

990

Return of Organization Exempt From Income Tax

OMB No. 1545-

0047 2021

Open to Public Inspection

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

Form 990 Department of the Treasury Internal Revenue Service

A For the 2021 calendar year, or tax year beginning 01-01-2021, and ending 12-31-2021

- B Check if applicable: Address change, Name change, Initial return, Final return/terminated, Amended return, Application pending

C Name of organization: FSHD SOCIETY. Doing business as. Number and street (or P.O. box if mail is not delivered to street address): 75 NORTH MAIN STREET 1073. Room/suite. City or town, state or province, country, and ZIP or foreign postal code: RANDOLPH, MA 02368

D Employer identification number: 52-1762747. E Telephone number: (781) 301-6060. G Gross receipts \$ 6,470,177

F Name and address of principal officer: MARK A STONE, 75 NORTH MAIN STREET 1073, RANDOLPH, MA 02368

H(a) Is this a group return for subordinates? No. H(b) Are all subordinates included? No. H(c) Group exemption number

I Tax-exempt status: 501(c)(3)

J Website: WWW.FSHDSOCIETY.ORG

K Form of organization: Corporation

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

Part I Summary

Table with 4 main sections: Activities & Governance, Revenue, Expenses, and Net Assets or Fund Balances. Includes rows for mission statement, membership counts, revenue breakdown, expenses, and asset/liability totals.

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.

Sign Here: Signature of officer (MARK A STONE CEO & PRESIDENT) and Date (2022-04-05)

Paid Preparer Use Only: Print/Type preparer's name, Preparer's signature, Date, Firm's name, Firm's address, Firm's EIN, Phone no.

May the IRS discuss this return with the preparer shown above? (see instructions) Yes No

Part III Statement of Program Service Accomplishments

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

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 \$ 2,966,300 including grants of \$ 2,315,936) (Revenue \$ 117,955)

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 \$ 886,963 including grants of \$ 0) (Revenue \$ 54,059)

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 in Schedule O.) (Expenses \$ including grants of \$) (Revenue \$)

4e Total program service expenses ▶ 3,853,263

Part IV Checklist of Required Schedules

Table with 3 columns: Question number, Question text, and Yes/No response columns. Rows include questions 1 through 21 regarding organizational requirements and schedules.

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? <i>If "Yes," complete Schedule I, Parts I and III</i>		No
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? <i>If "Yes," complete Schedule J</i>	Yes	
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? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>		No
24b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
24c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
24d	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? <i>If "Yes," complete Schedule L, Part I</i>		No
25b	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? <i>If "Yes," complete Schedule L, Part I</i>		No
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?		No
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? <i>If "Yes," complete Schedule L, Part III</i>		No
28	Was the organization a party to a business transaction with one of the following parties (see the Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):		
28a	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i>		No
28b	A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i>		No
28c	A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i>		No
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	Yes	
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions?		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>		No
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?		No
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>		No
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?		No
35b	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)? <i>If "Yes," complete Schedule R, Part V, line 2</i>		
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>		No
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? <i>If "Yes," complete Schedule R, Part VI</i>		No
38	Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19? Note. All Form 990 filers are required to complete Schedule O.	Yes	

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

		Yes	No
1a	Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable		
1b	Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable		
1c	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)

Table with 17 main rows and multiple sub-rows (a-e). Columns include question text, a grid for 'Yes/No' answers, and a grid for numerical values. Rows cover topics like employee reporting, foreign accounts, tax shelter transactions, and charitable contributions.

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

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members... 1b Enter the number of voting members included... 2 Did any officer, director, trustee... 3 Did the organization delegate control... 4 Did the organization make any significant changes... 5 Did the organization become aware... 6 Did the organization have members... 7a Did the organization have members... 7b Are any governance decisions... 8 Did the organization contemporaneously document... 8a The governing body? 8b Each committee... 9 Is there any officer, director, trustee...

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

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters... 10b If "Yes," did the organization have written policies... 11a Has the organization provided a complete copy... 11b Describe on Schedule O the process... 12a Did the organization have a written conflict of interest policy... 12b Were officers, directors, or trustees... 12c Did the organization regularly and consistently monitor... 13 Did the organization have a written whistleblower policy... 14 Did the organization have a written document retention... 15 Did the process for determining compensation... 15a The organization's CEO... 15b Other officers or key employees... 16a Did the organization invest in, contribute assets to... 16b If "Yes," did the organization follow a written policy...

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, 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
18 Section 6104 requires an organization to make its Form 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.
19 Describe in 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 75 NORTH MAIN STREET 1073 RANDOLPH, MA 02368 (781) 301-6060

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

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

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

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

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.

- List all of the organization's **current** key employees, if any. See the instructions for definition of "key employee."

- List the organization's five **current** highest compensated employees (other than an officer, director, trustee or key employee) who received reportable compensation (box 5 of Form W-2, Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.

- List all of the organization's **former** officers, key employees, or highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.

- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

See the instructions for the order in which to list the persons above.

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted 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/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(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) JAMES A CHIN SR CHAIRMAN	10.00	X		X			0	0	0	
(2) HOWARD L CHABNER JD VICE CHAIRMAN	10.00	X		X			0	0	0	
(3) CHRISTINE FORD SECRETARY	10.00	X		X			0	0	0	
(4) ELLEN K HANNAN TREASURER	10.00	X		X			0	0	0	
(5) AMY Z BEKIER BOARD MEMBER	10.00	X					0	0	0	
(6) STUART LAI BOARD MEMBER	1.00	X					0	0	0	
(7) DAVID RUBIN BOARD MEMBER	1.00	X					0	0	0	
(8) WILLIAM R LEWIS III MD BOARD MEMBER	1.00	X					0	0	0	
(9) MICHELLE HELEN MACKAY BOARD MEMBER	1.00	X					0	0	0	
(10) LEE FRANK KOLAKOWSKI PHD BOARD MEMBER	10.00	X					0	0	0	
(11) LINDA LAURELLO BOARD MEMBER	1.00	X					0	0	0	
(12) GEORGE POLLOCK JR BOARD MEMBER	10.00	X					0	0	0	
(13) NEIL ANDREW SOLOMON MD FACP BOARD MEMBER	1.00	X					0	0	0	
(14) CARDEN WYCKOFF BOARD MEMBER	1.00	X					0	0	0	
(15) MARIE MORRELL BOARD MEMBER	1.00	X					0	0	0	
(16) JACK GERBLICK BOARD MEMBER	1.00	X					0	0	0	
(17) BRUCE RYSKAMP 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 dotted 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/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(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) MARK STONE CEO & PRESIDENT	40.00			X				199,683	0	45,859
(19) LISA SCHIMMEL CFO	40.00			X				106,139	0	22,503
(20) JAMSHID ARJOMAND CHIEF SCIENCE OFFICER	40.00				X			190,401	0	19,018
(21) JUNE KINOSHITA DIR OF RESEARCH & PATIENT ENGAGEMENT	40.00					X		101,000	0	4,702
(22) BETH JOHNSTON CHIEF COMMUNITY ENGAGEMENT OFFICER	40.00					X		116,000	0	5,364
1b Sub-Total										
c Total from continuation sheets to Part VII, Section A										
d Total (add lines 1b and 1c)								713,223	0	97,446

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 or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		No
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? <i>If "Yes," complete Schedule J for such individual</i>	Yes	
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		No

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

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

Part VIII Statement of Revenue

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

	(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512 - 514
Contributions, Gifts, Grants, and Other Similar Amounts				
1a Federated campaigns			10,006	
b Membership dues				
c Fundraising events			818,299	
d Related organizations				
e Government grants (contributions)			285,077	
f All other contributions, gifts, grants, and similar amounts not included above			3,432,941	
g Noncash contributions included in lines 1a - 1f:\$			1,071,212	
h Total. Add lines 1a-1f				4,546,323

Program Service Revenue		Business Code		
			(A)	(B)
2a CORPORATE SPONSORSHIPS		900099	147,744	147,744
b RESEARCH MEETING REGISTRATIONS		900099	21,900	21,900
c CORPORATE PARTNERSHIPS		900099	1,500	1,500
d PATIENT MEETING REGISTRATIONS		900099	870	870
e				
f All other program service revenue.				
g Total. Add lines 2a-2f.			172,014	

Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		122,027		122,027	
	4 Income from investment of tax-exempt bond proceeds					
	5 Royalties					
	6a Gross rents	(i) Real				
		(ii) Personal				
		6b Less: rental expenses				
		6c Rental income or (loss)				
	d Net rental income or (loss)					
	7a Gross amount from sales of assets other than inventory	(i) Securities	1,200,616			
		(ii) Other				
		7b Less: cost or other basis and sales expenses	901,460			
		7c Gain or (loss)	299,156			
	d Net gain or (loss)		299,156		299,156	
	8a Gross income from fundraising events (not including \$ 818,299 of contributions reported on line 1c). See Part IV, line 18		80,497			
		8b Less: direct expenses	80,497			
		c Net income or (loss) from fundraising events		0		
	9a Gross income from gaming activities. See Part IV, line 19					
		9b Less: direct expenses				
		c Net income or (loss) from gaming activities				
	10a Gross sales of inventory, less returns and allowances					
10b Less: cost of goods sold						
c Net income or (loss) from sales of inventory						
Miscellaneous Revenue	Business Code					
11a STIMULUS/COVID CREDITS	900099	313,636	313,636			
b RETURN OF GRANT FUNDS	900099	34,640	34,640			
c OTHER INCOME	900099	424		424		
d All other revenue						
e Total. Add lines 11a-11d		348,700				
12 Total revenue. See instructions		5,488,220	520,290	0		

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	1,426,356	1,426,356		
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.	889,580	889,580		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	583,603	381,298	153,196	49,109
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	794,851	547,301	67,892	179,658
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits	151,471	111,016	8,133	32,322
10 Payroll taxes	107,148	72,455	16,362	18,331
11 Fees for services (non-employees):				
a Management				
b Legal	7,140	300	6,840	
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 Schedule O)	53,158	52,282	876	
12 Advertising and promotion	1,978	1,968		10
13 Office expenses	43,469	29,537	6,197	7,735
14 Information technology	129,168	96,192	14,571	18,405
15 Royalties				
16 Occupancy	46,814	30,982	7,971	7,861
17 Travel	53,831	50,638	871	2,322
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	70,593	70,593		
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	5,097		5,097	
23 Insurance	8,314	105	8,209	
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a BANK SERVICE CHARGES AN	74,765	22,643	8,765	43,357
b PRINTING	62,898	33,602	0	29,296
c FUNDRAISING EXPENSES	47,854			47,854
d RESEARCH PROJECTS	31,528	31,528		
e All other expenses	10,207	4,887	5,250	70
25 Total functional expenses. Add lines 1 through 24e	4,615,323	3,853,263	325,730	436,330
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 <input type="checkbox"/> if following SOP 98-2 (ASC 958-720).				

Part X Balance Sheet

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

		(A) Beginning of year		(B) End of year
Assets	1 Cash-non-interest-bearing		1	
	2 Savings and temporary cash investments	3,280,720	2	4,820,728
	3 Pledges and grants receivable, net	340,181	3	293,686
	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	61,251	9	123,679
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D 10a 0			
	b Less: accumulated depreciation 10b 0	5,097	10c	0
	11 Investments—publicly traded securities	1,943,769	11	2,246,249
	12 Investments—other securities. See Part IV, line 11		12	
	13 Investments—program-related. See Part IV, line 11	150,000	13	150,000
	14 Intangible assets		14	
	15 Other assets. See Part IV, line 11	54,477	15	4,477
16 Total assets: Add lines 1 through 15 (must equal line 33)	5,835,495	16	7,638,819	
Liabilities	17 Accounts payable and accrued expenses	43,016	17	51,730
	18 Grants payable	216,929	18	1,166,878
	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	41,878	25	67,801
	26 Total liabilities. Add lines 17 through 25	301,823	26	1,286,409
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	3,007,424	27	3,975,882
	28 Net assets with donor restrictions	2,526,248	28	2,376,528
	Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> 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	5,533,672	32	6,352,410
33 Total liabilities and net assets/fund balances	5,835,495	33	7,638,819	

Part XI Reconciliation of Net Assets

Check 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	5,488,220
2	Total expenses (must equal Part IX, column (A), line 25)	2	4,615,323
3	Revenue less expenses. Subtract line 2 from line 1	3	872,897
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	5,533,672
5	Net unrealized gains (losses) on investments	5	-51,655
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 in Schedule O)	9	-2,504
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (A))	10	6,352,410

Part XII Financial Statements and Reporting

Check 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: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain on 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: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		No
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: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	Yes	
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 in Schedule O.	Yes	
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?		No
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 in Schedule O and describe any steps taken to undergo such audits.		

Additional Data

Return to Form

Software ID:

Software Version:

Form 990, Special Condition Description:

Special Condition Description

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.
 Attach to Form 990 or Form 990-EZ.
 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 Reason for Public Charity Status (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

- 1 A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i)**.
- 2 A school described in **section 170(b)(1)(A)(ii)**. (Attach Schedule E (Form 990).)
- 3 A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii)**.
- 4 A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii)**. Enter the hospital's name, city, and state:

- 5 An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv)**. (Complete Part II.)
- 6 A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v)**.
- 7 An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 8 A community trust described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 9 An agricultural research organization described in **170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land grant college of agriculture. See instructions. Enter the name, city, and state of the college or university:
- 10 An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2)**. (Complete Part III.)
- 11 An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 12 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2)**. See **section 509(a)(3)**. Check the box on lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
 - a **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
 - b **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
 - c **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
 - d **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
 - e Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
 - f Enter the number of supported organizations _____
 - g Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
Total						

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 failed to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grant.") . . .	3,031,111	2,344,902	4,942,896	2,272,171	4,546,323	17,137,403
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	3,031,111	2,344,902	4,942,896	2,272,171	4,546,323	17,137,403
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) . . .						3,491,762
6 Public support. Subtract line 5 from line 4.						13,645,641

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
7 Amounts from line 4.	3,031,111	2,344,902	4,942,896	2,272,171	4,546,323	17,137,403
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	114,053	137,366	93,131	72,211	122,027	538,788
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.)	102,718	28,396	8,454	527	348,700	488,795
11 Total support. Add lines 7 through 10						18,164,986
12 Gross receipts from related activities, etc. (see instructions)					12	1,006,337
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 <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

14 Public support percentage for 2021 (line 6, column (f) divided by line 11, column (f))	14	75.120 %
15 Public support percentage for 2020 Schedule A, Part II, line 14	15	81.540 %
16a 33 1/3% support test—2021. 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 <input checked="" type="checkbox"/>		
b 33 1/3% support test—2020. 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 <input type="checkbox"/>		
17a 10%-facts-and-circumstances test—2021. 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 <input type="checkbox"/>		
b 10%-facts-and-circumstances test—2020. 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 <input type="checkbox"/>		
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 <input type="checkbox"/>		

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

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

Section A. Public Support

Calendar year (or fiscal year beginning in) ►	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(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) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(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 on line 10b, whether or not the business is regularly carried on.						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . .						
13 Total support. (Add lines 9, 10c, 11, and 12.)						
14 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here. <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

15 Public support percentage for 2021 (line 8, column (f) divided by line 13, column (f))	15	
16 Public support percentage from 2020 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2021 (line 10c, column (f) divided by line 13, column (f))	17	
18 Investment income percentage from 2020 Schedule A, Part III, line 17	18	

19a 33 1/3% support tests—2021. 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—2020. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization

20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions

Part IV Supporting Organizations

(Complete only if you checked a box on line 12 of Part I. If you checked box 12a, of Part I, complete Sections A and B. If you checked box 12b, of Part I, complete Sections A and C. If you checked box 12c, of Part I, complete Sections A, D, and E. If you checked box 12d, of 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 (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).		
8	Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? If "Yes," complete Part I of Schedule L (Form 990).		
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 on 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 on 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 on lines 11b and 11c below, the governing body of a supported organization?		
b A family member of a person described on 11a above?		
c A 35% controlled entity of a person described on line 11a or 11b above? <i>If "Yes" to 11a, 11b, or 11c, provide detail in Part VI</i>		

Section B. Type I Supporting Organizations

	Yes	No
1 Did the officers, directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>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 directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>		
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? <i>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.</i>		

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)? <i>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).</i>		

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?		
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? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
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? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		

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 government entity (see instructions)

2 Activities Test. **Answer lines 2a and 2b below.**

	Yes	No
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? <i>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.</i>		
b Did the activities described on line 2a, above constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>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.</i>		

3 Parent of Supported Organizations. **Answer lines 3a and 3b below.**

	Yes	No
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? <i>If "Yes" or "No", provide details in Part VI.</i>		
b Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? <i>If "Yes," describe in Part VI. the role played by the organization in this regard.</i>		

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):	1		
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 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)

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 - provide details in Part VI)	5	
6 Other distributions (describe in Part VI). 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 (provide details in Part VI). See instructions	8	
9 Distributable amount for 2021 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-2021	(iii) Distributable Amount for 2021
1 Distributable amount for 2021 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2021 (reasonable cause required-- explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2021:			
a From 2016.			
b From 2017.			
c From 2018.			
d From 2019.			
e From 2020.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2021 distributable amount			
i Carryover from 2016 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2021 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2021 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2021, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, explain in Part VI . See instructions.			
6 Remaining underdistributions for 2021. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, explain in Part VI . See instructions.			
7 Excess distributions carryover to 2022. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2017.			
b Excess from 2018.			
c Excess from 2019.			
d Excess from 2020.			
e Excess from 2021.			

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).

Facts And Circumstances Test

Return Reference	Explanation
SCHEDULE A, PART II, LINE 10, EXPLANATION OF OTHER INCOME:	STIMULUS/COVID CREDITS - 2021 AMOUNT: \$ 313,636. RETURN OF GRANT FUNDS - 2017 AMOUNT: \$ 100,870. 2018 AMOUNT: \$ 27,805. 2019 AMOUNT: \$ 7,779. 2021 AMOUNT: \$ 34,640. OTHER INCOME - 2017 AMOUNT: \$ 1,848. 2018 AMOUNT: \$ 591. 2019 AMOUNT: \$ 675. 2020 AMOUNT: \$ 527. 2021 AMOUNT: \$ 424.

Additional Data

Return to Form

Software ID:

Software Version:

Supplemental Financial Statements

2021

Open to Public Inspection

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.

Department of the Treasury Internal Revenue Service

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.

Table with 2 columns: (a) Donor advised funds, (b) Funds and other accounts. Rows include Total number at end of year, Aggregate value of contributions to (during year), Aggregate value of grants from (during year), and Aggregate value at end of year.

- 5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control?
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?

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).
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.

Table with 2 columns: Held at the End of the Year. Rows include 2a Total number of conservation easements, 2b Total acreage restricted by conservation easements, 2c Number of conservation easements on a certified historic structure included in (a), and 2d Number of conservation easements included in (c) acquired after 7/25/06.

- 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?
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)?
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.
1b 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:
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:

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

Part IV Escrow and Custodial Arrangements.

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

- 1a** Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? **Yes** **No**
- b** If "Yes," explain the arrangement in Part XIII and complete the following table:
- | | Amount |
|--|-----------|
| 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 in Part XIII

Part V Endowment Funds.

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance				2,106,221	959,883
b Contributions					932,237
c Net investment earnings, gains, and losses				-4,045	260,501
d Grants or scholarships					
e Other expenditures for facilities and programs				2,102,176	46,400
f Administrative expenses					
g End of year balance					2,106,221

- 2** Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a** Board designated or quasi-endowment ▶
 - b** Permanent endowment ▶
 - c** Term endowment ▶
- The percentages on lines 2a, 2b, and 2c should equal 100%.
- 3a** Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- | | Yes | No |
|--|-----|----|
| (i) Unrelated organizations | | No |
| (ii) Related organizations | | No |
| b If "Yes" on 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				
d Equipment				
e Other				

Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c.) . . . ▶ 0

Part VII Investments - Other Securities.

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

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives		
(2) Closely-held equity interests		
(3) Other _____		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
Total. (Column (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. (Column (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)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col.(B) line 25.)	67,801

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 FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII

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	5,661,765
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	-51,655	
b	Donated services and use of facilities	2b	225,200	
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	173,545
3	Subtract line 2e from line 1		3	5,488,220
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	5,488,220

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	4,843,027
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a	225,200	
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d	2,504	
e	Add lines 2a through 2d		2e	227,704
3	Subtract line 2e from line 1		3	4,615,323
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	4,615,323

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.

Return Reference	Explanation
PART XII, LINE 2D - OTHER ADJUSTMENTS:	BAD DEBT EXPENSE 2,504.

Additional Data

[Return to Form](#)

Software ID:
Software Version:

2021

Open to Public Inspection

Statement of Activities Outside the United States

▶ Complete if the organization answered "Yes" to 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.

SCHEDULE F (Form 990)

Department of the Treasury
Internal Revenue Service

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.

- For grantmakers.** Does the organization maintain records to substantiate the amount of its grants or other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? Yes No
- For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

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 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
(1) EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA, AUSTRIA, BELGIUM	0	0	GRANTS	N/A	415,798
(2) EAST ASIA AND THE PACIFIC	0	0	GRANTS	N/A	473,782
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
3a Sub-total	0	0			889,580
b Total from continuation sheets to Part I	0	0			0
c Totals (add lines 3a and 3b)	0	0			889,580

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)
(1)		EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA, AUSTRIA, BELGIUM	INHIBITION OF THE DOWNSTREAM CONSEQUENCES OF DUX4 EXPRESSION IN MUSCLES	104,973	WIRE TRANSFER	0	N/A	
(2)		EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA, AUSTRIA, BELGIUM	UNDERSTANDING AND TARGETING METABOLIC DYSFUNCTION IN FSHD	55,300	WIRE TRANSFER	0	N/A	
(3)		EUROPE (INCLUDING ICELAND & GREENLAND)	INTERACTION BETWEEN MESENCHYMAL STEM CELLS AND MYOBLASTS IN FSHD PATHOGENESIS	55,000	WIRE TRANSFER	0	N/A	
(4)		EUROPE (INCLUDING ICELAND & GREENLAND)	RESPONSIVENESS OF OUTCOME MEASURES ON FACIAL WEAKNESS IN	51,525	WIRE TRANSFER	0	N/A	
(5)		EUROPE (INCLUDING ICELAND & GREENLAND)	MUSCLE-TARGETED DELIVERY STRATEGIES FOR ANTISENSE TOOLS AGAINST DUX4	149,000	WIRE TRANSFER	0	N/A	
(6)		EAST ASIA AND THE PACIFIC	INVESTIGATING SMCHD1 STRUCTURE AND FUNCTION TO DEVELOP FSHD THERAPEUTICS	177,282	WIRE TRANSFER	0	N/A	
(7)		EAST ASIA AND THE PACIFIC	FSHD1 MODEL MICE WITH CHROMOSOME 4Q35 DERIVED FROM AN FSHD1 USING MAC	198,000	WIRE TRANSFER	0	N/A	
(8)		EAST ASIA AND THE PACIFIC	PEDIATRIC FSHD NATURAL HISTORY STUDY	98,500	WIRE TRANSFER	0	N/A	
(9)								
(10)								
(11)								
(12)								
(13)								
(14)								
(15)								
(16)								

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

3 Enter total number of other organizations or entities 1

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)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

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

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.

ReturnReference	Explanation
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 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 III ACCOUNTING METHOD:	

Additional Data

Software ID:

Software Version:

**Supplemental Information Regarding
Fundraising or Gaming Activities**

Complete if the organization answered "Yes" on Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.
 Attach to Form 990 or Form 990-EZ.
 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 Fundraising Activities. Complete if the organization answered "Yes" on Form 990, Part IV, line 17.
Form 990-EZ filers are not required to complete this part.

- 1** Indicate whether the organization raised funds through any of the following activities. Check all that apply.
- | | |
|--|---|
| a <input type="checkbox"/> Mail solicitations | e <input type="checkbox"/> Solicitation of non-government grants |
| b <input type="checkbox"/> Internet and email solicitations | f <input type="checkbox"/> Solicitation of government grants |
| c <input type="checkbox"/> Phone solicitations | g <input type="checkbox"/> Special fundraising events |
| d <input type="checkbox"/> In-person solicitations | |
- 2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? **Yes** **No**
- b** If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
Total						

3 List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.

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
		PEER TO PEER EVENTS (event type)	OTHER SPECIAL EVENTS (event type)	(total number)	(add col. (a) through col. (c))
Revenue	1 Gross receipts	784,149	114,647		898,796
	2 Less: Contributions	738,262	80,037		818,299
	3 Gross income (line 1 minus line 2)	45,887	34,610		80,497
Direct Expenses	4 Cash prizes		1,750		1,750
	5 Noncash prizes	7,678	0		7,678
	6 Rent/facility costs	4,160	9,295		13,455
	7 Food and beverages	4,336	4,991		9,327
	8 Entertainment	512	4,149		4,661
	9 Other direct expenses	29,201	14,425		43,626
	10 Direct expense summary. Add lines 4 through 9 in column (d) ▶				80,497
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))
		1 Gross revenue			
Direct Expenses	2 Cash prizes				
	3 Noncash prizes				
	4 Rent/facility costs				
	5 Other direct expenses				
6 Volunteer labor	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No		
7 Direct expense summary. Add lines 2 through 5 in column (d) ▶					
8 Net gaming income summary. Subtract line 7 from line 1, column (d) ▶					

9 Enter the state(s) in which the organization conducts gaming activities: _____

a Is the organization licensed to conduct gaming activities in each of these states? Yes No

b If "No," explain: _____

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? Yes No

b If "Yes," explain: _____

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 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.

Return Reference	Explanation
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Additional Data

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

2021

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.

(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
(1) THE RESEARCH INSTITUTE AT NATIONWIDE CHILDREN'S HOSPITAL 700 CHILDRENS DRIVE COLUMBUS, OH 43205	31-6056230	501(C)(3)	193,310	0	FMV	N/A	DEVELOPING AAV-CRISPR-CAS13 BASED GENE THERAPY FOR FSHD
(2) CHILDREN'S RESEARCH INSTITUTE CHILDRENS NATIONAL HEALTH SYSTEMS 801 ROEDER ROAD SUITE 500 SILVER SPRING, MD 20910	52-1654453	501(C)(3)	63,735	0	FMV	N/A	MEMBRANE REPAIR DEFICIT IN FSHD PATHOPHYSIOLOGY
(3) UNIVERSITY OF ROCHESTER 601 ELMWOOD AVENUE BOX 673 ROCHESTER, NY 14642	16-0743209	501(C)(3)	24,310	0	FMV	N/A	FSHD BIOLOGICAL RESOURCES AVAILABLE THROUGH THE CTRN (BIOAVAILABLE)
(4) UNIVERSITY OF KANSAS MEDICAL CENTER 4330 SHAWNEE MISSION PARKWAY SUITE 323 FAIRWAY, KS 66205	48-1108830	501(C)(3)	300,000	0	FMV	N/A	CLINICAL TRIALS RESEARCH NETWORK (CTRN) FOR FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY (FSHD)
(5) UNIVERSITY OF MARYLAND 220 ARCH STREET BALTIMORE, MD 21201	52-6002033	501(C)(3)	152,600	0	FMV	N/A	SLC34A2 AS A BIOMARKER FOR FSHD
(6) UNIVERSITY OF UTAH 201 S PRESIDENTS CIRCLE ROOM 406 SALT LAKE CITY, UT 841129023	87-6000525	501(C)(3)	49,621	0	FMV	N/A	NANOPORE CAS9-TARGETED SEQUENCING (NCATS DIAGNOSTICS FOR FSHD)
(7) YALE UNIVERSITY 2 WHITNEY AVENUE 6TH FLOOR NEW HAVEN, CT 06510	06-0646973	501(C)(3)	360,280	0	FMV	N/A	CHARACTERIZATION OF DUX4-INDUCED METABOLIC AND HYPOXIC CHANGES IN FSHD AND IDENTIFICATION OF TOXIC DUX4-INDUCED TRANSCRIPTS.
(8) UNIVERSITY OF COLORADO 1800 GRANT STREET DENVER, CO 80203	84-6000555	501(C)(3)	152,600	0	FMV	N/A	MECHANISM OF CONTEXT-SPECIFIC NMD INHIBITION BY DUX4
(9) ST LOUIS UNIVERSITY 3700 WEST PINE MALL 3RD FLOOR FUSZ HALL ST LOUIS, MO 63108	43-0654872	501(C)(3)	121,900	0	FMV	N/A	MOLECULAR MECHANISMS OF P38-DEPENDENT AND INDEPENDENT DUX4 ACTIVATION DURING MYOGENESIS

- 2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table 10
- 3** Enter total number of other organizations listed in the line 1 table 0

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 noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					

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

Return Reference	Explanation
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.

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Schedule J
(Form 990)

Compensation Information

OMB No. 1545-0047

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.**

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Department of the Treasury
Internal Revenue Service

Name of the organization
FSHD SOCIETY

Employer identification number

52-1762747

Part I Questions Regarding Compensation

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

- | | |
|---|--|
| <input type="checkbox"/> First-class or charter travel | <input type="checkbox"/> Housing allowance or residence for personal use |
| <input type="checkbox"/> Travel for companions | <input type="checkbox"/> Payments for business use of personal residence |
| <input type="checkbox"/> Tax idemnification and gross-up payments | <input type="checkbox"/> Health or social club dues or initiation fees |
| <input type="checkbox"/> Discretionary spending account | <input type="checkbox"/> Personal services (e.g., 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, officers, including the CEO/Executive Director, regarding the items checked on Line 1a?

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

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

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

- a** Receive a severance payment or change-of-control payment?
 - 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 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 in 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		No
4b		No
4c		No
5a		No
5b		No
6a		No
6b		No
7		No
8		No
9		

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

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

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

(A) Name and Title		(B) Breakdown of W-2, 1099-MISC compensation, and/or 1099-NEC			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation in column (B) reported as deferred on prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
1 MARK STONE CEO & PRESIDENT	(i)	199,683	0	0	27,640	18,219	245,542	0
	(ii)	0	0	0	0	0	0	0
2 JAMSHID ARJOMAND CHIEF SCIENCE OFFICER	(i)	189,401	1,000	0	7,640	11,378	209,419	0
	(ii)	0	0	0	0	0	0	0

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.

Return Reference	Explanation
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Noncash Contributions

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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 the latest information.**

Department of the Treasury
Internal Revenue Service

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FSHD SOCIETY

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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	9	1,071,212	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 IV, Donee Acknowledgement **29**

	Yes	No
30a During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least 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? If "Yes," describe the arrangement in Part II.		No
31 Does the organization have a gift acceptance policy that requires the review of any nonstandard contributions?		No
32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions? If "Yes," describe in Part II.		No
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.		

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

Return Reference	Explanation
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SCHEDULE O
(Form 990)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

2021**Open to Public
Inspection**Name of the organization
FSHD SOCIETY**Employer identification number**

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Return Reference	Explanation
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 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, SECTION C, LINE 19	UPON REQUEST, AVAILABLE ON ORGANIZATION'S WEBSITE AND THROUGH GUIDESTAR WEBSITE.
FORM 990, PART XI, LINE 9:	BAD DEBT EXPENSE -2,504.

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