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Return of Organization Exempt From Income Tax

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

OMB No. 1545-0047

▶ Do not enter social security numbers on this form as it may be made public. Open to Public Department of the Treasury ► Go to www.irs.gov/Form990 for instructions and the latest information. Inspection and ending A For the 2021 calendar year, or tax year beginning Check if applicable: C Name of organization D Employer identification number Address change FSHD SOCIETY Name change 52-1762747 Doing business as Initial return Number and street (or P.O. box if mail is not delivered to street address) Room/suite E Telephone number Final return/ (781) 301-606075 NORTH MAIN STREET 1073 termin-ated 6,470,177. G Gross receipts \$ City or town, state or province, country, and ZIP or foreign postal code Amended return RANDOLPH, MA 02368 H(a) Is this a group return Applica-F Name and address of principal officer: MARK A. STONE Yes X No for subordinates? pending SAME AS C ABOVE H(b) Are all subordinates included? Yes No Tax-exempt status: X = 501(c)(3) 501(c) () ◀ (insert no.) 4947(a)(1) or If "No," attach a list. See instructions J Website: WWW.FSHDSOCIETY.ORG **H(c)** Group exemption number ▶ **K** Form of organization: **X** Corporation Association Other > L Year of formation: 1991 M State of legal domicile: DC Part I Summary Briefly describe the organization's mission or most significant activities: INCREASE AWARENESS Activities & Governance UNDERSTANDING OF AND CONDUCT RESEARCH ON FACIOSCAPULOHUMERAL Check this box if the organization discontinued its operations or disposed of more than 25% of its net assets. 17 Number of voting members of the governing body (Part VI, line 1a) <u>17</u> Number of independent voting members of the governing body (Part VI, line 1b) <u>15</u> 5 Total number of individuals employed in calendar year 2021 (Part V, line 2a) <u>696</u> 6 Total number of volunteers (estimate if necessary) 7 a Total unrelated business revenue from Part VIII, column (C), line 12 7a b Net unrelated business taxable income from Form 990-T, Part I, line 11 7b **Prior Year Current Year** 2,272,171. 4,546,323. Contributions and grants (Part VIII, line 1h) Revenue 158,395. 172,014. Program service revenue (Part VIII, line 2g) 196,112. 421,183. Investment income (Part VIII, column (A), lines 3, 4, and 7d) 10 348,700. 527. Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) 5,488,220. 2,627,205. Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12) 625,018. 2,315,936. Grants and similar amounts paid (Part IX, column (A), lines 1-3) 0. 0. Benefits paid to or for members (Part IX, column (A), line 4) 1,622,282. 1,637,073. Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) Expenses 16a Professional fundraising fees (Part IX, column (A), line 11e) **b** Total fundraising expenses (Part IX, column (D), line 25) 617,504. 662,314. Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) 2,864,804. 4,615,323. Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) 872,897. -237,599. Revenue less expenses. Subtract line 18 from line 12 **Beginning of Current Year End of Year** 5,835,495. 7,638,819. 20 Total assets (Part X, line 16) 301,823. 1,286,409. 21 Total liabilities (Part X, line 26) 533,672. 6,352,410. Net assets or fund balances. Subtract line 21 from line 20. Part II | Signature Block

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

			04/04/2022
Sign	Signature of officer		Date
Here	MARK A. STONE, CEO & P	RESIDENT	
	Type or print name and title		
	Print/Type preparer's name	I FIGUATOL S SIGNALUTO	Date Check PTIN
Paid	SANDRA M. BROWN, CPA	Sandre M. Brun	03/30/22 if P00296843
Preparer	Firm's name SMITH, SULLIVAN	•	Firm's EIN ▶ 43-1985162
Use Only	Firm's address 80 FLANDERS ROAD		
	WESTBOROUGH, MA	01581	Phone no. (508) 871-7178
May the IF	RS discuss this return with the preparer shown abo	ove? See instructions	X Yes No.

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

3,853,263.

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Total program service expenses

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Form 990 (2021)

FSHD SOCIETY

Part IV Checklist of Required Schedules

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

			Yes	No
22	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on			
	Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III	22		X
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current			
	and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes," complete			
	Schedule J	23	Х	
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the			
	last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b through 24d and complete			
	Schedule K. If "No," go to line 25a	24a		X
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
С	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease			
	any tax-exempt bonds?	24c		
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
25 a	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit			
	transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I	25a		X
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and			
	that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If "Yes," complete			
	Schedule L, Part I	25b		X
26	Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current			
	or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35%			
	controlled entity or family member of any of these persons? If "Yes," complete Schedule L, Part II	26		X
27	Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee,			
	creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled			l
	entity (including an employee thereof) or family member of any of these persons? If "Yes," complete Schedule L, Part III	27		Х
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):			
а	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If			
	"Yes," complete Schedule L, Part IV	28a		X
	A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV	28b		Х
С	A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b?	00-		X
00	"Yes," complete Schedule L, Part IV	28c 29	Х	
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If</i> "Yes," <i>complete Schedule M</i> Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation	29	21	
30	contributions? If "Yes," complete Schedule M	30		X
31	Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I	31		X
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete	31		
OZ.	Schedule N, Part II	32		x
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations			
	sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I	33		x
34	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and			
	Part V, line 1	34		х
35 a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		Х
	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity			
	within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2	35b		
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization?			
	If "Yes," complete Schedule R, Part V, line 2	36		Х
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization			
	and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI	37		X
38	Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19?			
Da	Note: All Form 990 filers are required to complete Schedule 0 It V Statements Regarding Other IRS Filings and Tax Compliance	38	Х	
Pal				
	Check if Schedule O contains a response or note to any line in this Part V			<u> </u>
4.	Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable		Yes	No
ıa				
a	Effect the number of Forms wize included of line 1a. Effect 10-11 not applicable			
С	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming	10		
	(gambling) winnings to prize winners?	1c	000	

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

			Yes	No			
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements,						
	filed for the calendar year ending with or within the year covered by this return						
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b	X				
	Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file. See instructions.						
За	Did the organization have unrelated business gross income of \$1,000 or more during the year?	За		X			
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O	3b					
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a						
	financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4a		X			
b	If "Yes," enter the name of the foreign country						
	See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).						
5а	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a		X			
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b		X			
c If "Yes" to line 5a or 5b, did the organization file Form 8886-T?							
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit			.,			
	any contributions that were not tax deductible as charitable contributions?	6a		X			
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts						
_	were not tax deductible?	6b					
7	Organizations that may receive deductible contributions under section 170(c).	_	v				
а	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7a	X				
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	Λ				
С	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required	7.		х			
A	to file Form 8282? If "Yes," indicate the number of Forms 8282 filed during the year 7d	7c		25			
d e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e		х			
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f		X			
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g					
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7h					
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the						
	sponsoring organization have excess business holdings at any time during the year?	8		Х			
9	Sponsoring organizations maintaining donor advised funds.						
а	Did the sponsoring organization make any taxable distributions under section 4966?	9a		Х			
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9b		Х			
10	Section 501(c)(7) organizations. Enter:						
а	Initiation fees and capital contributions included on Part VIII, line 12						
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities						
11	Section 501(c)(12) organizations. Enter:						
а	Gross income from members or shareholders						
b	Gross income from other sources. (Do not net amounts due or paid to other sources against						
	amounts due or received from them.)						
	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a					
	If "Yes," enter the amount of tax-exempt interest received or accrued during the year						
13	Section 501(c)(29) qualified nonprofit health insurance issuers.	13a					
а	Is the organization licensed to issue qualified health plans in more than one state? Note: See the instructions for additional information the organization must report on Schedule O.	ısa					
b	Enter the amount of reserves the organization is required to maintain by the states in which the						
b	organization is licensed to issue qualified health plans						
С	Enter the amount of reserves on hand 13c						
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a		Х			
	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O	14b					
15	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or						
	excess parachute payment(s) during the year?	15		х			
	If "Yes," see the instructions and file Form 4720, Schedule N.						
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment income?	16		Х			
	If "Yes," complete Form 4720, Schedule O.						
17	Section 501(c)(21) organizations. Did the trust, any disqualified person, or mine operator engage in any						
	activities that would result in the imposition of an excise tax under section 4951, 4952 or 4953?	17					
	If "Yes," complete Form 6069.						

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

_	Crieck if Scriedule O contains a response or note to any line in this Part VI				21
Sec	tion A. Governing Body and Management				
			-	Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year	1a 1	7		
	If there are material differences in voting rights among members of the governing body, or if the governing				
	body delegated broad authority to an executive committee or similar committee, explain on Schedule 0.		_		
b	Enter the number of voting members included on line 1a, above, who are independent	1 _b 1	7		
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationsh	ip with any other			
	officer, director, trustee, or key employee?		2	Х	
3	Did the organization delegate control over management duties customarily performed by or under the	ne direct supervision			
	of officers, directors, trustees, or key employees to a management company or other person?		3		X
4	Did the organization make any significant changes to its governing documents since the prior Form				Х
5	Did the organization become aware during the year of a significant diversion of the organization's as	sets?	5		X
6	Did the organization have members or stockholders?		6		X
7a	Did the organization have members, stockholders, or other persons who had the power to elect or a				
	more members of the governing body?		7a		Х
b	Are any governance decisions of the organization reserved to (or subject to approval by) members,				
	persons other than the governing body?		7b		Х
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the ye				
а	The governing body?		8a	Х	
b	Each committee with authority to act on behalf of the governing body?			Х	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be rea				
_	organization's mailing address? If "Yes," provide the names and addresses on Schedule O		9		Х
Sec	tion B. Policies (This Section B requests information about policies not required by the Internal Fi		. , -		
	1			Yes	No
10a	Did the organization have local chapters, branches, or affiliates?		10a	Х	
	If "Yes," did the organization have written policies and procedures governing the activities of such control of the control of				
	and branches to ensure their operations are consistent with the organization's exempt purposes?		10b	Х	
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing boo		11a	Х	
b	Describe on Schedule O the process, if any, used by the organization to review this Form 990.	,			
12a	and the second s		12a	Х	
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise		12b	Х	
С	Did the organization regularly and consistently monitor and enforce compliance with the policy? If ")				
	on Schedule O how this was done		12c	Х	
13	Did the organization have a written whistleblower policy?			Х	
14	Did the organization have a written document retention and destruction policy?			Х	
15	Did the process for determining compensation of the following persons include a review and approv				
	persons, comparability data, and contemporaneous substantiation of the deliberation and decision?				
а	The organization's CEO, Executive Director, or top management official		15a	Х	
b	Other officers or key employees of the organization		15b	Х	
	If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions.				
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrange	ment with a			
	taxable entity during the year?		16a		Х
b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate				
·	in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organic				
	exempt status with respect to such arrangements?		16b		
Sec	tion C. Disclosure		_		
17	List the states with which a copy of this Form 990 is required to be filed ►MA, AK, AR, CA, C	CO,CT,DC,FL,G	A,HI	, IL	,KS
18	Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, a				
	for public inspection. Indicate how you made these available. Check all that apply.				
	X Own website X Another's website X Upon request Other (explain	on Schedule O)			
19	Describe on Schedule O whether (and if so, how) the organization made its governing documents, c	onflict of interest policy,	and fina	ncial	
	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 bo	ooks and records			
	LISA SCHIMMEL - (781) 301-6060	· —			
	75 NORTH MAIN STREET, 1073, RANDOLPH, MA 02368				
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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, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

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

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

	week (list any		cer an		rson i	than is bot or/trus	h an	Reportable compensation	Reportable compensation from related	Estimated amount of other
	hours for related organizations below line)	Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former	from the organization (W-2/1099-MISC/ 1099-NEC)	organizations (W-2/1099-MISC/ 1099-NEC)	compensation from the organization and related organizations
(1) MARK STONE CEO & PRESIDENT	40.00			х				199,683.	0.	15 950
	40.00			Δ	⊢			133,003.	0.	45,859.
(2) JAMSHID ARJOMAND CHIEF SCIENCE OFFICER	40.00	1			x			190,401.	0.	19,018.
(3) LISA SCHIMMEL	40.00							190,401.	0.	19,010.
CFO				х				106,139.	0.	22,503.
(4) BETH JOHNSTON	40.00									
CHIEF COMMUNITY ENGAGEMENT OFFICER						Х		116,000.	0.	5,364.
(5) JUNE KINOSHITA	40.00								_	
DIR OF RESEARCH & PATIENT ENGAGEMENT					L	Х		101,000.	0.	4,702.
(6) JAMES A. CHIN, SR.	10.00									
CHAIRMAN	1000	Х		Х	$ldsymbol{ldsymbol{ldsymbol{eta}}}$			0.	0.	0.
(7) HOWARD L. CHABNER, J.D.	10.00	١							•	•
VICE CHAIRMAN	10 00	Х		Х	<u> </u>			0.	0.	0.
(8) CHRISTINE FORD	10.00								0	•
SECRETARY	10 00	Х		Х	<u> </u>			0.	0.	0.
(9) ELLEN K. HANNAN	10.00	,,		,,					0	0
TREASURER	10 00	Х		Х	\vdash			0.	0.	0.
(10) AMY Z. BEKIER	10.00	x						0.	0.	0.
BOARD MEMBER	1.00	Δ			⊢			0.	0.	0.
(11) STUART LAI BOARD MEMBER	1.00	x						0.	0.	0.
(12) DAVID RUBIN	1.00	Δ			\vdash			0.	0.	0.
BOARD MEMBER	1.00	Х						0.	0.	0.
(13) WILLIAM R. LEWIS, III, M.D.	1.00	25						0.	0.	0.
BOARD MEMBER	1.00	Х						0.	0.	0.
(14) MICHELLE HELEN MACKAY	1.00									
BOARD MEMBER		x						0.	0.	0.
(15) LEE FRANK KOLAKOWSKI, PH.D.	10.00	 						•		•
BOARD MEMBER		x						0.	0.	0.
(16) LINDA LAURELLO	1.00	-								3.0
BOARD MEMBER		х						0.	0.	0.
(17) GEORGE POLLOCK, JR.	10.00				\vdash					
BOARD MEMBER		х						0.	0.	0.

Form **990** (2021)

Part VII Section A. Officers, Directors, Trus	tees, Key Em	ploy	ees	, an	d Hi	ighe	st C	Compensated Employe	es (continued)				
(A) (B)			(C)					(D)	(E)			(F)	
Name and title	Average	(do	not c	Pos heck	more) than	one	Reportable	Reportable		Es	timate	d
	hours per week			ss pe				compensation	compensatio			nount o	of
	(list any	\vdash					T	from the	from related organization		l	other	tion
	hours for	Individual trustee or director				L,		organization	(W-2/1099-MIS			pensat om the	
	related	e or (stee			nsateo		(W-2/1099-MISC/	1099-NEC)			anizati	
	organizations	truste	Institutional trustee		yee	umbei		1099-NEC)			·	d relate	
	below	idual	tution	er	Key employee	est co	Jer.	·			orga	anizatio	ons
	line)	lndi	Insti	Officer	Keye	Highest compensated employee	Вm						
(18) NEIL ANDREW SOLOMON, MD, FACP	1.00												
BOARD MEMBER		Х						0.		0.			0.
(19) CARDEN WYCKOFF	1.00							_					
BOARD MEMBER		Х						0.		0.			0.
(20) MARIE MORRELL	1.00												_
BOARD MEMBER		Х						0.		0.			0.
(21) JACK GERBLICK	1.00	l											•
BOARD MEMBER	1 00	Х				_		0.		0.			0.
(22) BRUCE RYSKAMP	1.00												_
BOARD MEMBER		Х						0.		0.			0.
		-											
						-							
		-											
						-							
		1											
						\vdash							
		1											
4h Cubtatal								713,223.		0.	a	7,4	16
1b Subtotal								713,223.		0.		<i>,</i> , 4.	• 0 •
c Total from continuation sheets to Part V								713,223.		0.	a	7,4	
d Total (add lines 1b and 1c) 2 Total number of individuals (including but r							20 1		000 of reported			,,	<u> </u>
compensation from the organization	ioi iirriitea to ti	1056	11516	eu ai	DOV	e) wi	10 1	eceived more than \$100	,000 or reportable	Æ			5
compensation from the organization												Yes	No
3 Did the organization list any former officer	director trust	ا مم	(AV	emn	love	ae 0	r hic	sheet compensated emr	Novee on	ľ			
line 1a? If "Yes," complete Schedule J for s			•		•		_		•		3		Х
4 For any individual listed on line 1a, is the s													
and related organizations greater than \$15	-		-					•	the organization		4	х	
5 Did any person listed on line 1a receive or									idual for services				
rendered to the organization? If "Yes," con	•				•			•			5		Х
Section B. Independent Contractors	.,			,	,								
Complete this table for your five highest co	mpensated in	depe	ende	ent c	onti	racto	ors t	that received more than	\$100,000 of com	npens	ation f	rom	
the organization. Report compensation for										•			
(A)								(B)			(0	;)	
Name and business	address	N	INC	E				Description of s	ervices	C	ompe	nsatior	ı
O Total number of independent continues	in aludis - but	o+ !!	mi+-	ما لم	+ b <	oc !'		d aboug) who received a	ave ther				
Total number of independent contractors (\$100,000 of compensation from the organ	-	iot II	mite	:u 10	(110	0	siec	above) who received n	юе шап			200	

Form **990** (2021)

FSHD SOCIETY 52-1762747 Page 9 Form 990 (2021) Part VIII Statement of Revenue Check if Schedule O contains a response or note to any line in this Part VIII (B) (C) Revenuè éxcluded Related or exempt Unrelated Total revenue from tax under function revenue business revenue sections 512 - 514 Contributions, Gifts, Grants and Other Similar Amounts 10,006 1 a Federated campaigns 1a **b** Membership dues 1b 818,299. c Fundraising events 1c d Related organizations 1d 285,077 Government grants (contributions) 1e f All other contributions, gifts, grants, and similar amounts not included above 3,432,941 1f 1,071,212 g Noncash contributions included in lines 1a-1f 1g |\$ 4,546,323 h Total. Add lines 1a-1f **Business Code** 2 a CORPORATE SPONSORSHIPS 147,744 Program Service Revenue 900099 147,744. RESEARCH MEETING REGISTRATIONS 900099 21,900 21,900 CORPORATE PARTNERSHIPS 900099 1,500 1,500 PATIENT MEETING REGISTRATIONS 900099 870. 870 All other program service revenue g Total. Add lines 2a-2f 172,014, \blacktriangleright Investment income (including dividends, interest, and 122,027 122,027 other similar amounts) Income from investment of tax-exempt bond proceeds 5 Royalties (i) Real (ii) Personal 6 a Gross rents **b** Less: rental expenses ... 6b c Rental income or (loss) d Net rental income or (loss) 7 a Gross amount from sales of (i) Securities (ii) Other 1,200,616 assets other than inventory 7a b Less: cost or other basis Other Revenue 901,460 7b and sales expenses 299,156. c Gain or (loss) 299,156. 299,156. d Net gain or (loss) 8 a Gross income from fundraising events (not 818,299. of including \$ contributions reported on line 1c). See Part IV, line 18 80,497 **b** Less: direct expenses _____ 80,497 c Net income or (loss) from fundraising events 0 9 a Gross income from gaming activities. See Part IV, line 19 **b** Less: direct expenses 9b c Net income or (loss) from gaming activities 10 a Gross sales of inventory, less returns and allowances **b** Less: cost of goods sold c Net income or (loss) from sales of inventory **Business Code** Miscellaneous Revenue 11 a STIMULUS/COVID CREDITS 900099 313,636 313,636 b RETURN OF GRANT FUNDS 900099 34,640 34,640

12 132009 12-09-21 421,607.

424.

424

520,290

348,700

5,488,220

OTHER INCOME

Total. Add lines 11a-11d

Total revenue. See instructions

All other revenue

900099

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Form 990 (2021) FSHD SOCIETY 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).

Do :	Check if Schedule O contains a respon not include amounts reported on lines 6b,	(A)	(B)	(C)	(D)
7b,	8b, 9b, and 10b of Part VIII.	Total expenses	Program service expenses	Management and general expenses	Fundraising expenses
1	Grants and other assistance to domestic organizations	1 426 256	1 426 256		
	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	000 500	000 500		
	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,	E02 602	201 200	152 106	40 100
_	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)	704 051	F 4 7 2 0 1	67 000	170 (50
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)	1 - 1 4 - 1	111 016	0 100	20 202
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 (nonemployees):				
а	Management			6 0 4 0	
b	Legal	7,140.	300.	6,840.	
С	Accounting	15,500.		15,500.	
d	Lobbying				
е	Professional fundraising services. See Part IV, line 17				
f	Investment management fees				
g	Other. (If line 11g amount exceeds 10% of line 25,				
	column (A), amount, list line 11g expenses on Sch O.)	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 on line 24e. If				
	line 24e amount exceeds 10% of line 25, column (A), amount, list line 24e expenses on Schedule 0.)				
а	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.		<u> </u>
-	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 if following SOP 98-2 (ASC 958-720)				
	11 00 01				Earm 990 (2021

Form **990** (2021)

52-1762747 Page **11** Form 990 (2021)
Part X Balance Sheet FSHD SOCIETY

Pa	πλ	Balance Sheet						
		Check if Schedule O contains a response of	or note t	o ar	this Part X			
						(A) Beginning of year		(B) End of year
	1	Cash - non-interest-bearing					1	
	2	Savings and temporary cash investments .				3,280,720		
	3	Pledges and grants receivable, net				340,181	• 3	293,686
	4	Accounts receivable, net			4			
	5	Loans and other receivables from any curre	ent or fo	rme	director,			
		trustee, key employee, creator or founder, s	substan	ntial	tor, or 35%			
		controlled entity or family member of any of	f these	pers			5	
	6	Loans and other receivables from other dis-	squalifie	d pe	s defined			
		under section 4958(f)(1)), and persons desc	58(c)(3)(B)		6			
ST.	7	Notes and loans receivable, net			7			
Assets	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 oth	her					
		basis. Complete Part VI of Schedule D	1	0a	0.			
	b	Less: accumulated depreciation	1	0b	0.	5,097		
	11	Investments - publicly traded securities				1,943,769	. 1	2,246,249
	12	Investments - other securities. See Part IV,		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				
	16	Total assets. Add lines 1 through 15 (must	t equal I	ine 3		5,835,495		
	17	Accounts payable and accrued expenses .				43,016		
	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. Comp	olete Pai	rt IV	dule D		2	1
es	22	Loans and other payables to any current or	r former	offi	ctor,			
		trustee, key employee, creator or founder, s	substan	itial (tor, or 35%			
Liabilities		controlled entity or family member of any of	f these	pers			22	2
_	23	Secured mortgages and notes payable to u					23	3
	24	Unsecured notes and loans payable to unre	elated ti	hird			24	1
	25	Other liabilities (including federal income tax	ıx, payal	bles	ed third			
		parties, and other liabilities not included on	lines 1	7-24	ete Part X	44 0=0		4- 44
		of Schedule D				41,878		•
	26	Total liabilities. Add lines 17 through 25 .				301,823	• 26	1,286,409
S		Organizations that follow FASB ASC 958	3, check	her	<u>X</u>			
ဥ		and complete lines 27, 28, 32, and 33.						
<u>a</u>	27	Net assets without donor restrictions				3,007,424		
Ď	28	Net assets with donor restrictions				2,526,248	• 28	2,376,528
<u> </u>		Organizations that do not follow FASB A	• ▶ ☐ │					
Ž		and complete lines 29 through 33.						
īs.	29	Capital stock or trust principal, or current fu			29	9		
SSe	30	Paid-in or capital surplus, or land, building,	or equip	ome			30)
Net Assets or Fund Balances	31	Retained earnings, endowment, accumulate					3-	
Š	32	Total net assets or fund balances				5,533,672		
	33	Total liabilities and net assets/fund balance	es			5,835,495	• 33	7,638,819

Form **990** (2021)

Pai	rt XI Reconciliation of Net Assets							
	Check if Schedule O contains a response or note to any line in this Part XI				X			
1	Total revenue (must equal Part VIII, column (A), line 12)	1	5,48					
2	Total expenses (must equal Part IX, column (A), line 25)	2	4,61		$\frac{23.}{97.}$			
3	Revenue less expenses. Subtract line 2 from line 1							
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	5,53					
5	Net unrealized gains (losses) on investments	5	-5	1,6	55.			
6	Donated services and use of facilities	6						
7	Investment expenses	7			-			
8	Prior period adjustments	8			,			
9	Other changes in net assets or fund balances (explain on Schedule O)	9	_	2,5	04.			
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32,							
	column (B))	10	6,35	2,4	10.			
Pai	rt 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: Cash X Accrual Other							
	If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedul	e O.						
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?		. 2a		X			
	If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed	d on a						
	separate basis, consolidated basis, or both:							
	Separate basis Consolidated basis Both consolidated and separate basis							
b	Were the organization's financial statements audited by an independent accountant?		. 2b	X				
	If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate	e basis,						
	consolidated basis, or both:							
	X Separate basis Consolidated basis Both consolidated and separate basis							
С	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the	e audit,						
	review, or compilation of its financial statements and selection of an independent accountant?		. 2c	X				
	If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.							
За	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?		. 3a		X			
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the requ							
	or audits, explain why on Schedule O and describe any steps taken to undergo such audits		. 3b					
			Form	990	(2021)			

SCHEDULE A

(Form 990)

Total

Department of the Treasury Internal Revenue Service

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.

OMB No. 1545-0047

Open to Public Inspection

Employer identification number Name of the organization FSHD SOCIETY 52-1762747 Reason for Public Charity Status. (All organizations must complete this part.) See instructions. Part I 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). 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: 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.) A federal, state, or local government or governmental unit described in section 170(b)(1)(A)(v). 7 X 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.) An agricultural research organization described in section 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. 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. 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. its supported organization(s) (see instructions). You must complete Part IV, Sections A, D, and E. ☐ 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. Check this box if the organization received a written determination from the IRS that it is a Type I, Type III, Type III functionally integrated, or Type III non-functionally integrated supporting organization. f Enter the number of supported organizations Provide the following information about the supported organization(s). (iv) Is the organization listed (i) Name of supported (ii) EIN (iii) Type of organization (v) Amount of monetary (vi) Amount of other ì your governing document? (described on lines 1-10 organization support (see instructions) support (see instructions) Yes No above (see instructions))

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

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

Sec	ction A. Public Support	7.1	•	•			
Cale	ndar year (or fiscal year beginning in)	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
	Gifts, grants, contributions, and	, ,	` '	, ,	, ,	, ,	.,
	membership fees received. (Do not						
	include any "unusual grants.")	3031111.	2344902.	4942896.	2272171.	4546323.	17137403.
2	Tax revenues levied for the organ-						
	ization'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	2021111	0244000	4040006	0000101	4546202	1 7 1 2 7 4 0 2
	Total. Add lines 1 through 3	3031111.	2344902.	4942896.	2272171.	4546323.	17137403.
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,						2401760
	column (f)						3491762.
	Public support. Subtract line 5 from line 4.						13645641.
	etion B. Total Support						<u> </u>
	ndar year (or fiscal year beginning in)	(a) 2017 3031111.	(b) 2018 2344902.	(c) 2019 4942896.	(d) 2020 2272171.	(e) 2021	(f) Total 17137403.
	Amounts from line 4	3031111.	2344902.	4942090.	22/21/1.	4340323.	1/13/403.
8	Gross income from interest,						
	dividends, payments received on						
	securities loans, rents, royalties,	114,053.	137,366.	93,131.	72,211.	122,027.	538,788.
_	and income from similar sources	114,033.	137,300.	93,131.	12,211.	122,027.	330,700.
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			7	<u> </u>		18164986.
12	Gross receipts from related activities,	etc. (see instructi	ons)				,006,337.
	First 5 years. If the Form 990 is for the	•	,				
	organization, check this box and stop	here					
Sec	ction C. Computation of Publ						
14	Public support percentage for 2021 (I	line 6, column (f), c	divided by line 11,	column (f))		14	75.12 %
15	Public support percentage from 2020	Schedule A, Part	II, line 14			15	81.54 %
16a	33 1/3% support test - 2021. If the o						
	$\ensuremath{\mathbf{stop}}$ here. The organization qualifies	as a publicly supp	orted organization				▶ X
b	33 1/3% support test - 2020. If the o	-					
	and stop here. The organization qual						
17a	10% -facts-and-circumstances tes	-					
	and if the organization meets the fact			=	•	VI how the organiz	zation
	meets the facts-and-circumstances to	_	· · · · · · · · · · · · · · · · · · ·	* * * * * * * * * * * * * * * * * * * *	-		
b	10% -facts-and-circumstances tes	-					10% or
	more, and if the organization meets the				-		
	organization meets the facts-and-circle		-				
<u>18</u>	Private foundation. If the organization	n did not check a	box on line 13, 16	a, 16b, 17a, or 17k	o, check this box a	ana see instruction	ıs

Schedule A (Form 990) 2021

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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	relow, please com	ipietė Part II.)				
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 per-						
formed, 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 bus-						
iness under section 513						
4 Tax revenues levied for the organ-						
ization's benefit and either paid to						
or expended on its behalf 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		#1.0040	1 (10040	1 , , , , , ,	() 000/	(0
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	ne organization's f	first, second, third,	fourth, or fifth tax	year as a section	501(c)(3) organizat	tion,
check this box and stop here						<u></u> ▶□
Section C. Computation of Publ	ic Support Pe	ercentage				
15 Public support percentage for 2021 (line 8, column (f),	divided by line 13,	column (f))		15	%
16 Public support percentage from 2020					16	%
Section D. Computation of Inve	stment Incom	ne Percentage)			
17 Investment income percentage for 20)21 (line 10c, colu	mn (f), divided by l	ine 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					33 1/3%, and line	17 is not
more than 33 1/3%, check this box a	ınd stop here. The	organization qual	ifies as a publicly s	supported organiz	zation	
b 33 1/3% support tests - 2020. If the						and
line 18 is not more than 33 1/3%, che	eck this box and s	top here. The orga	anization qualifies a	as a publicly supp	orted organization	
20 Private foundation. If the organization						

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Schedule A (Form 990) 2021 FSHD SOCIETY

Part IV | Supporting Organizations

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

Section A. All Supporting Organizations

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

	Yes	No
1		
2		
3a		
3b		
3с		
4a		
4b		
4c		
5a		
5b		
5c		
6		
7		
8		
9a		
9b		
0-		
9с		
10a		
10b		

Par	Supporting Organizations (continued)			
			Yes	No
11	Has the organization accepted a gift or contribution from any of the following persons?			
а	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?	11a		
b	A family member of a person described on line 11a above?	11b		
С	A 35% controlled entity of a person described on line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide			
_	detail in Part VI.	11c		
Sec	tion B. Type I Supporting Organizations			
	г		Yes	No
1	Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or			
	more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, directors, or trustees at all times during the tax year? If "No," describe in Part VI how the supported organization(s)			
	effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported			
	organization, describe how the powers to appoint and/or remove officers, directors, or trustees were allocated among the			
	supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.	1		
2	Did the organization operate for the benefit of any supported organization other than the supported			
	organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in			
	Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated,			
C	supervised, or controlled the supporting organization.	2		
Sec	tion C. Type II Supporting Organizations		1	
			Yes	No
1	Were a majority of the organization's directors or trustees during the tax year also a majority of the directors			
	or trustees of each of the organization's supported organization(s)? If "No," describe in Part VI how control			
	or management of the supporting organization was vested in the same persons that controlled or managed			
Sact	the supported organization(s). tion D. All Type III Supporting Organizations	1		
000			Yes	Na
4	Did the expenization provide to each of its supported expenizations, by the last day of the fifth month of the		res	No
1	Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax			
	year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the			
	organization's governing documents in effect on the date of notification, to the extent not previously provided?	1		
2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported			
_	organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how			
	the organization maintained a close and continuous working relationship with the supported organization(s).	2		
3	By reason of the relationship described on line 2, above, did the organization's supported organizations have a	_		
•	significant voice in the organization's investment policies and in directing the use of the organization's			
	income or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's			
	supported organizations played in this regard.	3		
Sec	tion 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 yea(see instructions).			
а	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.			
С	The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see ins	structio	ns).	
2	Activities Test. Answer lines 2a and 2b below.		Yes	No
а	Did substantially all of the organization's activities during the tax year directly further the exempt purposes of			
	the supported organization(s) to which the organization was responsive? If "Yes," then in Part VI identify			
	those supported organizations and explain how these activities directly furthered their exempt purposes,			
	how the organization was responsive to those supported organizations, and how the organization determined			
	that these activities constituted substantially all of its activities.	2a		
b	Did the activities described on line 2a, above, constitute activities that, but for the organization's involvement,			
	one or more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in			
	Part VI the reasons for the organization's position that its supported organization(s) would have engaged in			
	these activities but for the organization's involvement.	2b		
	Parent of Supported Organizations. Answer lines 3a and 3b below.			
а	Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or			
_	trustees of each of the supported organizations? If "Yes" or "No" provide details in Part VI.	3a		
h	Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each			

of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.

3b | 132025 01-04-22 | Schedule A (Form 990) 2021

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Schedule A (Form 990) 2021

FSHD SOCIETY

Pa	rt V Type III Non-Functionally Integrated 509(a)(3) Supporting	ng Orga	nizations					
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.							
Sect	ion 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						
Sect	ion 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):							
а	Average monthly value of securities	1a						
b	Average monthly cash balances	1b						
С	Fair market value of other non-exempt-use assets	1c						
d	Total (add lines 1a, 1b, and 1c)	1d						
е	Discount claimed for blockage or other factors							
	(explain in detail in Part VI):							
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						
Sect	ion C - Distributable Amount			Current Year				
1	Adjusted net income for prior year (from Section A, line 8, column A)	1						
2	Enter 0.85 of line 1.	2						
3	Minimum asset amount for prior year (from Section B, line 8, column A)	3						
4	Enter greater of line 2 or line 3.	4						
5	Income tax imposed in prior year	5						
6	Distributable Amount. Subtract line 5 from line 4, unless subject to							
	emergency temporary reduction (see instructions).	6						
7	Check here if the current year is the organization's first as a non-functional	ılly integra	ited Type III supporting org	anization (see				
	instructions).							

Schedule A (Form 990) 2021

Par	t V Type III Non-Functionally Integrated 509	(a)(3) Supporting Orga	anızatıons _{(continu}	ıed)	
Secti	on D - Distributions		•	·	Current Year
1	Amounts paid to supported organizations to accomplish exe	mpt purposes		1	
2	Amounts paid to perform activity that directly furthers exemp	ot purposes of supported			
	organizations, in excess of income from activity			2	
3	Administrative expenses paid to accomplish exempt purpose	es of supported organizatior	ns	3	
4	Amounts paid to acquire exempt-use assets			4	
5	Qualified set-aside amounts (prior IRS approval required - pro	ovide 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	he organization is responsive	е		
	(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	
Secti	on E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistribution Pre-2021	ıs	(iii) Distributable Amount for 2021
1	Distributable amount for 2021 from Section C, line 6				
2	Underdistributions, if any, for years prior to 2021 (reason-				
	able cause required - explain in Part VI). See instructions.				
3	Excess distributions carryover, if any, to 2021				
а	From 2016				
b	From 2017				
С	From 2018				
d	From 2019				
е	From 2020				
f	Total of lines 3a through 3e				
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				
С	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. For result greater				
	than zero, explain in Part VI. See instructions.				
6	Remaining underdistributions for 2021. Subtract lines 3h				
	and 4b from line 1. For result 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:				
а	Excess from 2017				
b	Excess from 2018				
	Excess from 2019				
	Excess from 2020				
	Excess from 2021				

Schedule A (Form 990) 2021

Supplemental Information. Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a, and 3b; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions.)

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

SCHEDULE D (Form 990)

Department of the Treasury Internal Revenue Service

Supplemental Financial Statements

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

► Attach to Form 990.

►Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Inspection

Name of the organization

FSHD SOCIETY

Employer identification number 52-1762747

Par	t I Organizations Maintaining Donor Advise	ed Funds or Other Similar Funds or	Accounts. Complete if the
	organization answered "Yes" on Form 990, Part IV, lir	ne 6.	
		(a) Donor advised funds	(b) Funds and other accounts
1	Total number at end of year	1	
2	Aggregate value of contributions to (during year)	1,008,635.	
3	Aggregate value of grants from (during year)	1,000,000.	
4	Aggregate value at end of year	2,178,448.	
5	Did the organization inform all donors and donor advisors in	writing that the assets held in donor advised fu	
	are the organization's property, subject to the organization's	exclusive legal control?	X Yes No
6	Did the organization inform all grantees, donors, and donor a	advisors in writing that grant funds can be used	d only
	for charitable purposes and not for the benefit of the donor of	or donor advisor, or for any other purpose conf	
Par	t II Conservation Easements. Complete if the org	ganization answered "Yes" on Form 990, Part I	V, line 7.
1	Purpose(s) of conservation easements held by the organizat	ion (check all that apply).	
	Preservation of land for public use (for example, recrea	ation or education) Preservation of a his	storically important land area
	Protection of natural habitat	Preservation of a ce	rtified historic structure
	Preservation of open space		
2	Complete lines 2a through 2d if the organization held a quali	fied conservation contribution in the form of a	
	day of the tax year.		Held at the End of the Tax Year
а	Total number of conservation easements		
b			
С	Number of conservation easements on a certified historic str		2c
d	Number of conservation easements included in (c) acquired		
_	listed in the National Register		
3	Number of conservation easements modified, transferred, re	leased, extinguished, or terminated by the org	anization during the tax
_	year >		
4	Number of states where property subject to conservation ea		
5	Does the organization have a written policy regarding the pe		□ v _a a □ Na
	violations, and enforcement of the conservation easements i		
6	Staff and volunteer hours devoted to monitoring, inspecting,	nandling of violations, and enforcing conserva	ation easements during the year
7	Amount of expenses incurred in monitoring, inspecting, hand	dling of violations, and enforcing concernation	accoments during the year
′	S	diling of violations, and emorcing conservation	easements during the year
8	Does each conservation easement reported on line 2(d) above	we estisfy the requirements of section 170/h)///	MR)(i)
Ü	and section 170(h)(4)(B)(ii)?		
9	In Part XIII, describe how the organization reports conservat		
•	balance sheet, and include, if applicable, the text of the foot	•	
	organization's accounting for conservation easements.		
Par	t III Organizations Maintaining Collections o	f Art, Historical Treasures, or Othe	r Similar Assets.
	Complete if the organization answered "Yes" on Form	n 990, Part IV, line 8.	
1a	If the organization elected, as permitted under FASB ASC 95	58, not to report in its revenue statement and b	palance sheet works
	of art, historical treasures, or other similar assets held for pul	blic exhibition, education, or research in furthe	rance of public
	service, provide in Part XIII the text of the footnote to its fina	ncial statements that describes these items.	
b	If the organization elected, as permitted under FASB ASC 95	58, to report in its revenue statement and balar	nce sheet works of
	art, historical treasures, or other similar assets held for public	c exhibition, education, or research in furtherar	nce of public service,
	provide the following amounts relating to these items:		
	(i) Revenue included on Form 990, Part VIII, line 1		▶ \$
	(ii) Assets included in Form 990, Part X		
2	If the organization received or held works of art, historical tre		
	the following amounts required to be reported under FASB A	ASC 958 relating to these items:	
а	Revenue included on Form 990, Part VIII, line 1		• \$
b	Assets included in Form 990, Part X		
	For Paperwork Reduction Act Notice, see the Instruction		Schedule D (Form 990) 2021

Pai	rt III Organizations	Maintaining Coll	lections of A	rt, Hist	torical Tr	easures, d	or Other	Similar	Assets	continue	∍d)
3	Using the organization's acquisition, accession, and other records, check any of the following that make significant use of its										
	collection items (check al	I that apply):									
а	Public exhibition		C	ı 🔲 ı	Loan or exc	hange progra	am				
b	Scholarly research		e	, 🔲	Other						
С	Preservation for fut	ure generations									
4	Provide a description of t	he organization's collec	ctions and expla	in how th	ney further t	he organizati	on's exemp	t purpose	e in Part X	III.	
5	During the year, did the o	rganization solicit or re	ceive donations	of art, hi	storical trea	sures, or oth	er similar as	sets			
	to be sold to raise funds	rather than to be maint	ained as part of	the orga	nization's c	ollection?			🔲 \	Yes	No_
Pai	rt IV Escrow and C	Sustodial Arrange	ments. Compl	ete if the	organizatio	n answered '	'Yes" on Fo	rm 990, I	Part IV, line	e 9, or	
	reported an amou	nt on Form 990, Part X	, line 21.								
1a	Is the organization an age	ent, trustee, custodian	or other interme	diary for	contributior	ns or other as	sets not inc	luded			
	on Form 990, Part X?								Y	Yes	L No
b	If "Yes," explain the arran	igement in Part XIII and	d complete the fo	ollowing t	able:						
									A	mount	
С	Beginning balance							1c			
d	Additions during the year							1d			
е	Distributions during the y	ear						1e			
f	Ending balance							1f			
	Did the organization inclu						•	?	Y	Yes	∐_ No
	If "Yes," explain the arran										
Pai	rt V Endowment F	unds. Complete if the						Thuasuas	ua baali (1 Farmer	ana baali
			a) Current year	(b) P	rior year	(c) Two year	s back (d)				
1a	0 0 ,							2,106	5,221.		59,883.
b	Contributions										32,237.
С	Net investment earnings,	gains, and losses						- 4	1,045.	2	60,501.
d											
е	Other expenditures for fa	cilities									45 400
_								2,102	2,176.		46,400.
f	Administrative expenses										06.001
g				<u> </u>						2,1	06,221.
2	Provide the estimated pe		t year end baland	-	g, column (a	a)) held as:					
а	Board designated or qua		0.4	%							
b	Permanent endowment		%								
С	· —	%	1.4000/								
_	The percentages on lines		•								
за	Are there endowment fun	ias not in the possessi	on of the organiz	ation tha	at are neid a	ina administe	rea for the	organizat	ion	Ī.	es No
	by:								Г		X
	(i) Unrelated organization									3a(i)	X
L	(ii) Related organizations If "Yes" on line 3a(ii), are									3a(ii)	
	Describe in Part XIII the in								L	3b	
4 Pai		gs, and Equipmer		ownent	iuiius.						
		ganization answered "\		0. Part I\	/. line 11a. 9	See Form 990). Part X. line	e 10.			
	Description of p		(a) Cost or o			or other	(c) Accu		16	l) Book v	value
	Description of p	roperty	basis (investi			(other)		ciation	") DOOK V	alue
12	Land		<u> </u>		22310	/	25,0				
	Leasehold improvements										
	Other										
	L Add lines 1a through 1e			X colun	nn (B) line 1	10c)					0.

Schedule D (Form 990) 2021

Schedule D (Form 990) 2021 FSHD SOCIETY	-1762747 Page		
Part VII Investments - Other Securities.	_		
Complete if the organization answered "Yes"			
(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end	-of-year market value
(1) Financial derivatives			
(2) Closely held equity interests			
(3) Other			
(A)			
(B)			
(C)			
(D)			
(E)			
(F)			
(G)			
(H)			
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 12.)			
Part VIII Investments - Program Related.			
Complete if the organization answered "Yes"		•	
(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end	-of-year market value
(1)			
(2)			
(3)			
(4)			
(5)			
(6)			
(7)			
(8)			
(9)			
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 13.) ▶			
Part IX Other Assets.			
Complete if the organization answered "Yes"	on Form 990, Part IV, line	11d. See Form 990, Part X, line 15.	
(a) [Description		(b) Book value
(1)			
(2)			
(3)			
(4)			
(5)			
(6)			
(7)			
(8)			
(9)			
Total. (Column (b) must equal Form 990, Part X, col. (B) line	: 15.)	>	
Part X Other Liabilities.			
Complete if the organization answered "Yes"	on Form 990, Part IV, line	11e or 11f. See Form 990, Part X, line 25.	
1. (a) Description of liability			(b) Book value
(1) Federal income taxes			
(2) LONG-TERM DEFERRED COMPENS	SATION		
(3) LIABILITY			67,801
(4)			
(5)			
(6)			

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

Schedule D (Form 990) 2021

(7) (8)

Total. (Column (b) must equal Form 990, Part X, col. (B) line 25.)

67,801.

Par	Reconciliation of Revenue per Audited Financial Sta		Revenue per R	leturr	1.
1	Complete if the organization answered "Yes" on Form 990, Part IV, lir Total revenue, gains, and other support per audited financial statements			1	5,661,765.
	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			-	3,001,703
	Net unrealized gains (losses) on investments	2a	-51,655.		
	Donated services and use of facilities		225,200.	-	
	Recoveries of prior year grants			1	
	Other (Describe in Part XIII.)				
	Add lines 2a through 2d			2e	173,545.
	Subtract line 2e from line 1			3	5,488,220.
	Amounts included on Form 990, Part VIII, line 12, but not on line 1:				
а	Investment expenses not included on Form 990, Part VIII, line 7b	4a			
b	Other (Describe in Part XIII.)	4b			
С	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.
Par	t XII Reconciliation of Expenses per Audited Financial St		h Expenses per	Retu	rn.
	Complete if the organization answered "Yes" on Form 990, Part IV, lin				4 0 4 2 0 0 0
	Total expenses and losses per audited financial statements			1	4,843,027.
	Amounts included on line 1 but not on Form 990, Part IX, line 25:	1 - 1	225 200		
	Donated services and use of facilities		225,200.	-	
	Prior year adjustments			-	
	Other losses		2,504.	-	
	Other (Describe in Part XIII.) Add lines 2a through 2d			1 1	227,704.
	•			2e	4,615,323
	Subtract line 2e from line 1 Amounts included on Form 990, Part IX, line 25, but not on line 1:			3	1,013,323
	Investment expenses not included on Form 990, Part VIII, line 7b	4a			
	Other (Describe in Part XIII.)			-	
	Add lines 4a and 4b			4c	0.
	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 1			5	4,615,323.
	t XIII Supplemental Information.	,			
	de the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 42d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide a			4; Part	X, line 2; Part XI,
	T XII, LINE 2D - OTHER ADJUSTMENTS:				2,504.
	DEBI EAFENGE				2,304

SCHEDULE F (Form 990)

Statement of Activities Outside the United States

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

➤ Attach to Form 990.

Inspection

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service

► Go to www.irs.gov/Form990 for instructions and the latest information.

Name of the organization					Employer identi	ncation number
FSHD SOCIETY					52-17627	47
		ctivities Ou	tside the United States. Compl	ete if the organ	ization answered "	Yes" on
Form 990, Part IV						
			ds to substantiate the amount of its gr			Yes X No
the grantees' eligibility to	or the grants or a	assistance, and	the selection criteria used to award the	e grants or ass	istance? L	Yes X No
2 For grantmakers. Desc	ribo in Part V the	organization's	procedures for monitoring the use of it	e grante and o	thor assistance ou	tsido tho
United States.	inde in Fait V the	organization's	procedures for monitoring the use of it	.s grants and o	irier assistance ou	iside trie
	he following Part	L line 3 table c	an be duplicated if additional space is	needed.)		
(a) Region	(b) Number of	(c) Number of			vity listed in (d)	(f) Total
	offices	employees, agents, and	(by type) (such as, fundraising, pro-	1 .	gram service,	expenditures for and
	in the region	independent contractors	gram services, investments, grants to	I .	e specific type	investments
		in the region	recipients located in the region)	of service	(s) in the region	in the region
EUROPE (INCLUDING						
ICELAND & GREENLAND)						
- ALBANIA, ANDORRA,						
AUSTRIA, BELGIUM	0	0	GRANTS	N/A		415,798.
EAST ASIA AND THE						
PACIFIC	0	0	GRANTS	N/A		473,782.
						
3 a Subtotal	0	(889,580.
b Total from continuation						133,330.
sheets to Part I	0	(0.
c Totals (add lines 3a						
and 3b)	0	C				889,580.

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

Schedule F (Form 990) 2021

FSHD SOCIETY

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.

(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV appraisal, other)
	EUROPE (INCLUDING	INHIBITION OF THE					
	ICELAND &	DOWNSTREAM					
	GREENLAND) -	CONSEQUENCES OF DUX4					
	ALBANIA, ANDORRA,	EXPRESSION IN MUSCLES	104,973.	WIRE TRANSFER	0.	N/A	
	EUROPE (INCLUDING						
	ICELAND &	UNDERSTANDING AND					
	GREENLAND) -	TARGETING METABOLIC					
	ALBANIA, ANDORRA,	DYSFUNCTION IN FSHD	55,300.	WIRE TRANSFER	0.	N/A	
		INTERACTION BETWEEN					
	EUROPE (INCLUDING	MESENCHYMAL STEM					
	ICELAND &	CELLS AND MYOBLASTS					
	GREENLAND)	IN FSHD PATHOGENES	55,000.	WIRE TRANSFER	0.	N/A	
	EUROPE (INCLUDING	RESPONSIVENESS OF					
	ICELAND &	OUTCOME MEASURES ON					
	GREENLAND)	FACIAL WEAKNESS IN	51,525.	WIRE TRANSFER	0.	N/A	
		MUSCLE-TARGETED					
	EUROPE (INCLUDING	DELIVERY STRATEGIES					
	ICELAND &	FOR ANTISENSE TOOLS					
	GREENLAND)	AGAINST DUX4	149,000.	WIRE TRANSFER	0.	N/A	
		INVESTIGATING SMCHD1					
		STRUCTURE AND					
	EAST ASIA AND THE	FUNCTION TO DEVELOP					
	PACIFIC	FSHD THERAPEUTICS	177,282.	WIRE TRANSFER	0.	N/A	
		FSHD1 MODEL MICE WITH					
		CHROMOSOME 4Q35					
	EAST ASIA AND THE	DERIVED FROM AN FSHD1					
	PACIFIC	USING MAC	198,000.	WIRE TRANSFER	0.	N/A	
	EAST ASIA AND THE	PEDIATRIC FSHD					
		NATURAL HISTORY STUDY	98,500.	WIRE TRANSFER	0.	N/A	

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

3 Enter total number of other organizations or entities

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

Schedule F (Form 990) 2021 FSHD SOCIETY 52-1762747 Page 4
Part IV Foreign Forms

	1 Stelgit 1 Strille	
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 X 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 X 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 X 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 X 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 X 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 X No

Schedule F (Form 990) 2021

52-1762747 Page 5

Part V | Supplemental Information

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

PART I, LINE 2:
THE SOCIETY MAKES RESEARCH GRANTS TO ELIGIBLE APPLICANTS AFTER REQUESTS
FOR RESEARCH FUNDING HAVE BEEN REVIEWED AND APPROVED BY THE SOCIETY'S
SCIENTIFIC ADVISORY BOARD (SAB) AND, THEREAFTER, APPROVED BY THE
SOCIETY'S BOARD OF DIRECTORS. THE SOCIETY ALSO PROVIDES OTHER ASSISTANCE
TO RESEARCHERS AND TO PATIENTS PARTICIPATING IN RESEARCH, AND PROVIDES
FUNDS FOR RESEARCH BIOMATERIALS. 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.

SCHEDULE G (Form 990)

Department of the Treasury

Internal Revenue Service

Supplemental Information Regarding Fundraising or Gaming Activities

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

OMB No. 1545-0047

2021

Open to Public Inspection

Employer identification number Name of the organization FSHD SOCIETY 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. Mail solicitations Solicitation of non-government grants b Internet and email solicitations Solicitation of government grants ☐ Phone solicitations ☐ Special fundraising events In-person solicitations 2 a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees, or No Yes key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? 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. (iii) Did (v) Amount paid (vi) Amount paid (i) Name and address of individual (iv) Gross receipts to (or retained by) have custody or control of contributions? (ii) Activity to (or retained by) fundraiser or entity (fundraiser) from activity organization listed in col. (i) Yes No 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.

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

Schedule G (Form 990) 2021

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

		of fundraising event contributions and gr	oss income on Form 990	FEZ, III les Tario ob. List e	events with gross receip	ns greater than \$5,000.
			(a) Event #1 PEER TO PEER	(b) Event #2	(c) Other events NONE	(d) Total events
				SPECIAL EVEN	NONE	(add col. (a) through
			(event type)	(event type)	(total number)	col. (c))
ne			(event type)	(event type)	(total number)	
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.
	4	Cash prizes		1,750.		1,750.
	5	Noncash prizes	7,678.	0.		7,678.
Direct Expenses	6	Rent/facility costs	4,160.	9,295.		13,455.
irect E	7	Food and beverages	4,336.	4,991.		9,327.
莅	_	Catastainesset	512.	4,149.		4,661.
	8	Entertainment Other direct expenses	29,201.	14,425.		43,626.
	10			11/1231		80,497.
		Net income summary. Subtract line 10 from li			_	0.
Pa	irt					
		\$15,000 on Form 990-EZ, line 6a.			•	
ന			(a) Bingo	(b) Pull tabs/instant	(c) Other gaming	(d) Total gaming (add
Revenue			(a) Birigo	bingo/progressive bingo	(c) Other garming	col. (a) through col. (c))
Seve						
<u> </u>	1	Gross revenue				
es	2	Cash prizes				
ens						
Exp	3	Noncash prizes				
Direct Expenses	4	Rent/facility costs				
	5	Other direct expenses				
	Ť	Cutof direct expenses	Yes %	Yes %	Yes %	
	6	Volunteer labor	No No	No No	No No	
	7	Direct expense summary. Add lines 2 through	n 5 in column (d)		>	
	8	Net gaming income summary. Subtract line 7	from line 1, column (d)		>	
	E∽.	tor the state(s) in which the arganization and	uoto gamina activitias:			
		ter the state(s) in which the organization condu the organization licensed to conduct gaming a	_	etetee?		Yes No
		No," explain:				. L res L NO
IJ	' 11	ito, capialii.				
10a	We	ere any of the organization's gaming licenses re	evoked, suspended, or to	erminated during the tax	year?	Yes No
		Yes," explain:				

132082 10-21-21 Schedule G (Form 990) 2021

Sch	edule G (Form 990) 2021	FSHD SOCIETY	Y	52-1	762	747	Page 3
11	Does the organization conduct ga	ming activities with nonr	nembers?			Yes	☐ No
12	Is the organization a grantor, bene	eficiary or trustee of a tru	st, or a member of a partnership or other entity formed				
	to administer charitable gaming?					Yes	└─ No
13	Indicate the percentage of gaming	g activity conducted in:					
а	The organization's facility				13a		%
b	An outside facility				13b		%
14	Enter the name and address of the	e person who prepares t	the organization's gaming/special events books and reco	ords:			
	Name						
	Address >						
15a	Does the organization have a conf	tract with a third party fro	om whom the organization receives gaming revenue? \dots			Yes	☐ No
b			the organization > \$ and the am	ount			
	of gaming revenue retained by the	e 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	<u> </u>					
	Director/officer	Employee	Independent contractor				
17	Mandatory distributions:						
		r state law to make charit	table distributions from the gaming proceeds to				
_			and the state of t			Yes	☐ No
b			to be distributed to other exempt organizations or spen				
	organization's own exempt activiti	· ·					
Pa			xplanations required by Part I, line 2b, columns (iii) and (/); and Part	: III, liı	nes 9,	9b, 10b,
			e any additional information. See instructions.				, ,

Schedule (G (Form 990) FSHD SOCIETY	52-1762747 Page 4
Part IV	G (Form 990) FSHD SOCIETY Supplemental Information (continued)	
	, ,	
-		
-		

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

Open to Public Inspection

Name of the organization FSHD SOCI	ЕТҮ						Employer identification number $52-1762747$
Part I General Information on Grants a							0 = 1,0=1,=7
 Does the organization maintain records criteria used to award the grants or assi Describe in Part IV the organization's pr 	stance?					sistance, and the selec	
Part II Grants and Other Assistance to					anization answered "	Yes" on Form 990. Par	t IV. line 21. for any
recipient that received more than					,		,, ,
1 (a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
THE RESEARCH INSTITUTE AT							
NATIONWIDE CHILDREN'S HOSPITAL -							DEVELOPING
700 CHILDREN'S DRIVE - COLUMBUS,							AAV-CRISPR-CAS13 BASED
OH 43205	31-6056230	501(C)(3)	193,310.	0.	, FMV	N/A	GENE THERAPY FOR FSHD
CHILDREN'S RESEARCH INSTITUTE:							
CHILDRENS NATIONAL HEALTH SYSTEMS							
- 801 ROEDER ROAD SUITE 500 -							MEMBRANE REPAIR DEFICIT
SILVER SPRING, MD 20910	52-1654453	501(C)(3)	63,735.	0.	.FMV	N/A	IN FSHD PATHOPHYSIOLOGY
UNIVERSITY OF ROCHESTER							FSHD BIOLOGICAL RESOURCES
601 ELMWOOD AVENUE, BOX 673	16 0742200	E01/G1/21	24 210	0	E167	h. / 3	AVAILABLE THROUGH THE
ROCHESTER, NY 14642 UNIVERSITY OF KANSAS MEDICAL	16-0743209	501(C)(3)	24,310.	0,	.FMV	N/A	CTRN (BIOAVAILABLE)
CENTER - 4330 SHAWNEE MISSION							CLINICAL TRIALS RESEARCH
							NETWORK (CTRN) FOR
PARKWAY, SUITE 323 - FAIRWAY, KS	40 1100030	E01/G1/21	300 000	0	E167	h. / 3	FACIOSCAPULOHUMERAL
66205	48-1108830	501(C)(3)	300,000.	0,	FMV	N/A	MUSCULAR DYSTROPHY (FSHD)
UNIVERSITY OF MARYLAND							
220 ARCH STREET							SLC34A2 AS A BIOMARKER
BALTIMORE, MD 21201	52-6002033	501(C)(3)	152,600.	0.	.FMV	N/A	FOR FSHD
UNIVERSITY OF UTAH							NANOPORE CAS9-TARGETED
201 S. PRESIDENTS CIRCLE ROOM 406							SEQUENCING (NCATS
SALT LAKE CITY, UT 84112-9023	87-6000525	501(C)(3)	49,621.	0.	.FMV	N/A	DIAGNOSTICS FOR FSHD)
2 Enter total number of section 501(c)(3) a	and government o	rganizations listed in t	he line 1 table				> 10.
3 Enter total number of other organization							> 0.

(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
ALE UNIVERSITY WHITNEY AVENUE, 6TH FLOOR EW 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
NIVERSITY OF COLORADO 800 GRANT STREET ENVER, CO 80203	84-6000555	501(C)(3)	152,600.	0.	FMV	N/A	MECHANISM OF CONTEXT-SPECIFIC NMD INHIBITION BY DUX4
T. LOUIS UNIVERSITY 700 WEST PINE MALL, 3RD FLOOR FUS2 T. LOUIS, MO 63108		501(C)(3)	121,900.	0.	FMV	N/A	MOLECULAR MECHANISMS OF P38-DEPENDENT AND INDEPENDENT DUX4 ACTIVATION DURING

Part III Grants and Other Assistance to Domestic Individuals Part III can be duplicated if additional space is needed.	. Complete if the	e organization answe	ered "Yes" on Form 9	990, Part IV, line 22.	
(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non- cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
Part IV Supplemental Information. Provide the information req	uired in Part I, lin	ne 2; Part III, column	(b); and any other a	dditional information.	
PART I, LINE 2:					
THE SOCIETY MAKES RESEARCH GRANTS	TO ELIGI	BLE APPLIC	ANTS AFTER	REQUESTS FOR	
RESEARCH FUNDING HAVE BEEN REVIEWE	D AND AP	PROVED BY	THE SOCIET	Y'S	
SCIENTIFIC ADVISORY BOARD (SAB) AN	D, THERE	AFTER, APP	ROVED BY T	HE SOCIETY'S	
BOARD OF DIRECTORS. THE SOCIETY A	LSO PROV	IDES OTHER	ASSISTANC	E TO	
RESEARCHERS AND TO PATIENTS PARTIC	IPATING	IN RESEARC	H, AND PRO	VIDES FUNDS	
FOR RESEARCH BIOMATERIALS. GRANTE	ES ARE R	EQUIRED TO	SUBMIT PE	RIODIC	
PROGRESS REPORTS, WHICH ARE REVIEW	ED BY TH	E SAB AND	THE SOCIET	Y'S SENIOR	
EXECUTIVES. WITH REGARD TO ASSIST	ANCE OTH	ER THAN RE	SEARCH GRA	NTS, THE	
132102 10-26-21		40			Schedule I (Form 990) 2021

Part IV Supplemental Information
RECIPIENT OF THE ASSISTANCE IS REQUIRED TO SUBMIT PERIODIC PROGRESS REPORTS
OR OTHER WRITTEN DETAIL ABOUT THE USE OF THE FUNDS, AS DETERMINED BY THE
SAB, BOARD OF DIRECTORS AND SENIOR EXECUTIVES.
PART II, LINE 1, COLUMN (H):
NAME OF ORGANIZATION OR GOVERNMENT: YALE UNIVERSITY
(H) PURPOSE OF GRANT OR ASSISTANCE: CHARACTERIZATION OF DUX4-INDUCED
METABOLIC AND HYPOXIC CHANGES IN FSHD AND IDENTIFICATION OF TOXIC
DUX4-INDUCED TRANSCRIPTS.
NAME OF ORGANIZATION OR GOVERNMENT: ST. LOUIS UNIVERSITY
(H) PURPOSE OF GRANT OR ASSISTANCE: MOLECULAR MECHANISMS OF
P38-DEPENDENT AND INDEPENDENT DUX4 ACTIVATION DURING MYOGENESIS

SCHEDULE J (Form 990)

Department of the Treasury

Internal Revenue Service

Compensation Information

For certain Officers, Directors, Trustees, Key Employees, and Highest

Compensated Employees

Complete if the organization answered "Yes" on Form 990, Part IV, line 23. ► Attach to Form 990.

► Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public Inspection

Name of the organization

Part I Questions Regarding Compensation

FSHD SOCIETY

Employer identification number 52-1762747

			Yes	No	
1a	Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990,				
	Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.				
	First-class or charter travel Housing allowance or residence for personal use				
	Travel for companions Payments for business use of personal residence				
	Tax indemnification and gross-up payments Health or social club dues or initiation fees				
	Discretionary spending account Personal services (such as maid, chauffeur, chef)				
b	If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or				
	reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain	1b			
2	Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors,				
	trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a?	2			
3	Indicate which, if any, of the following the organization used to establish the compensation of the organization's				
	CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to				
	establish compensation of the CEO/Executive Director, but explain in Part III.				
	Compensation committee Written employment contract				
	Independent compensation consultant X Compensation survey or study				
	X 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:				
а	Receive a severance payment or change-of-control payment?	4a		X	
b	b Participate in or receive payment from a supplemental nonqualified retirement plan?				
С	Participate in or receive payment from an equity-based compensation arrangement?	4c		X	
	If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.				
_	Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.				
5	For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation				
	contingent on the revenues of:	_		v	
a L	The organization?	5a		X	
b	Any related organization?	5b		Λ	
_	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:	C-		Х	
a	The organization?	6a		X	
a	Any related organization?	6b		-21	
7	If "Yes" on line 6a or 6b, describe in Part III.				
7	For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described on lines 5 and 6? If "Yes," describe in Part III	7		Х	
8	Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the	<u> </u>		-2	
o	initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III	8		Х	
9	If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in	3			
3	Regulations section 53.4958-6(c)?	9			
	negalations section 30.4300°0(0):	J		1	

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

Schedule J (Form 990) 2021

Schedule J (Form 990) 2021

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

FSHD SOCIETY

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

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

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

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SCHEDULE M (Form 990)

Noncash Contributions

OMB No. 1545-0047

► Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30. Attach to Form 990. Department of the Treasury Internal Revenue Service

FSHD SOCIETY

► Go to www.irs.gov/Form990 for instructions and the latest information.

Open to Public Inspection

Name of the organization

Employer identification number 52-1762747

Pai	rt I Types of Property							
		(a)	(b)	(c)	(d)			
		Check if applicable	Number of contributions or	Noncash contribution amounts reported on	Method of de noncash contribu		-	
		applicable		Form 990, Part VIII, line 1g	noncash contribu	ilion a	mount	S
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 - Oldsely Held stock Securities - Partnership, LLC, or							
••	• • • •							
12	trust interests Securities - Miscellaneous							
13	Qualified conservation contribution -							
13								
44	Historic structures Qualified conservation contribution - Other							
14	***							
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 organic		•					
	for which the organization completed Form 82	83, Part V, [Donee Acknowledg	gement 29				
							Yes	No
30a	During the year, did the organization receive b							
	must hold for at least three years from the date		•	·				
	exempt purposes for the entire holding period	?				30a		X
b	If "Yes," describe the arrangement in Part II.							
31	Does the organization have a gift acceptance					31		X
32a	Does the organization hire or use third parties	or related or	rganizations to soli	cit, process, or sell noncash				
	contributions?					32a		Х
b	If "Yes," describe in Part II.							
33	If the organization didn't report an amount in c	column (c) fo	r a type of propert	y for which column (a) is che	cked,			
	describe in Part II.							
LHA	For Paperwork Reduction Act Notice, see	the Instruc	tions for Form 99	0.	Schedule M	1 (Forr	n 990)	2021

Schedule M (Form 990) 2021

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 Form 990-EZ.

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

2021
Open to Public Inspection

Name of the organization

FSHD SOCIETY

Employer identification number 52-1762747

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

MUSCULAR DYSTROPHY.

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

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

Schedule O (Form 990) 2021

Schedule O (Form 990) 2021 Page **2**

Name of the organization **Employer identification number** FSHD SOCIETY 52-1762747 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, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990: MA, AK, AR, CA, CO, CT, DC, FL, GA, HI, IL, KS, KY, MD, ME, MI, MN, MO, MS, NH, NJ, NV, NC, ND, NM NY, OH, OK, OR, PA, RI, SC, TN, UT, VA, WA, WI, WV, AL FORM 990, PART VI, SECTION C, LINE 19: UPON REQUEST, AVAILABLE ON ORGANIZATION'S WEBSITE AND THROUGH GUIDESTAR WEBSITE. FORM 990, PART XI, LINE 9, CHANGES IN NET ASSETS: -2,504.BAD DEBT EXPENSE