Type or print name and title				
Paid Preparer Use Only	Print/Type preparer's name SANDRA M. BROWN, CPA	Preparer's signature <i>Sandra M. Brown</i>	Date 03/29/21	Check if self-employed ☐	PTIN P00296843
	Firm's name ▶ SMITH, SULLIVAN & BROWN, P.C.	Firm's EIN ▶ 43-1985162			
	Firm's address ▶ 80 FLANDERS ROAD - SUITE #200 WESTBOROUGH, MA 01581	Phone no. (508) 871-7178			

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

Part III Statement of Program Service AccomplishmentsCheck if Schedule O contains a response or note to any line in this Part III ☐**1** Briefly describe the organization's mission:**INCREASE AWARENESS, UNDERSTANDING OF AND CONDUCT RESEARCH ON FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY.****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 ☒ No

If "Yes," describe these new services on Schedule O.

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

If "Yes," describe these changes on Schedule O.

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.**4a** (Code:) (Expenses \$ 1,304,707. including grants of \$ 625,018.) (Revenue \$ 99,420.)
RESEARCH**THE SOCIETY SEEKS TO ACCELERATE RESEARCH TO EXPEDITE TREATMENTS AND A CURE FOR FSHD MUSCULAR DYSTROPHY. ORGANIZING AND FUNDING RESEARCH INTO THE CAUSES OF FSHD, AND, ULTIMATELY DEVELOPING TREATMENTS AND A CURE, IS THE SOCIETY'S CORE MISSION.****4b** (Code:) (Expenses \$ 809,421. including grants of \$ 0.) (Revenue \$ 58,975.)
PATIENT ADVOCACY AND EDUCATION**THE SOCIETY SEEKS TO ENLARGE, ENGAGE, & EMPOWER AN ACTIVE GLOBAL COMMUNITY. THE FSHD SOCIETY'S PATIENT ADVOCACY AND EDUCATION PROGRAMS DIRECTLY BENEFIT PATIENTS AND THEIR FAMILIES BY CONNECTING FSHD MUSCULAR DYSTROPHY PATIENTS AND FAMILIES TO HEALTHCARE PROVIDERS, RESEARCH INSTITUTIONS, AND SUPPORT GROUPS, PROVIDING HIGH-QUALITY EDUCATIONAL MATERIALS, ORGANIZING EDUCATIONAL MEETINGS AND CONFERENCES, AND CREATING OPPORTUNITIES AND SUPPORT FOR ADVOCACY AND RAISING PUBLIC AWARENESS.****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 **2,114,128.**

Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A</i>	1 X	
2 Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ?	2 X	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i>	3	X
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II</i>	4	X
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? <i>If "Yes," complete Schedule C, Part III</i>	5	X
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I</i>	6 X	
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i>	7	X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i>	8	X
9 Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV</i>	9	X
10 Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi endowments? <i>If "Yes," complete Schedule D, Part V</i>	10	X
11 If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI</i>	11a X	
b Did the organization report an amount for investments - other securities in Part X, line 12, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII</i>	11b	X
c Did the organization report an amount for investments - program related in Part X, line 13, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII</i>	11c	X
d Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX</i>	11d	X
e Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i>	11e X	
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i>	11f	X
12a Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i>	12a X	
b Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i>	12b	X
13 Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>	13	X
14a Did the organization maintain an office, employees, or agents outside of the United States?	14a	X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV</i>	14b X	
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV</i>	15 X	
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV</i>	16	X
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I</i>	17	X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II</i>	18 X	
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i>	19	X
20a Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>	20a	X
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b	
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21 X	

Part IV Checklist of Required Schedules (continued)

	Yes	No
22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III		X
23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes," complete Schedule J	X	
24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a		X
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		
25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I		X
b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If "Yes," complete Schedule L, Part I		X
26 Did the organization report any amount on Part X, line 5 or 22, for receivables from or 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? If "Yes," complete Schedule L, Part II		X
27 Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? If "Yes," complete Schedule L, Part III		X
28 Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions, for applicable filing thresholds, conditions, and exceptions):		
a A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If "Yes," complete Schedule L, Part IV		X
b A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV		X
c A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? If "Yes," complete Schedule L, Part IV		X
29 Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	X	
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If "Yes," complete Schedule M		X
31 Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I		X
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete Schedule N, Part II		X
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I		X
34 Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1		X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2		
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? If "Yes," complete Schedule R, Part V, line 2		X
37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI		X
38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19?	X	

Note: All Form 990 filers are required to complete Schedule O

Part V Statements Regarding Other IRS Filings and Tax ComplianceCheck if Schedule O contains a response or note to any line in this Part V ☐

	Yes	No
1a Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable		
b Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable		
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?		

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

		Yes	No
2a Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return	2a 14		
b If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b	X	
Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)			
3a Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a		X
b If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O	3b		
4a At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4a		X
b If "Yes," enter the name of the foreign country			
See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).			
5a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a		X
b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b		X
c If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c		
6a Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?	6a		X
b If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b		
7 Organizations that may receive deductible contributions under section 170(c).			
a Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7a		X
b If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b		
c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c		X
d If "Yes," indicate the number of Forms 8282 filed during the year	7d		
e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e		X
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f		X
g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g		
h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7h		
8 Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?	8		X
9 Sponsoring organizations maintaining donor advised funds.			
a Did the sponsoring organization make any taxable distributions under section 4966?	9a		X
b Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9b		X
10 Section 501(c)(7) organizations. Enter:			
a Initiation fees and capital contributions included on Part VIII, line 12	10a		
b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b		
11 Section 501(c)(12) organizations. Enter:			
a Gross income from members or shareholders	11a		
b Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)	11b		
12a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a		
b If "Yes," enter the amount of tax-exempt interest received or accrued during the year	12b		
13 Section 501(c)(29) qualified nonprofit health insurance issuers.			
a Is the organization licensed to issue qualified health plans in more than one state?	13a		
Note: See the instructions for additional information the organization must report on Schedule O.			
b Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans	13b		
c Enter the amount of reserves on hand	13c		
14a Did the organization receive any payments for indoor tanning services during the tax year?	14a		X
b If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O	14b		
15 Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year?	15		X
If "Yes," see instructions and file Form 4720, Schedule N.			
16 Is the organization an educational institution subject to the section 4968 excise tax on net investment income?	16		X
If "Yes," complete Form 4720, Schedule O.			

Form 990 (2020)

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

☒**Section A. Governing Body and Management**

	Yes	No
1a Enter the number of voting members of the governing body at the end of the tax year 1a 17 If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain on Schedule O.		
b Enter the number of voting members included on line 1a, above, who are independent 1b 17		
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? 2	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? 3		X
4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? 4		X
5 Did the organization become aware during the year of a significant diversion of the organization's assets? 5		X
6 Did the organization have members or stockholders? 6		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? 7a		X
b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? 7b		X
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a The governing body? 8a	X	
b Each committee with authority to act on behalf of the governing body? 8b	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 9		X

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

	Yes	No
10a Did the organization have local chapters, branches, or affiliates? 10a	X	
b 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? 10b	X	
11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? 11a	X	
b Describe in 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 12a	X	
b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? 12b	X	
c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done 12c	X	
13 Did the organization have a written whistleblower policy? 13	X	
14 Did the organization have a written document retention and destruction policy? 14	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 15a	X	
b Other officers or key employees of the organization 15b	X	
If "Yes" to line 15a or 15b, describe the process in 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? 16a	X	
b 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? 16b	X	

Section C. Disclosure

17 List the states with which a copy of this Form 990 is required to be filed ► **MA, AK, AR, CA, CO, CT, DC, FL, GA, HI, IL, KS**

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.
☒ Own website ☒ Another's website ☒ 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 ►
LISA SCHIMMEL - (781) 301-6060
75 NORTH MAIN STREET, NO. 1073, RANDOLPH, MA 02368

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent ContractorsCheck 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 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 and/or Box 7 of Form 1099-MISC) 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 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) Name and title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) 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 CEO & PRESIDENT	40.00			X				206,719.	0.	47,176.
(2) JAMSHID ARJOMAND CHIEF SCIENCE OFFICER	40.00				X			188,883.	0.	27,620.
(3) LISA SCHIMMEL CFO	30.00			X				111,991.	0.	27,919.
(4) BETH JOHNSTON CHIEF COMMUNITY ENGAGEMENT	40.00				X			117,550.	0.	6,491.
(5) JUNE KINOSHITA DIRECTOR OF RESEARCH AND PATIENT ENG	40.00				X			101,000.	0.	5,620.
(6) JAMES A. CHIN, SR. CHAIRMAN	10.00	X		X				0.	0.	0.
(7) HOWARD L. CHABNER, J.D. VICE CHAIRMAN	10.00	X		X				0.	0.	0.
(8) CHRISTINE FORD SECRETARY	10.00	X		X				0.	0.	0.
(9) ELLEN K. HANNAN TREASURER	10.00	X		X				0.	0.	0.
(10) AMY Z. BEKIER BOARD MEMBER	10.00	X						0.	0.	0.
(11) DAVID J. GLASS, M.D. FORMER BOARD MEMBER	1.00	X						0.	0.	0.
(12) STUART LAI BOARD MEMBER	1.00	X						0.	0.	0.
(13) DAVID RUBIN BOARD MEMBER	1.00	X						0.	0.	0.
(14) WILLIAM R. LEWIS, III, M.D. BOARD MEMBER	1.00	X						0.	0.	0.
(15) MICHELLE HELEN MACKAY BOARD MEMBER	1.00	X						0.	0.	0.
(16) LEE FRANK KOLAKOWSKI, PH.D. BOARD MEMBER	10.00	X						0.	0.	0.
(17) LINDA LAURELLO BOARD MEMBER	1.00	X						0.	0.	0.

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) 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) GEORGE POLLOCK, JR. BOARD MEMBER	10.00	X						0.	0.	0.
(19) THOMAS F. RUEKERT FORMER BOARD MEMBER	1.00	X						0.	0.	0.
(20) NEIL ANDREW SOLOMON, MD, FACP BOARD MEMBER	1.00	X						0.	0.	0.
(21) CARDEN WYCKOFF BOARD MEMBER	1.00	X						0.	0.	0.
(22) MARIE MORRELL BOARD MEMBER	1.00	X						0.	0.	0.
(23) JACK GERBLICK BOARD MEMBER	1.00	X						0.	0.	0.
(24) BRUCE RYSKAMP BOARD MEMBER	1.00	X						0.	0.	0.
1b Subtotal								726,143.	0.	114,826.
c Total from continuation sheets to Part VII, Section A								0.	0.	0.
d Total (add lines 1b and 1c)								726,143.	0.	114,826.

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 **5**

	Yes	No
3 Did the organization list any former officer, director, trustee, key employee, or highest compensated employee on line 1a? If "Yes," complete Schedule J for such individual		X
4 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	
5 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) Name and business address	(B) Description of services	(C) 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 RevenueCheck 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	9,366.				
	b Membership dues	1b					
	c Fundraising events	1c	523,209.				
	d Related organizations	1d					
	e Government grants (contributions)	1e	194,500.				
	f All other contributions, gifts, grants, and similar amounts not included above	1f	1,545,096.				
	g Noncash contributions included in lines 1a-1f	1g	\$ 93,960.				
	h Total. Add lines 1a-1f						
Program Service Revenue	2 a CORPORATE SPONSORSHIPS	Business Code 900099		135,620.	135,620.		
	b RESEARCH MEETING REGISTRATIONS	900099		9,800.	9,800.		
	c PATIENT MEETING REGISTRATIONS	900099		7,975.	7,975.		
	d CORPORATE PARTNERSHIPS	900099		5,000.	5,000.		
	e						
	f All other program service revenue						
	g Total. Add lines 2a-2f			158,395.			
	Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)			72,211.		
4 Income from investment of tax-exempt bond proceeds							
5 Royalties							
6 a Gross rents		6a	(i) Real (ii) Personal				
b Less: rental expenses		6b					
c Rental income or (loss)		6c					
d Net rental income or (loss)							
7 a Gross amount from sales of assets other than inventory		7a	(i) Securities (ii) Other				
b Less: cost or other basis and sales expenses		7b					
c Gain or (loss)		7c					
d Net gain or (loss)				123,901.			123,901.
8 a Gross income from fundraising events (not including \$ 523,209. of contributions reported on line 1c). See Part IV, line 18		8a		18,698.			
b Less: direct expenses		8b		18,698.			
c Net income or (loss) from fundraising events				0.			
9 a Gross income from gaming activities. See Part IV, line 19		9a					
b Less: direct expenses	9b						
c Net income or (loss) from gaming activities							
10 a Gross sales of inventory, less returns and allowances	10a						
b Less: cost of goods sold	10b						
c Net income or (loss) from sales of inventory							
Miscellaneous Revenue	11 a OTHER INCOME	Business Code 900099		527.			527.
	b						
	c						
	d All other revenue						
	e Total. Add lines 11a-11d			527.			
	12 Total revenue. See instructions			2,627,205.	158,395.	0.	196,639.

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 ☐

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	551,134.	551,134.		
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	73,884.	73,884.		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	610,308.	394,229.	165,300.	50,779.
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	743,586.	507,951.	50,642.	184,993.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits	173,390.	125,606.	6,924.	40,860.
10 Payroll taxes	94,998.	63,446.	14,498.	17,054.
11 Fees for services (nonemployees):				
a Management				
b Legal	47,760.	38,977.	8,783.	
c Accounting	15,500.		15,500.	
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.)	24,879.	9,000.	4,634.	11,245.
12 Advertising and promotion	5,156.	4,547.		609.
13 Office expenses	37,012.	25,074.	5,059.	6,879.
14 Information technology	117,458.	88,731.	11,947.	16,780.
15 Royalties				
16 Occupancy	44,185.	29,709.	6,490.	7,986.
17 Travel	46,075.	38,692.	2,709.	4,674.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	90,452.	90,452.		
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	2,011.		2,011.	
23 Insurance	7,137.		7,137.	
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 PRINTING	67,272.	38,171.		29,101.
b FUNDRAISING EXPENSES	43,093.			43,093.
c BANK SERVICE CHARGES AND	42,039.	12,318.	4,399.	25,322.
d CHAPTER AND VOLUNTEER D	22,207.	22,207.		
e All other expenses	5,268.		5,268.	
25 Total functional expenses. Add lines 1 through 24e	2,864,804.	2,114,128.	311,301.	439,375.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.				

Check here ☐ if following SOP 98-2 (ASC 958-720)

Part X Balance SheetCheck if Schedule O contains a response or note to any line in this Part X ☐

		(A) Beginning of year		(B) End of year
Assets	1 Cash - non-interest-bearing		1	
	2 Savings and temporary cash investments	2,617,796.	2	3,280,720.
	3 Pledges and grants receivable, net	739,710.	3	340,181.
	4 Accounts receivable, net		4	
	5 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		5	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	45,761.	9	61,251.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 27,230.		
	b Less: accumulated depreciation	10b 22,133.	10c	5,097.
	11 Investments - publicly traded securities	2,653,048.	11	1,943,769.
	12 Investments - other securities. See Part IV, line 11		12	
	13 Investments - program-related. See Part IV, line 11		13	150,000.
	14 Intangible assets		14	
	15 Other assets. See Part IV, line 11	429,043.	15	54,477.
16 Total assets. Add lines 1 through 15 (must equal line 33)	6,492,466.	16	5,835,495.	
Liabilities	17 Accounts payable and accrued expenses	269,978.	17	43,016.
	18 Grants payable	418,145.	18	216,929.
	19 Deferred revenue		19	
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22 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		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	
	25 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	86,905.	25	41,878.
	26 Total liabilities. Add lines 17 through 25	775,028.	26	301,823.
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here ☒ and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	1,927,614.	27	3,007,424.
	28 Net assets with donor restrictions	3,789,824.	28	2,526,248.
	Organizations that do not follow FASB ASC 958, check here ☐ and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		29	
	30 Paid-in or capital surplus, or land, building, or equipment fund		30	
	31 Retained earnings, endowment, accumulated income, or other funds		31	
	32 Total net assets or fund balances	5,717,438.	32	5,533,672.
	33 Total liabilities and net assets/fund balances	6,492,466.	33	5,835,495.

Form 990 (2020)

Part XI Reconciliation of Net AssetsCheck if Schedule O contains a response or note to any line in this Part XI ☒

1	Total revenue (must equal Part VIII, column (A), line 12)	1	2,627,205.
2	Total expenses (must equal Part IX, column (A), line 25)	2	2,864,804.
3	Revenue less expenses. Subtract line 2 from line 1	3	-237,599.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	5,717,438.
5	Net unrealized gains (losses) on investments	5	203,767.
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	-149,934.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	5,533,672.

Part XII Financial Statements and ReportingCheck if Schedule O contains a response or note to any line in this Part XII ☐

	Yes	No
1 Accounting method used to prepare the Form 990: ☐ Cash ☒ Accrual ☐ Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.		
2a Were the organization's financial statements compiled or reviewed by an independent accountant? _____ 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: ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis		X
b Were the organization's financial statements audited by an independent accountant? _____ 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: ☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis	X	
c 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? _____ If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.	X	
3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133? _____		X
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 (2020)

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) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	2150152.	3031111.	2344902.	4942896.	2272171.	14741232.
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	2150152.	3031111.	2344902.	4942896.	2272171.	14741232.
5 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)						2352523.
6 Public support. Subtract line 5 from line 4.						12388709.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
7 Amounts from line 4	2150152.	3031111.	2344902.	4942896.	2272171.	14741232.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	34,669.	114,053.	137,366.	93,131.	72,211.	451,430.
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
11 Total support. Add lines 7 through 10						15192662.
12 Gross receipts from related activities, etc. (see instructions)					12	
13 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

14 Public support percentage for 2020 (line 6, column (f), divided by line 11, column (f))	14	81.54 %
15 Public support percentage from 2019 Schedule A, Part II, line 14	15	79.62 %
16a 33 1/3% support test - 2020. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization		☒
b 33 1/3% support test - 2019. 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 stop here. The organization qualifies as a publicly supported organization		☐
17a 10% -facts-and-circumstances test - 2020. 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 stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization		☐
b 10% -facts-and-circumstances test - 2019. 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 stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization		☐
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions		☐

Schedule A (Form 990 or 990-EZ) 2020

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

Calendar year (or fiscal year beginning in) ►	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in 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**

15 Public support percentage for 2020 (line 8, column (f), divided by line 13, column (f))	15	%
16 Public support percentage from 2019 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2020 (line 10c, column (f), divided by line 13, column (f))	17	%
18 Investment income percentage from 2019 Schedule A, Part III, line 17	18	%

19a 33 1/3% support tests - 2020. 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 ☐**b 33 1/3% support tests - 2019.** 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 in line 12 on 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
1 Are all of the organization's supported organizations listed by name in the organization's governing documents? 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.		
2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).		
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer lines 3b and 3c below.		
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)? If "Yes," describe in Part VI when and how the organization made the determination.		
c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in Part VI what controls the organization put in place to ensure such use.		
4a Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes," and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.		
b Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? 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.		
c 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)? 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.		
5a Did the organization add, substitute, or remove any supported organizations during the tax year? 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).		
b Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
c Substitutions only. Was the substitution the result of an event beyond the organization's control?		
6 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? If "Yes," provide detail in Part VI .		
7 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? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).		
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).		
9a 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))? If "Yes," provide detail in Part VI .		
b Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? If "Yes," provide detail in Part VI .		
c Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? If "Yes," provide detail in Part VI .		
10a 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)? If "Yes," answer line 10b below.		
b Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)		

Part IV Supporting Organizations (continued)

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

Section B. Type I Supporting Organizations

	Yes	No
1 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 Part VI 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.		
1		
2 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 Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.		
2		

Section C. Type II Supporting Organizations

	Yes	No
1 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 Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).		
1		

Section D. All Type III Supporting Organizations

	Yes	No
1 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?		
1		
2 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 Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).		
2		
3 By reason of the relationship described in 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 Part VI the role the organization's supported organizations played in this regard.		
3		

Section E. Type III Functionally Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).			
a ☐ The organization satisfied the Activities Test. Complete line 2 below.			
b ☐ The organization is the parent of each of its supported organizations. Complete line 3 below.			
c ☐ The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see instructions).			
2 Activities Test. Answer lines 2a and 2b below.			
a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.			
2a			
b Did the activities described in 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 Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.			
2b			
3 Parent of Supported Organizations. Answer lines 3a and 3b below.			
a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? If "Yes" or "No" provide details in Part VI .			
3a			
b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.			
3b			

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 Adjusted Net Income (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 Total (add lines 1a, 1b, and 1c)	1d		
e Discount 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 Minimum Asset Amount (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 Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6		
7 ☐ Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).			

Schedule A (Form 990 or 990-EZ) 2020

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

Section D - Distributions		Current Year
1 Amounts paid to supported organizations to accomplish exempt purposes	1	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	3	
4 Amounts paid to acquire exempt-use assets	4	
5 Qualified set-aside amounts (prior IRS approval required - <i>provide details in Part VI</i>)	5	
6 Other distributions (<i>describe in Part VI</i>). See instructions.	6	
7 Total annual distributions. Add lines 1 through 6.	7	
8 Distributions to attentive supported organizations to which the organization is responsive (<i>provide details in Part VI</i>). See instructions.	8	
9 Distributable amount for 2020 from Section C, line 6	9	
10 Line 8 amount divided by line 9 amount	10	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2020	(iii) Distributable Amount for 2020
1 Distributable amount for 2020 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2020 (reasonable cause required - <i>explain in Part VI</i>). See instructions.			
3 Excess distributions carryover, if any, to 2020			
a From 2015			
b From 2016			
c From 2017			
d From 2018			
e From 2019			
f Total of lines 3a through 3e			
g Applied to underdistributions of prior years			
h Applied to 2020 distributable amount			
i Carryover from 2015 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2020 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2020 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2020, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, <i>explain in Part VI</i> . See instructions.			
6 Remaining underdistributions for 2020. Subtract lines 3h and 4b from line 1. For result greater than zero, <i>explain in Part VI</i> . See instructions.			
7 Excess distributions carryover to 2021. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2016			
b Excess from 2017			
c Excess from 2018			
d Excess from 2019			
e Excess from 2020			

Schedule A (Form 990 or 990-EZ) 2020

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, and 3b; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information.
(See instructions.)

SCHEDULE D
(Form 990)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 for instructions and the latest information.**

OMB No. 1545-0047

2020**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	1	
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year)	1,000,000.	
4 Aggregate value at end of year	1,901,891.	
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?	☒ Yes	☐ 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?	☒ Yes	☐ 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 in (a)	2c
d Number of conservation easements included in (c) acquired after 7/25/06, 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 2(d) 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

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

Schedule D (Form 990) 2020

032051 12-01-20

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

d ☐ Loan or exchange program

b ☐ Scholarly research

e ☐ Other _____

c ☐ Preservation for future generations

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
c Beginning balance	1c
d Additions during the year	1d
e Distributions during the year	1e
f Ending balance	1f

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 on 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
1a Beginning of year balance			2,106,221.	959,883.	85,835.
b Contributions				932,237.	854,179.
c Net investment earnings, gains, and losses			-4,045.	260,501.	55,869.
d Grants or scholarships					
e Other expenditures for facilities and programs			2,102,176.	46,400.	36,000.
f Administrative expenses					
g End of year balance				2,106,221.	959,883.

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:

(i) Unrelated organizations

(ii) Related organizations

	Yes	No
3a(i)		X
3a(ii)		X
3b		

b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R? ☐

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
1a Land				
b Buildings				
c Leasehold improvements		7,100.	7,100.	0.
d Equipment		7,976.	7,976.	0.
e Other		12,154.	7,057.	5,097.
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.)				5,097.

Schedule D (Form 990) 2020

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)		
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 12.) ▶		

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)		
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 13.) ▶		

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)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 15.) ▶	

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) LONG-TERM DEFERRED COMPENSATION	
(3) LIABILITY	41,878.
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶	41,878.

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 D (Form 990) 2020

Part XI	Reconciliation of Revenue per Audited Financial Statements With Revenue per Return.
----------------	--

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements	1	2,907,047.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
a	Net unrealized gains (losses) on investments	2a	203,767.
b	Donated services and use of facilities	2b	76,075.
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII.)	2d	
e	Add lines 2a through 2d	2e	279,842.
3	Subtract line 2e from line 1	3	2,627,205.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII.)	4b	
c	Add lines 4a and 4b	4c	0.
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.)	5	2,627,205.

Part XII	Reconciliation of Expenses per Audited Financial Statements With Expenses per Return.
-----------------	--

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements	1	3,090,813.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:		
a	Donated services and use of facilities	2a	76,075.
b	Prior year adjustments	2b	
c	Other losses	2c	149,934.
d	Other (Describe in Part XIII.)	2d	
e	Add lines 2a through 2d	2e	226,009.
3	Subtract line 2e from line 1	3	2,864,804.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII.)	4b	
c	Add lines 4a and 4b	4c	0.
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.)	5	2,864,804.

Part XIII Supplemental Information.

Provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

**SCHEDULE F
(Form 990)**

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 for instructions and the latest information.

OMB No. 1545-0047

2020

Open to Public
Inspection

Name of the organization

FSHD SOCIETY

Employer identification number

52-1762747

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

1 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**

2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

3 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 (INCLUDING ICELAND & GREENLAND)	0	0	GRANTS	N/A	73,884.
3 a Subtotal	0	0			73,884.
b Total from continuation sheets to Part I	0	0			0.
c Totals (add lines 3a and 3b)	0	0			73,884.

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

Schedule F (Form 990) 2020

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 (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 (INCLUDING ICELAND & GREENLAND)	STUDY OF A NOVEL DRUGGABLE TARGET REQUIRED FOR DUX4 EXPRESSION IN FSHD	60,684.	WIRE TRANSFER	0.	N/A	
		EUROPE (INCLUDING ICELAND & GREENLAND)	CHARACTERISING HETEROGENEITY IN FSHD-ANALYSIS OF WORLDWIDE PATIENT	13,200.	WIRE TRANSFER	0.	N/A	

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

2

3 Enter total number of other organizations or entities

0

SEE PART V FOR COLUMN (D) DESCRIPTIONS

Schedule F (Form 990) 2020

Part III Grants and Other Assistance to Individuals Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 16.

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of noncash assistance	(g) Description of noncash assistance	(h) Method of valuation (book, FMV, appraisal, other)

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 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 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 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 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 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 Instructions for Form 5713; don't file with Form 990)* ☐ Yes ☒ No

Schedule F (Form 990) 2020

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 SOCIETY MAKES RESEARCH GRANTS TO ELIGIBLE APPLICANTS AFTER REQUESTS FOR RESEARCH FUNDING HAVE BEEN REVIEWED AND APPROVED BY THE SOCIETY'S SCIENTIFIC ADVISORY BOARD (SAB) AND, THEREAFTER, APPROVED BY THE SOCIETY'S BOARD OF DIRECTORS. THE SOCIETY ALSO PROVIDES OTHER ASSISTANCE TO RESEARCHERS AND TO PATIENTS PARTICIPATING IN RESEARCH, AND PROVIDES FUNDS FOR RESEARCH BIOMATERIALS. GRANTEEES ARE REQUIRED TO SUBMIT PERIODIC PROGRESS REPORTS, WHICH ARE REVIEWED BY THE SAB AND THE SOCIETY'S SENIOR EXECUTIVES. WITH REGARD TO ASSISTANCE OTHER THAN RESEARCH GRANTS, THE RECIPIENT OF THE ASSISTANCE IS REQUIRED TO SUBMIT PERIODIC PROGRESS REPORTS OR OTHER WRITTEN DETAIL ABOUT THE USE OF THE FUNDS, AS DETERMINED BY THE SAB, BOARD OF DIRECTORS AND SENIOR EXECUTIVES.

PART II, COLUMN (D):

REGION: EUROPE (INCLUDING ICELAND & GREENLAND)

(D) PURPOSE OF GRANT: CHARACTERISING HETEROGENEITY IN FSHD-ANALYSIS OF WORLDWIDE PATIENT COHORT

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 (add col. (a) through col. (c))
		PEER TO PEER EVENTS (event type)	(event type)	1 (total number)	
Revenue	1 Gross receipts	541,907.			541,907.
	2 Less: Contributions	523,209.			523,209.
	3 Gross income (line 1 minus line 2)	18,698.			18,698.
Direct Expenses	4 Cash prizes				
	5 Noncash prizes	9,879.			9,879.
	6 Rent/facility costs	400.			400.
	7 Food and beverages	74.			74.
	8 Entertainment				
	9 Other direct expenses	8,345.			8,345.
	10 Direct expense summary. Add lines 4 through 9 in column (d)				18,698.
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 bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add 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	☐ Yes _____ % ☐ No	☐ Yes _____ % ☐ No	☐ Yes _____ % ☐ 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: _____

- 11** Does the organization conduct gaming activities with nonmembers? ☐ Yes ☐ No
- 12** Is the organization a grantor, beneficiary or trustee of a trust, or a member of a partnership or other entity formed to administer charitable gaming? ☐ Yes ☐ No
- 13** Indicate the percentage of gaming activity conducted in:
- | | | |
|--------------------------------------|------------|---|
| a The organization's facility | 13a | % |
| b An outside facility | 13b | % |
- 14** Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name ► _____

Address ► _____

- 15a** Does the organization have a contract with a third party from whom the organization receives gaming revenue? ☐ Yes ☐ No

b If "Yes," enter the amount of gaming revenue received by the organization ► \$ _____ and the amount of gaming revenue retained by the third party ► \$ _____

c If "Yes," enter name and address of the third party:

Name ► _____

Address ► _____

16 Gaming manager information:

Name ► _____

Gaming manager compensation ► \$ _____

Description of services provided ► _____

☐ Director/officer☐ Employee☐ Independent contractor**17** Mandatory distributions:

a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? ☐ Yes ☐ No

b Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ► \$ _____

Part IV Supplemental Information. Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information. See instructions.

Part IV	Supplemental Information <i>(continued)</i>
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[illegible]

SCHEDULE I
(Form 990)

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 for the latest information.**

OMB No. 1545-0047

2020

**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 non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
THE RESEARCH INSTITUTE AT NATIONWIDE CHILDREN'S HOSPITAL - 700 CHILDREN'S DRIVE - COLUMBUS, OH 43205	31-6056230	501(C)(3)	80,100.	0.			IN VIVO DETECTION OF DUX4 MRNA USING RNASCOPE
OHIO STATE UNIVERSITY MEDICAL CENTER: DEVELOPMENT & ALUMNI AFFAIRS - 660 ACKERMAN ROAD, P.O. BOX 183112 - COLUMBUS, OH 43218	31-1145986	501(C)(3)	5,000.	0.			FSHD RESEARCH FUND
CHILDREN'S RESEARCH INSTITUTE: CHILDRENS NATIONAL HEALTH SYSTEMS - 801 ROEDER ROAD SUITE 500 - SILVER SPRING, MD 20910	52-1654453	501(C)(3)	74,829.	0.			MEMBRAN REPAIR DEFICIT IN FSHD PATHOPHYSIOLOGY
UNIVERSITY OF ROCHESTER 601 ELMWOOD AVENUE, BOX 673 ROCHESTER, NY 14642	16-0743209	501(C)(3)	7,545.	0.			DIGITIZING THE US FSHD PATIENT REGISTRY
UNIVERSITY OF KANSAS MEDICAL CENTER - 4330 SHAWNEE MISSION PARKWAY, SUITE 323 - FAIRWAY, KS 66205	48-1108830	501(C)(3)	348,000.	0.			CLINICAL TRIALS RESEARCH NETWORK (CTRN) FOR FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY (FSHD)
UNIVERSITY OF MARYLAND 220 ARCH STREET BALTIMORE, MD 21201	52-6002033	501(C)(3)	19,700.	0.			DEVELOPING A "SANDWICH" IMMUNOASSAY FOR SLC34A2, A POTENTIAL BIOMARKER FOR FSHD

- 2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table **6.**
- 3** Enter total number of other organizations listed in the line 1 table **0.**

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

Schedule I (Form 990) 2020

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

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 SOCIETY MAKES RESEARCH GRANTS TO ELIGIBLE APPLICANTS AFTER REQUESTS FOR RESEARCH FUNDING HAVE BEEN REVIEWED AND APPROVED BY THE SOCIETY'S SCIENTIFIC ADVISORY BOARD (SAB) AND, THEREAFTER, APPROVED BY THE SOCIETY'S BOARD OF DIRECTORS. THE SOCIETY ALSO PROVIDES OTHER ASSISTANCE TO RESEARCHERS AND TO PATIENTS PARTICIPATING IN RESEARCH, AND PROVIDES FUNDS FOR RESEARCH BIOMATERIALS. GRANTEES ARE REQUIRED TO SUBMIT PERIODIC PROGRESS REPORTS, WHICH ARE REVIEWED BY THE SAB AND THE SOCIETY'S SENIOR EXECUTIVES. WITH REGARD TO ASSISTANCE OTHER THAN RESEARCH GRANTS, THE

Part IV Supplemental Information

RECIPIENT OF THE ASSISTANCE IS REQUIRED TO SUBMIT PERIODIC PROGRESS REPORTS OR OTHER WRITTEN DETAIL ABOUT THE USE OF THE FUNDS, AS DETERMINED BY THE SAB, BOARD OF DIRECTORS AND SENIOR EXECUTIVES.

PART II, LINE 1, COLUMN (H):

NAME OF ORGANIZATION OR GOVERNMENT: UNIVERSITY OF KANSAS MEDICAL CENTER

(H) PURPOSE OF GRANT OR ASSISTANCE: CLINICAL TRIALS RESEARCH NETWORK

(CTRN) FOR FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY (FSHD) AND ARTIFICIAL INTELLIGENCE PROOF OF CONCEPT FOR FSHD RESEARCH

**SCHEDULE J
(Form 990)**

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 for instructions and the latest information.

OMB No. 1545-0047

2020

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.

- | | |
|--|--|
| ☐ First-class or charter travel | ☐ Housing allowance or residence for personal use |
| ☐ Travel for companions | ☐ Payments for business use of personal residence |
| ☐ Tax indemnification and gross-up payments | ☐ Health or social club dues or initiation fees |
| ☐ Discretionary spending account | ☐ 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.

- | | |
|---|---|
| ☐ Compensation committee | ☐ Written employment contract |
| ☐ Independent compensation consultant | ☒ Compensation survey or study |
| ☒ Form 990 of other organizations | ☒ 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?

b Participate in or receive payment from a supplemental nonqualified retirement plan?

c Participate in or receive payment from an equity-based compensation arrangement?

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?

b Any related organization?

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?

b Any related organization?

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

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

9 If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?

Yes No

1b		
2		
4a		X
4b		X
4c		X
5a		X
5b		X
6a		X
6b		X
7		X
8		X
9		

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

Schedule J (Form 990) 2020

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.

Schedule J (Form 990) 2020

Part III	Supplemental Information
-----------------	---------------------------------

Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II. Also complete this part for any additional information.

[illegible]

SCHEDULE M
(Form 990)

Department of the Treasury
Internal Revenue Service

Noncash Contributions

OMB No. 1545-0047

2020

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- ▶ **Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.**
▶ **Attach to Form 990.**
▶ **Go to 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) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) 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				
9 Securities - Publicly traded	X	7	93,960.FMV	
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 Acknowledgement

29

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 three years from the date of the initial contribution, and which isn't required to be used for
exempt purposes for the entire holding period?

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?

32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash
contributions?

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.

	Yes	No
30a		X
31		X
32a		X
33		

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

Schedule M (Form 990) 2020

Supplemental Information.

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.

SCHEDULE O
(Form 990 or 990-EZ)

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 990-EZ.

▶ Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

2020

Open to Public
Inspection

Name of the organization

FSHD SOCIETY

Employer identification number
52-1762747

FORM 990, PART VI, SECTION A, LINE 2:

BOARD MEMBERS JAMES CHIN AND CHRISTINE FORD ARE BROTHER-IN-LAW AND
SISTER-IN-LAW.

FORM 990, PART VI, SECTION B, LINE 11B:

THE BOARD OF DIRECTORS REVIEWS THE FORM 990 PRIOR TO ITS FILING. THE FORM
990 WAS THEN AUTHORIZED AND SIGNED BY THE ORGANIZATION'S PRESIDENT & CEO.

FORM 990, PART VI, SECTION B, LINE 12C:

THE BOARD OF DIRECTORS REQUIRES AN ANNUAL DECLARATION FROM ALL BOARD
MEMBERS AND SENIOR MANAGEMENT AS TO THE EXISTENCE AND DISCLOSURE OF ANY
POTENTIAL CONFLICTS OF INTEREST. THE BOARD MEMBERS SIGN A DISCLOSURE
STATEMENT. ANY POTENTIAL CONFLICTS ARE DISCUSSED BY THE DIS-INTERESTED
BOARD MEMBERS, WHILE THE PARTY IN POTENTIAL CONFLICT IS REQUIRED TO LEAVE
THE MEETING. BOARD MEETING MINUTES WILL DOCUMENT THE DISCUSSION AND
DECISION-MAKING PROCESS. IN THE EVENT OF A POTENTIAL CONFLICT, PROCEDURES
TO OBTAIN COMPETITIVE BIDS AND DILIGENCE ON FAIR MARKET VALUE WILL BE
ESTABLISHED.

FORM 990, PART VI, SECTION B, LINE 15:

FSHD SOCIETY'S EXECUTIVE COMPENSATION PROGRAM IS ADMINISTERED BY THE BOARD
OF DIRECTORS. 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 PROGRAM
AND MAKE RECOMMENDATIONS FOR ANY CHANGES, AS APPROPRIATE. A PERFORMANCE
EVALUATION IS CONDUCTED AND REVIEWED EACH YEAR AND IS INTENDED TO ENSURE

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

Schedule O (Form 990 or 990-EZ) 2020

Name of the organization

FSHD SOCIETY

Employer identification number

52-1762747

THAT THE COMPENSATION PROGRAM FALLS WITHIN A REASONABLE RANGE OF COMPETITIVE PRACTICES FOR COMPARABLE POSITIONS AMONG SIMILARLY SITUATED ORGANIZATIONS. FOLLOWING THIS REVIEW, THE BOARD REVIEWS AND APPROVES, FOR SELECTED KEY EXECUTIVES, BASE SALARIES AND ANNUAL INCENTIVE OPPORTUNITY ADJUSTMENTS, AND OBJECTIVES AND GOALS FOR THE UPCOMING YEAR'S ANNUAL INCENTIVE PLAN.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:
MA, AK, AR, CA, CO, CT, DC, FL, GA, HI, IL, KS, KY, MD, ME, MI, MN, MO, MS, NH, NJ, NV, NC, ND, NM
NY, OH, OK, OR, PA, RI, SC, TN, UT, VA, WA, WI, WV, AL

FORM 990, PART VI, SECTION C, LINE 19:
UPON REQUEST, AVAILABLE ON ORGANIZATION'S WEBSITE AND THROUGH GUIDESTAR WEBSITE.

FORM 990, PART XI, LINE 9, CHANGES IN NET ASSETS:

OTHER LOSSES	-99,934.
BAD DEBT EXPENSE	-50,000.
TOTAL TO FORM 990, PART XI, LINE 9	-149,934.

PART XI, LINE 9

OTHER LOSSES: IN APRIL 2020, THE SOCIETY DISCOVERED THAT IT WAS A VICTIM OF AN EMAIL PHISHING SCAM. \$111,934 WAS TRANSFERRED TO A FRAUDULENT BANK ACCOUNT. FOLLOWING AN INVESTIGATION BY THE SOCIETY'S ONLINE BILL PAYMENT SERVICE, THE SOCIETY WAS ABLE TO RECOVER \$12,000, WHICH RESULTED IN A NET LOSS OF \$99,934, WHICH IS REPORTED ON PART XII OF SCHEDULE D IN THE FORM 990. MANAGEMENT TOOK SEVERAL ACTIONS BECAUSE OF THIS FRAUD, INCLUDING THE IMPLEMENTATION OF ADDITIONAL

Name of the organization

FSHD SOCIETY

Employer identification number

52-1762747

CONTROLS OVER ELECTRONIC BILL PAYMENTS AND WIRE TRANSFERS AS WELL AS
CYBERSECURITY TRAINING AND MONITORING FOR THE SOCIETY'S STAFF. THE
SOCIETY HAS ALSO PURCHASED SOCIAL ENGINEERING INSURANCE.