

FSHD SOCIETY
FINANCIAL STATEMENTS

with

INDEPENDENT AUDITORS' REPORT

YEAR ENDED DECEMBER 31, 2020
(With Summarized Comparative Information for 2019)

Smith  Sullivan
& Brown PC
CERTIFIED PUBLIC ACCOUNTANTS

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FSHD SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2020
(With Summarized Comparative Information for 2019)



Our Vision

To deliver treatments and a cure for FSH muscular dystrophy.

Mission

*Be the premier catalyst for connecting all the stakeholders.
Promote research focused on FSHD through thought
leadership, networking, and funding.*

Strategic Imperatives

- 1. To accelerate research and to advance treatments and a cure.*
- 2. To enlarge, to engage, and to empower an active community.*
- 3. To raise and to leverage resources.*
- 4. To ensure organizational capacity to achieve the mission.*

FSHD SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2020

(With Summarized Comparative Information for 2019)

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INDEPENDENT AUDITORS' REPORT

To the Board of Directors
FSHD Society
Lexington, Massachusetts

We have audited the accompanying financial statements of FSHD Society (a District of Columbia nonprofit corporation), which comprise the statement of financial position as of December 31, 2020, and the related statements of activities, functional expenses and cash flows for the year then ended, and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditors' Responsibility

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the Organization's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Organization's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of FSHD Society as of December 31, 2020, and the changes in its net assets and its cash flows for the year then ended in conformity with accounting principles generally accepted in the United States of America.

Report on Summarized Comparative Information

We have previously audited FSHD Society's 2019 financial statements, and our report dated March 17, 2020, expressed an unmodified opinion on those audited financial statements. In our opinion, the summarized comparative information presented herein as of and for the year ended December 31, 2019, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Smith, Sullivan & Brown, PC

Westborough, Massachusetts
March 16, 2021

FSHD SOCIETY

STATEMENTS OF FINANCIAL POSITION
AS OF DECEMBER 31, 2020 AND 2019

<u>ASSETS</u>	<u>2020</u>	<u>2019</u>
<u>CURRENT ASSETS:</u>		
Cash and Cash Equivalents	\$ 3,280,720	\$ 2,617,796
Contributions Receivable	340,181	739,710
Prepaid Expenses	61,251	45,761
Total Current Assets	<u>3,682,152</u>	<u>3,403,267</u>
<u>NET PROPERTY AND EQUIPMENT</u>	<u>5,097</u>	<u>7,108</u>
<u>NON-CURRENT ASSETS:</u>		
Contributions Receivable	50,000	424,566
Deposits	4,477	4,477
Investments	2,093,769	2,653,048
Total Non-Current Assets	<u>2,148,246</u>	<u>3,082,091</u>
<u>TOTAL ASSETS</u>	<u>\$ 5,835,495</u>	<u>\$ 6,492,466</u>
<u>LIABILITIES AND NET ASSETS</u>		
<u>CURRENT LIABILITIES:</u>		
Grants Payable	\$ 216,929	\$ 418,145
Accounts Payable and Accrued Expenses	43,016	50,040
Accrued Payroll and Related Costs	-	219,938
Total Current Liabilities	<u>259,945</u>	<u>688,123</u>
<u>LONG TERM LIABILITIES:</u>		
Long-Term Deferred Compensation Liability	41,878	19,000
Long-Term Grants Payable	-	67,905
Total Long-term Liabilities	<u>41,878</u>	<u>86,905</u>
<u>TOTAL LIABILITIES</u>	<u>301,823</u>	<u>775,028</u>
<u>NET ASSETS:</u>		
Net Assets Without Donor Restrictions	3,007,424	1,927,614
Net Assets With Donor Restrictions	2,526,248	3,789,824
Total Net Assets	<u>5,533,672</u>	<u>5,717,438</u>
<u>TOTAL LIABILITIES AND NET ASSETS</u>	<u>\$ 5,835,495</u>	<u>\$ 6,492,466</u>

FSHD SOCIETY

STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED DECEMBER 31, 2020
(With Summarized Comparative Totals for 2019)

	<u>WITHOUT</u> <u>DONOR</u> <u>RESTRICTIONS</u>	<u>WITH</u> <u>DONOR</u> <u>RESTRICTIONS</u>	<u>TOTAL ACTIVITIES</u>	
			<u>2020</u>	<u>2019</u>
<u>SUPPORT, REVENUES AND RECLASSIFICATIONS</u>				
<i>Support and Revenues:</i>				
Gifts, Grants and Contributions	\$ 1,019,643	\$ 729,319	\$ 1,748,962	\$ 4,548,469
Gross special events revenue	541,807	100	541,907	443,830
Less: Cost of Direct Benefits to Donors	(18,698)	-	(18,698)	(51,017)
Donated Goods and Services	76,075	-	76,075	80,738
Program Revenue	158,395	-	158,395	202,448
Total Support and Revenues	<u>1,777,222</u>	<u>729,419</u>	<u>2,506,641</u>	<u>5,224,468</u>
<i>Investment and Other Income:</i>				
Investment Return, Net	7,487	392,392	399,879	378,260
Return of Grant Funds	-	-	-	7,779
Other Income (Loss)	527	-	527	675
Total Investment and Other Income	<u>8,014</u>	<u>392,392</u>	<u>400,406</u>	<u>386,714</u>
<i>Reclassification of Net Assets:</i>				
Net Assets Released From Restriction	<u>2,385,387</u>	<u>(2,385,387)</u>	<u>-</u>	<u>-</u>
<u>TOTAL SUPPORT, REVENUES AND RECLASSIFICATIONS</u>	<u>4,170,623</u>	<u>(1,263,576)</u>	<u>2,907,047</u>	<u>5,611,182</u>
<u>EXPENSES:</u>				
<i>Program Services:</i>				
Research	1,364,207	-	1,364,207	1,933,640
Patient Advocacy and Education	820,896	-	820,896	636,188
Total Program Services	<u>2,185,103</u>	<u>-</u>	<u>2,185,103</u>	<u>2,569,828</u>
<i>Supporting Services:</i>				
Administrative	366,401	-	366,401	328,083
Fund Raising	439,375	-	439,375	423,187
Total Supporting Services	<u>805,776</u>	<u>-</u>	<u>805,776</u>	<u>751,270</u>
<u>TOTAL EXPENSES</u>	<u>2,990,879</u>	<u>-</u>	<u>2,990,879</u>	<u>3,321,098</u>
<u>CHANGE IN NET ASSETS BEFORE OTHER CHANGES</u>	<u>1,179,744</u>	<u>(1,263,576)</u>	<u>(83,832)</u>	<u>2,290,084</u>
<u>OTHER CHANGE IN NET ASSETS:</u>				
Other Loss (See Note 13)	<u>(99,934)</u>	<u>-</u>	<u>(99,934)</u>	<u>-</u>
<u>TOTAL CHANGES IN NET ASSETS</u>	<u>1,079,810</u>	<u>(1,263,576)</u>	<u>(183,766)</u>	<u>2,290,084</u>
<u>NET ASSETS - BEGINNING OF YEAR</u>	<u>1,927,614</u>	<u>3,789,824</u>	<u>5,717,438</u>	<u>3,427,354</u>
<u>NET ASSETS - END OF YEAR</u>	<u>\$ 3,007,424</u>	<u>\$ 2,526,248</u>	<u>\$ 5,533,672</u>	<u>\$ 5,717,438</u>

FSHD SOCIETY

STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2020

(With Summarized Comparative Totals for 2019)

	<u>RESEARCH</u>	<u>PATIENT ADVOCACY AND EDUCATION</u>	<u>TOTAL PROGRAM SERVICES</u>	<u>ADMINI- STRATIVE</u>	<u>FUND RAISING</u>	<u>TOTAL FUNCTIONAL EXPENSES</u>	
						<u>2020</u>	<u>2019</u>
Salaries and Related Expenses	\$ 470,234	\$ 620,998	\$ 1,091,232	\$ 237,364	\$ 293,686	\$ 1,622,282	\$ 1,444,769
Scientific Advisory Board Grants	625,018	-	625,018	-	-	625,018	974,862
Travel, Lodging and Meals	10,483	28,209	38,692	2,709	5,221	46,622	183,595
Consultants and Professional Fees	43,477	4,500	47,977	13,417	11,745	73,139	133,206
Patient Meetings and Research Conferences	73,900	16,552	90,452	-	-	90,452	103,501
Website and Computer Related Expenses	43,048	45,683	88,731	11,947	16,780	117,458	86,072
Donated Services	59,500	11,475	70,975	5,100	-	76,075	80,738
Printing	9,221	28,950	38,171	-	34,064	72,235	77,166
Fundraising Expenses	-	-	-	-	53,774	53,774	66,493
Bad Debt Expense	-	-	-	50,000	-	50,000	-
Bank Service Charges and Credit Card Processing Fees	5,341	6,977	12,318	4,399	25,322	42,039	59,092
Office Expenses	10,661	14,413	25,074	5,059	7,599	37,732	49,941
Occupancy	12,774	16,935	29,709	6,490	7,986	44,185	41,660
Chapter and Volunteer Development	-	22,207	22,207	-	-	22,207	19,977
Directors Expenses	-	-	-	5,268	-	5,268	19,216
Accounting, Auditing and Financial Consultants	-	-	-	15,500	-	15,500	14,000
Insurance	-	-	-	7,137	-	7,137	8,339
Depreciation Expense	-	-	-	2,011	-	2,011	5,108
Public Awareness	550	3,997	4,547	-	1,896	6,443	4,380
Total Functional Expenses	1,364,207	820,896	2,185,103	366,401	458,073	3,009,577	3,372,115
Less: Cost of Direct Benefits to Donors	-	-	-	-	(18,698)	(18,698)	(51,017)
Total Expenses per Statement of Activities	\$ 1,364,207	\$ 820,896	\$ 2,185,103	\$ 366,401	\$ 439,375	\$ 2,990,879	\$ 3,321,098

FSHD SOCIETY

STATEMENTS OF CASH FLOWS
FOR THE YEARS ENDED DECEMBER 31, 2020 AND 2019

	<u>2020</u>	<u>2019</u>
<u>CASH FLOWS FROM OPERATING ACTIVITIES:</u>		
Change in Net Assets	\$ (183,766)	\$ 2,290,084
<i>Adjustments to Reconcile Changes in Net Assets to Net Cash Provided (Used) by Operating Activities:</i>		
Depreciation Expense	2,011	5,108
Contributions of Mutual Funds to Lewis Family Donor Advised Fund for FSHD	-	(349,676)
Contributions Restricted for Lewis Family Donor Advised Fund for FSHD	(7,500)	(668,204)
Investment Return, Net	(392,343)	(376,397)
Deferrals to Deferred Compensation Plan	(22,878)	(19,000)
<i>Changes in Operating Assets and Liabilities:</i>		
Contributions Receivable - Current and Long-Term	774,095	(1,044,276)
Prepaid Expenses	(15,490)	(13,675)
Grants Payable - Current and Long-Term	(269,121)	20,520
Accounts Payable and Accrued Expenses	(7,024)	1,662
Accrued Payroll and Related Costs	(219,938)	203,393
Net Adjustment	<u>(158,188)</u>	<u>(2,240,545)</u>
<u>NET CASH PROVIDED (USED) BY OPERATING ACTIVITIES</u>	<u>(341,954)</u>	<u>49,539</u>
<u>CASH FLOWS FROM INVESTING ACTIVITIES:</u>		
Proceeds from Donor Advised Fund Grant	1,132,000	589,155
Purchase of Investments	(150,000)	(668,204)
Net Cash Flows From Investing Activities	<u>982,000</u>	<u>(79,049)</u>
<u>CASH FLOWS FROM FINANCING ACTIVITIES:</u>		
Proceeds from Contributions Restricted for Lewis Family Donor Advised Fund for FSHD	-	668,204
Increase in Long-Term Deferred Compensation Liability	22,878	19,000
Net Cash Flows From Financing Activities	<u>22,878</u>	<u>687,204</u>
<u>NET INCREASE IN CASH BALANCES</u>	<u>662,924</u>	<u>657,694</u>
<u>CASH BALANCES - BEGINNING OF YEAR</u>	<u>2,617,796</u>	<u>1,960,102</u>
<u>CASH BALANCES - END OF YEAR</u>	<u>\$ 3,280,720</u>	<u>\$ 2,617,796</u>
 <i>Non-Cash Investing and Financing Activities:</i>		
Contributions of Mutual Funds to Lewis Family Donor Advised Fund for FSHD	<u>\$ -</u>	<u>\$ 349,676</u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020

(With Summarized Comparative Information for 2019)

NOTE 1 OPERATIONS AND NONPROFIT STATUS

Operations:

The FSHD Society (the “Society” or the “Organization”) is a world leader in combating facioscapulohumeral muscular dystrophy (FSH muscular dystrophy or FSHD). The Society is the premier catalyst for connecting all stakeholders of FSHD. The Society promotes research focused on FSHD through thought leadership, networking, and funding. Patients and families are aided through patient advocacy and education.

Nonprofit Status:

The Organization was originally incorporated as the Facioscapulohumeral (FSH) Society in 1991, under the provisions of the District of Columbia Nonprofit Corporation Act and qualifies as a tax-exempt not-for-profit corporation under Section 501(c)(3) of the Internal Revenue Code. Effective October 2, 2019, the Society legally changed its name to FSHD Society. The FSHD Society is not classified as a private foundation under Section 509(a); accordingly, contributions made to this Organization qualify for the maximum charitable deduction for Federal income tax purposes.

NOTE 2 SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

The accounting policies which affect significant elements of the Organization’s financial statements are described below to enhance the usefulness of the financial statements to the reader. The preparation of financial statements in conformity with generally accepted accounting principles requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates; however, adherence to generally accepted accounting principles has, in management’s opinion, resulted in reliable and consistent financial reporting by the Organization.

Basis of Accounting:

The Organization’s policy is to maintain its books and prepare its financial statements on the accrual basis of accounting in accordance with generally accepted accounting principles. Consequently, revenues and gains are recognized when earned and expenses and losses are recognized when a liability has been incurred.

Cash and Cash Equivalents:

Cash and Cash Equivalents consist of cash and highly liquid financial instruments with original maturities of three months or less, which are neither held for nor restricted by donors for long-term purposes.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020

(With Summarized Comparative Information for 2019)

(Continued)

NOTE 2 *(Continued)*

Fair Value of Financial Instruments:

The Organization reports its fair value measures by using a three-level hierarchy that prioritizes the inputs used to measure fair value. This hierarchy, established by generally accepted accounting principles, requires that entities maximize the use of observable inputs and minimize the use of unobservable inputs when measuring fair value.

The three levels of inputs used to measure fair value are defined as follows:

- Level 1 - Quoted prices for identical assets or liabilities in active markets to which the Organization has access at the measurement date.

- Level 2 - Inputs other than quoted prices included in Level 1 that are observable for the asset or liability, either directly or indirectly. Level 2 inputs include quoted prices for similar assets or liabilities in active markets; quoted prices for identical or similar assets in markets that are not active; observable inputs other than quoted prices for the asset or liability (for example, interest rate and yield curves); and inputs derived principally from, or corroborated by, observable market data by correlation or by other means.

- Level 3 - Unobservable inputs for the asset or liability. Unobservable inputs should be used to measure the fair value to the extent that observable inputs are not available.

The primary use of fair value measures in the Organization's financial statements is the recurring measurement of investments. There have been no changes to this valuation methodology.

Financial Statement Presentation:

As required by the *FASB Accounting Standards Codification*TM, the Organization classifies its net assets based on the existence or absence of donor or grantor-imposed restrictions. Accordingly, net assets and changes in net assets therein are classified and reported as follows:

Net Assets Without Donor Restrictions - consists of assets, public support and program revenues which are available and used for activities and programs. Net assets without donor restrictions represents the portion of net assets of the Organization that is not restricted by donor-imposed stipulations. Contributions are considered without restriction unless specifically restricted by the donor. In addition, net assets without donor restrictions may include funds which represent unrestricted resources designated by the Board of Directors for specific purposes.

Net Assets With Donor Restrictions - includes funds with donor-imposed restrictions which permit the donee organization to expend the assets as specified and are satisfied either by the passage of time or by actions of the Organization. Resources of this nature originate from gifts, grants, bequests, and contracts, and may include investment income earned on restricted funds.

These may also include resources which have a permanent donor-imposed restriction which stipulates that the assets are to be maintained permanently but permits the Organization to expend part or all the income derived from the donated assets.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020

(With Summarized Comparative Information for 2019)

(Continued)

NOTE 2 *(Continued)*

Contributions Receivable:

Contributions Receivable are classified as current if they are scheduled for receipt within one year and non-current when the expected date of receipt exceeds one year. Unconditional promises to give that are expected to be collected within one year are reported at net realizable value. Unconditional promises to give due in future years are initially valued at a discounted rate when such amounts are considered material. For each of the years presented, non-current contributions receivable were due within five years. Management determines the allowance for uncollectable contributions receivable on historical experience, an assessment of economic conditions, and a review of subsequent collections. Contributions receivable are written off when deemed uncollectable. At December 31, 2020 the allowance for uncollectable accounts was \$50,000. Management determined that no allowance was required in 2019.

Investments:

The Organization holds two types of investments: (i) long-term investments made to increase earnings in support of the Society's mission and underlying planned giving agreements; and (ii) effective with the year ending December 31, 2020, programmatic investments made to provide equity capital to directly fund companies to accelerate the development of a cure for FSH muscular dystrophy.

The Organization maintains an investment portfolio which consists of cash, mutual funds, exchange traded funds (ETFs) and preferred stocks and bonds. Investments are recorded at fair value. As required by FASB Accounting Standards Codification™, the Organization reports the investments' net realized and unrealized gains and losses at each reporting date in the Organization's Statement of Activities. Purchases and sales of securities are recorded on the trade date. In determining the gains (losses) realized on the sales of securities, the cost of the securities sold has been determined on a first in, first out basis. Cash held in brokerage accounts is reported as investments for purposes of these financial statements. Investments are classified as either short-term or long-term depending on the underlying intentions. See Footnote 5.

Programmatic investments are subject to the same accounting standards as similar financial instruments. The Society's programmatic investment as of December 31, 2020, is accounted for under the equity method of accounting as further discussed in Note 5.

Property and Equipment:

FSHD Society records all property and equipment at cost, if purchased (exceeding \$5,000), or if donated, at fair value on the date of receipt. Expenditures for maintenance, repairs and renewals are charged to expense as incurred, whereas major betterments (exceeding \$5,000) are capitalized as additions to property and equipment. Depreciation of property and equipment is computed using the straight-line method over the estimated useful lives of the assets, as expressed in terms of years.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020

(With Summarized Comparative Information for 2019)

(Continued)

NOTE 2 *(Continued)*

Donor Advised Funds:

The Lewis Family Donor Advised Fund for FSHD is restricted by the donor for the purpose of advancing research or therapeutic efforts on behalf of FSHD patients. As a donor advised fund, the FSHD Society has ultimate variance power over the use of funds; however, the agreement allows donors to recommend grant recipients subject to the Society's approval. The Lewis Family Donor Advised Fund for FSHD includes a specification by the donor as to the area of interest they recommend the funds to be spent; therefore, the Society has elected to report these funds as net assets with donor restrictions in the accompanying financial statements.

Contributions, Gifts and Grants:

As required by the FASB Accounting Standards Codification™, contributions are required to be recorded as receivables and revenues, and the Organization is required to distinguish between contributions received for each net asset category in accordance with donor-imposed restrictions.

The Organization recognizes contributions when cash, securities, or other assets; an unconditional promise to give; or a notification of a beneficial interest is received. Conditional promises to give - that is, those with a measurable performance or other barrier and right of return - are not recognized until the conditions on which they depend have been met. Contributions of assets other than cash are reported at their estimated fair value.

Multi-year unconditional commitments are recognized in the year during which the initial commitment was made. Contributions to be received after one year are discounted at an appropriate discount rate commensurate with the risk involved, when such amounts are considered material.

Support that is restricted by the donor is reported as an increase in net assets with donor restrictions until the restrictions expire, at which time the assets are reclassified to net assets without donor restrictions.

Grants Expense, Return of Grant Funds, and Grants Payable:

The Society makes grants to eligible applicants after requests for research funding have been reviewed and recommended by the Society's Scientific Advisory Board ("SAB"). The Society recognizes an expense for *Scientific Advisory Board Grants* at the time the Board of Directors votes to approve the SAB recommendations on awards and all significant conditions have been met. *Grants Payable* are classified as current if they are scheduled to be paid within one year, and non-current when they are expected to be paid in more than one year. Conditional commitments are not recognized in the financial statements until measurable performance or other barriers have substantially been met. *Return of Grant Funds* represents unused grant funds that are returned to the Organization by the grantee and is reflected in the accompanying Statement of Activities under *Investment and Other Income*.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020

(With Summarized Comparative Information for 2019)

(Continued)

NOTE 2 *(Continued)*

Donated Goods and Services:

As required by the *FASB Accounting Standards Codification*TM, the Organization maintains a policy whereby the value of donated goods and services which create or enhance nonfinancial assets; require a specialized skill; and which would have otherwise been purchased by the Organization are recognized as revenue and expense on the Statement of Activities and are listed as expenses on the Statement of Functional Expenses.

The Society pays for most services requiring specific expertise. However, many individuals volunteer their time and perform a variety of tasks that assist the Society with its meetings and events, peer review of grant applications, research programs, committee assignments and publications. Substantially all these tasks are performed through donated services.

Functional Expenses:

The Organization allocates its expenses on a functional basis among various programs and support services. Expenses that can be identified with a specific program and support service are allocated directly according to their natural expense classification. Other expenses, such as *Salaries and Related Expenses, Website and Computer Related Expenses, Office Expenses, and Occupancy*, that are common to several functions are allocated based on salary dollars. Supporting services are those related to operating and managing the Organization and its programs on a day-to-day basis. Supporting services have been sub-classified as follows:

Administrative - includes all activities related to FSHD Society's internal management and accounting for program services.

Fund Raising - includes all activities related to maintaining contributor information, writing grant proposals, direct mail solicitation, distribution of materials and other similar projects related to the procurement of funds.

NOTE 3 CONDITIONAL GRANT

During 2018, the Society was awarded a \$350,000 conditional grant over three years from the Economic Justice Fund of the Tides Foundation. The grant is restricted to the Society's clinical trial research network and FSHD Therapeutic efforts. As of December 31, 2019, the Organization had received \$250,000 in accordance with the original grant agreement. The remaining conditional installment of \$100,000 was received in 2020 upon receipt and review of reports demonstrating that a fundraising goal of \$567,233 per year had been met, and project milestones were reached.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020

(With Summarized Comparative Information for 2019)

(Continued)

NOTE 4 PROPERTY AND EQUIPMENT

The following is a summary of property and equipment as of December 31, 2020 and 2019:

<u>Asset Category</u>	<u>Est. Life</u>	<u>Cost</u>	<u>Accumulated Depreciation</u>	<u>Net Book Value</u>	
				<u>2020</u>	<u>2019</u>
Computer, Technology and Office Equipment	3 - 5	\$ 7,976	\$ 7,976	\$ -	\$ 287
Furniture and Fixtures	7	12,154	7,057	5,097	6,821
Leasehold Improvements	3	<u>7,100</u>	<u>7,100</u>	<u>-</u>	<u>-</u>
Total		<u>\$27,230</u>	<u>\$22,133</u>	<u>\$5,097</u>	<u>\$7,108</u>

NOTE 5 INVESTMENTS

Investment Components:

As of December 31, 2020, and 2019 *Investments* on the Statements of Financial Position consist of the following:

<u>Investment Components</u>	<u>2020</u>	<u>2019</u>
Lewis Family Donor Advised Fund for FSHD	\$1,901,891	\$2,634,048
Deferred Compensation Investments	<u>41,878</u>	<u>19,000</u>
Total Fair Value Investments	1,943,769	2,653,048
Programmatic Equity Investments	<u>150,000</u>	<u>-</u>
Total Investments	<u>\$2,093,769</u>	<u>\$2,653,048</u>

As of December 31, 2020 and 2019, investment costs and unrealized gains and losses consisted of the following components:

<u>Investment Type</u>	<u>December 31, 2020</u>					
	<u>Cost Basis</u>	<u>Unrealized Gains</u>	<u>Unrealized Losses</u>	<u>Fair Value (Level 1)</u>	<u>Fair Value (Level 2)</u>	<u>Total Fair Value</u>
Cash and Sweep Accounts	\$ 12,323	\$ -	\$ -	\$ 12,323	\$ -	\$ 12,323
Mutual Funds	1,105,425	438,849	(91)	1,544,183	-	1,544,183
Exchange Traded Funds	164,576	37,180	-	201,756	-	201,756
Preferred Stocks and Bonds	<u>180,742</u>	<u>6,744</u>	<u>(1,979)</u>	<u>-</u>	<u>185,507</u>	<u>185,507</u>
Total	<u>\$1,463,066</u>	<u>\$482,773</u>	<u>\$(2,070)</u>	<u>\$1,758,262</u>	<u>\$185,507</u>	<u>\$1,943,769</u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020

(With Summarized Comparative Information for 2019)

(Continued)

NOTE 5 (Continued)

<u>Investment Type</u>	<u>December 31, 2019</u>					
	<u>Cost Basis</u>	<u>Unrealized Gains</u>	<u>Unrealized Losses</u>	<u>Fair Value (Level 1)</u>	<u>Fair Value (Level 2)</u>	<u>Total Fair Value</u>
Cash and Sweep Accounts	\$ 711,277	\$ -	\$ -	\$ 711,277	\$ -	\$ 711,277
Mutual Funds	1,358,790	257,939	(1,737)	1,614,992	-	1,614,992
Exchange Traded Funds	97,005	18,900	-	115,905	-	115,905
Preferred Stocks and Bonds	<u>208,043</u>	<u>5,208</u>	<u>(2,377)</u>	<u>-</u>	<u>210,874</u>	<u>210,874</u>
Total	<u>\$2,375,115</u>	<u>\$282,047</u>	<u>\$(4,114)</u>	<u>\$2,442,174</u>	<u>\$210,874</u>	<u>\$2,653,048</u>

The Organization uses the following ways to determine the fair value of its investments:

Mutual Funds and ETFs: Valued at the daily closing prices as reported by the mutual funds and ETFs. The funds held by the Organization are deemed to be actively traded and are valued using Level 1 inputs (See Page 8).

Preferred Stocks and Bonds: Determined by independent unadjusted market-based prices received from a third-party pricing service that utilizes pricing models that consider standard input factors such as observable market data, benchmark yields, interest rate volatilities, broker/dealer quotes, credit spreads, and new issue data. Preferred stocks and bonds are valued using level 2 inputs (See Page 8).

Components of *Investment Return* for the years ended December 31, 2020 and 2019, is as follows:

<u>Components of Investment Return</u>	<u>2020</u>	<u>2019</u>
Interest and Dividends	\$ 72,211	\$ 93,131
Unrealized Gains (Losses)	203,767	261,928
Realized Gains (Losses)	<u>123,901</u>	<u>23,201</u>
Net Investment Return	<u>\$399,879</u>	<u>\$378,260</u>

Programmatic Equity Investment:

During 2020, the Organization purchased 13,298 units of in InformiR Holdings, LLC (“InformiR”) for a total investment of \$150,000. The primary purpose of the investment is to accelerate research towards a cure for FSH muscular dystrophy. InformiR was incorporated primarily as a temporary vehicle to pool capital from investors to simplify miRecule’s application for the Maryland Biotechnology Investment Incentive Tax Credit Program. InformiR uses all investment proceeds to purchase Class B Common Stock of miRecule RNA Therapeutics (“miRecule”). MiRecule is an early-stage biotechnology company developing RNA-based therapeutics. MiRecule is applying its platform to a variety of diseases, including cancer and muscular dystrophy. The Society’s investment is restricted for research in FSH muscular dystrophy. Total units issued and outstanding in InformiR as of December 31, 2020 was 31,030; therefore, the Society’s ownership is 43% of all units issued and outstanding in InformiR. Accordingly, the organization accounts for this programmatic investment using the equity method. It is management’s opinion that the profit and loss of InformiR for the year ended December 31, 2020 is immaterial. It is also the opinion of management that no reserve for impairment loss is required for the year ended December 31, 2020.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

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(With Summarized Comparative Information for 2019)

(Continued)

NOTE 6 DESIGNATIONS AND RESTRICTIONS OF NET ASSETS

Net Assets With Donor Restrictions:

As of December 31, 2020, and 2019, net assets with donor restrictions were designated for research and education and consisted of the following balances:

<u>Nature of Restriction</u>	<u>2020</u>	<u>2019</u>
Lewis Family Donor Advised Fund for FSHD	\$1,901,891	\$2,639,048
FSHD Therapeutics	390,181	815,869
Research and Education	<u>234,176</u>	<u>334,907</u>
Total	<u>\$2,526,248</u>	<u>\$3,789,824</u>

Net assets released from restrictions by incurring expenses which satisfied the restricted purpose, by the passage of time or by the occurrence of events specified by the donors during the years presented were as follows:

<u>Nature of Restriction</u>	<u>2020</u>	<u>2019</u>
Donations Designated for FSHD Therapeutics:		
Grant From Lewis Family Donor Advised Fund for FSHD	\$1,000,000	\$1,000,000
Helen Younger Memorial Fund	29,225	94,957
Other	490,560	462,107
Clinical Trial Research Network:		
Tides Foundation	100,000	100,000
Donations Designated for Research and Education:		
Ed and Betty Jane Schechter Memorial Fund	104,600	-
S&L Marx Foundation	-	120,000
Lincoln and Irene Lai Wellness Fund	250	1,000
Appropriation from Lewis Family		
Donor Advised Fund from FSHD	132,000	91,000
Other	334,252	249,745
Donations Designated for General Operations:		
Payroll Protection Program	<u>194,500</u>	<u>-</u>
Total	<u>\$2,385,387</u>	<u>\$2,118,809</u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020

(With Summarized Comparative Information for 2019)

(Continued)

NOTE 7 DONATED GOODS AND SERVICES

Volunteers are an integral component of FSHD Society. For the years presented, the Organization recognized the following in-kind contributions in the accompanying financial statements:

<u>Description</u>	<u>2020</u>	<u>2019</u>
Scientific Committees Expenses	\$59,500	\$44,413
Science time for FSHD Connect and Patient Education	11,475	32,725
Investment Advisory Services	<u>5,100</u>	<u>3,600</u>
Total	<u>\$76,075</u>	<u>\$80,738</u>

NOTE 8 FSHD CANADA AGREEMENT

On November 8, 2012, an Agency Agreement was signed between the FSHD Society and the FSHD Canada Foundation. FSHD Canada Foundation is registered under the Income Tax Act (Canada) as a “charitable Organization.” The FSHD Society intends to assist the FSHD Canada Foundation in carrying out its charitable purposes and to perform certain activities on behalf of the FSHD Canada Foundation as follows: (1) funding specific FSHD-related scientific and clinical research and development activities in the United States of America as may be specified by the FSHD Canada Foundation from time to time; and (2) performing other activities in the United States consistent with the furtherance of the FSHD Canada Foundation’s charitable object of promoting scientific and clinical research and development of the causes, alleviation of suffering, treatment, and cure of facioscapulohumeral muscular dystrophy.

NOTE 9 LINE OF CREDIT

During 2018, the Society entered into a line of credit agreement with a bank for \$250,000. There were no borrowings against the line as of December 31, 2020 and 2019. The line bears interest at the bank’s base rate. As of December 31, 2020, and 2019, the bank’s base rate was 3.75% and 5.25%, respectively. Under the terms of the line of credit, during each successive twelve-month period of the line of credit, the outstanding principal balance shall be paid in full for a period of thirty consecutive days. The Society is also required to have unencumbered liquidity, as defined, in an amount not less than \$500,000 measured at the end of each fiscal year.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

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(With Summarized Comparative Information for 2019)

(Continued)

NOTE 10 LEASING ARRANGEMENTS

Through 2018 and through July 31, 2019, the Society was a party to a 3-year lease agreement to occupy 1,835 square feet of office space in Lexington, Massachusetts. The basic rent was \$2,452 per month and additional amounts were assessed each month for operating costs and utilities.

In October 2018, the Society entered a three-year lease to renew 1,835 square feet of office space through July 2022. The basic rent commencing on August 1, 2019 was \$2,982 and additional amounts are assessed each month for operating costs and utilities. The basic annual rent increases each August 1st through 2021 by \$1.00 per square foot. The following is a schedule of future minimum rental payments as of December 31, 2020:

<u>Fiscal Year Ending</u>	<u>Amount</u>
December 31, 2021	\$38,382
December 31, 2022	<u>23,014</u>
Total	<u>\$61,396</u>

Rent expense for the years ended December 31, 2020 and 2019 was \$36,547 and \$32,072, respectively, which is included in *Occupancy* in the accompanying Statement of Functional Expenses.

NOTE 11 COMMITMENTS AND CONTINGENCIES

Employment Agreements:

The Society entered into a compensation agreement with its former Chief Science Officer (“CSO”) effective as of November 1, 2017. The agreement states that the former CSO’s employment is at will. The agreement also provides for annual base salary of \$75,000 beginning November 1, 2017. In addition, it provides for certain benefits, including reimbursement for health insurance in the event group coverage is not available, up to \$1,496 per month. The maximum contingency obligation under this arrangement was two times the annual salary.

During November 2019, the Society entered into a Separation and Release Agreement with the former CSO which supersedes the November 1, 2017 compensation agreement. The Separation and Release Agreement stipulates the last date of employment was December 31, 2019. Obligations under this agreement include a severance amount of \$206,787 payable in January 2020. The severance payment is accrued as of December 31, 2019 and is included in *Accrued Payroll and Related Costs* in the accompanying Statement of Financial Position and is also included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses. In addition, the Society has agreed to pay monthly COBRA premiums for medical insurance, in an amount not to exceed \$1,660 until COBRA continuation coverage terminates in accordance with the provisions of COBRA.

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NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020

(With Summarized Comparative Information for 2019)

(Continued)

NOTE 11 *(Continued)*

Clinical Trial Research Network Memorandum of Understanding

During 2019, the Society entered a memorandum of understanding (“MOU”) with the University of Kansas Medical Center (“KUMC”) for the development and management of the FSH Clinical Trial Research Network (“CTRN”). Per the MOU, the Society has agreed to pay KUMC \$180,000 in 2021 contingent upon reasonable determination that KUMC has made sufficient progress in developing the CTRN during the prior calendar year. In addition, the Society commits to awarding KUMC up to an additional \$120,000 per year in 2021-2022 for up to four new CTRN members. CTRN expenses for the years ended December 31, 2020 and 2019 were \$300,000 and \$180,000, respectively, which are included in *Scientific Grants and Research Projects* in the accompanying Statement of Functional Expenses.

Impact of COVID-19:

In early 2020, an outbreak of a novel strain of coronavirus (COVID-19) emerged globally. As a result, events have occurred including mandates from federal, state and local authorities leading to an overall decline in economic activity which could result in a loss of grants, contributions, revenue and other material adverse effects to the Organization’s financial position, change in net assets and cash flows. The Organization is not able to estimate the length of severity of this outbreak and the related financial impact. Management plans to adjust its operations accordingly and will continue to assess and monitor the situation as it evolves. If the length of the outbreak and related effect on the Organization’s operations continue for an extended period, the Organization may have to seek alternative measures to finance its operation. There is no assurance these measures will be successful.

NOTE 12 CARES ACT FUNDING

The Society was granted a \$194,500 loan under the Paycheck Protection Program (“PPP”) administered by a Small Business Administration (“SBA”) approved partner. The loan is uncollateralized and is fully guaranteed by the Federal government. The Society initially recorded the loan as a refundable advance and subsequently recognized grant revenue in accordance with guidance for conditional contributions; that is, once the measurable performance or other barrier and right of return of the PPP loan no longer existed. The Society has recognized \$194,500 as grant revenue in the accompanying statement of activities for the year ended December 31, 2020. The loan forgiveness application for \$194,500 was approved by the SBA on November 2, 2020.

NOTE 13 OTHER LOSS

In April 2020, the Society discovered that it was a victim of an email phishing scam. \$111,934 was transferred to a fraudulent bank account. Following an investigation by the Society’s online bill payment service, the Society was able to recover \$12,000, which resulted in a net loss of \$99,934, which has been recorded as *Other Loss* in the accompanying Statement of Activities. Management took several actions because of this fraud, including the implementation of additional controls over electronic bill payments and wire transfers as well as cybersecurity training and monitoring for the Society’s staff. In addition to its cyber insurance, the Society has also purchased social engineering insurance which insures against email phishing scams.

FSHD SOCIETY

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(Continued)

NOTE 14 RETIREMENT PLANS

Effective January 1, 2018, the Society maintains a defined contribution plan qualified under IRC Section 401(k). The defined contribution plan provides that employees who have attained age 21 may voluntarily contribute their earnings to the plan, up to the maximum allowed by the IRS. Employer contributions are discretionary and are authorized by the Board of Directors each plan year. In 2020 and 2019, the Society elected to make safe harbor matches of up to 4% of employees' earnings.

Effective December 15, 2020, the Society transitioned to a Professional Employer Organization ("PEO") for its payroll, benefits, and human resource needs. The Society transitioned to the PEO 401(k) Plan effective December 15, 2020. The PEO 401(k) plan provides that employees who have attained age 21 and completion of three consecutive month of employment may voluntarily contribute their earnings to the plan, up to the maximum allowed by the IRS. Employer contributions are discretionary and are authorized by the Board of Directors each plan year. In 2020, the Society elected to make safe harbor matches of up to 4% of employees' earnings.

For the years ended December 31, 2020 and 2019, the total employer contributions to each of the retirement plans outlined above were \$46,488 and \$36,867, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

NOTE 15 457(b) DEFERRED COMPENSATION PLAN

During 2019, the Society's Board of Directors approved a 457(b) deferred compensation plan that allows eligible employees to defer pretax annual compensation up to certain limitations imposed by the IRS. Eligible employees are determined by the Board of Directors. During the years presented, the only eligible employee is the Society's Chief Executive Officer & President. The Society reports assets and liabilities of equal amounts attributable to the amount deferred, as the Society has opted to set aside amounts contributed to the plan; however, these assets are owned by the Society until a vesting event occurs. Eligible employees must remain employed by the Society until December 31, 2024 for employer contributions in the plan to vest. For the years ended December 31, 2020 and 2019, the Board voted to fund this plan in the amount of \$19,500 and \$19,000, respectively. The assets and liability related to the 457(b) deferred compensation plan are included in *Investments and Long-Term Compensation Liability* in the accompanying statement of financial position and represent the cumulative amount of contributions to the 457(b) deferred compensation plan, as well as accumulated earning and losses since the plan's inception. The related deferred compensation expense for the years ended, December 31, 2020 and 2019 were \$22,878 and \$19,000, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

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(Continued)

NOTE 16 CONCENTRATIONS

Financial instruments which potentially subject the Organization to concentrations of credit and market risk consist principally of the Organization's cash balances, investment portfolio, and contributions receivable.

Cash:

The Organization is subject to concentrations in credit risk relating to cash balances. The Society maintains two bank accounts with one financial institution: (1) a Negotiable Order of Withdrawal account ("NOW account") and (2) an Insured Cash Sweep account ("ICS account"). After all debit and credit transactions have posted at the end of each business day, excess balances from the NOW account are automatically moved to the ICS account. ICS account funds are divided into amounts under the standard Federal Deposit Insurance Corporation ("FDIC") maximum and placed with other ICS network members, each an FDIC insured institution. As of December 31, 2020, and 2019, cash balances in excess of the FDIC limit were \$31,498 and \$132,392, respectively. The Organization has not experienced any losses on uninsured cash balances and management considers risk on cash balances to be low.

Investments:

The Organization invests or holds a variety of investment vehicles, including money market funds, mutual fund, EFTS, preferred stocks, and bonds. These investments are exposed to interest rate, market, credit, and other risks depending upon the nature of the investment. Accordingly, it is reasonably possible that these factors will result in changes in the value of the Organization's investments; however, the Organization's investments do not represent significant concentrations of market risk considering the Organization's portfolio is widely diversified among issuers.

Gifts, Grants, and Contributions:

During 2019, one significant donor represented 18% of the Society's gross support and revenues. There were no significant donors in 2020.

Contributions Receivable:

As of December 31, 2019, 59% of *Contributions Receivable* was owed from three donors. As of December 31, 2020, 51% of *Contributions Receivable* was owed from two donors.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

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(With Summarized Comparative Information for 2019)

(Continued)

NOTE 17 AVAILABLE RESOURCES AND LIQUIDITY

As part of the Society's liquidity management, it has a policy to structure its financial assets to be available as its general expenditures, liabilities, and other obligations come due. The Society has various sources of liquidity at its disposal, including cash and cash equivalents, marketable debt and equity securities, and a line of credit. See Note 9 for information about the Society's line of credit.

For purposes of analyzing resources available to meet general expenditures over a 12-month period, the Society considers all expenditures related to its ongoing activities of promoting research and patient advocacy and education as well as the conduct of services undertaken to support those activities to be general expenditures. The Society manages its cash available to meet general expenditures following three guiding principles:

- Operating within a prudent range of financial soundness and stability,
- Maintaining adequate liquid assets, and
- Maintaining sufficient reserves to provide reasonable assurance that grant commitments will continue to be met.

The Society strives to maintain year-end financial assets available to meet general expenditures at a level that represents 50% of annual operating expenses plus an amount that represents the next expected payment for semi-annual grant commitments plus all current grants payable approved by the Board.

The table below presents financial assets available for general expenditures within two years as of December 31, 2020 and 2019:

	<u>2020</u>	<u>2019</u>
Financial Assets at Year End:		
Cash and Cash Equivalents	\$ 3,280,720	\$ 2,617,796
Contributions Receivable	340,181	739,710
Investments	<u>2,093,769</u>	<u>2,653,048</u>
Total Financial Assets	<u>5,714,670</u>	<u>6,010,554</u>
Less Amounts Not Available to be Used Within One Year:		
Investments in Donor Advised Fund		
With Donor-Imposed Restrictions	\$(1,901,891)	\$(2,639,048)
Programmatic Equity Investment	(150,000)	-
Deferred Compensation Liability	(41,878)	(19,000)
Contributions Receivable for Restricted Gifts, Net	(340,181)	(739,710)
Grants Payable Due Within One Year	(266,550)	(466,145)
Severance Liability	-	(206,787)
Reserves for Bi-Annual International Research and Patient Conference	<u>(157,000)</u>	<u>(157,000)</u>
Financial Assets Not Available to be Used Within One Year	<u>(2,857,500)</u>	<u>(4,227,690)</u>
Financial Assets Available to Meet General Expenditures Within One Year	<u>\$ 2,857,170</u>	<u>\$ 1,782,864</u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

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(With Summarized Comparative Information for 2019)

(Continued)

NOTE 18 SUBSEQUENT EVENTS

Management is required to consider events subsequent to the financial statement date for potential adjustment to or disclosure in the financial statements. Therefore, Management has evaluated subsequent events through March 16, 2021, the date which the financial statements were available for issue, and noted the following events which met the criteria:

Scientific Advisory Board Grants:

As of December 31, 2020, the Society had \$216,929 in expected future disbursements on all research grants awarded to that date which are reported as Grants Payable in the accompanying financial statements. Since then, two research grant awards totaling \$70,451 have been approved by the Board and accepted by the grantee, and \$84,087 have been paid to recipients. Hence, on March 16, 2021, on all grants awarded to that date, the total expected future disbursements are \$203,293, all of which is payable in 2021 through 2022.

Paycheck Protection Program Second Draw

On February 8, 2021, the FSHD Society received a second draw of the Paycheck Protection Program (“PPP”) loan proceeds of \$285,077 (“PPP2 Loan”), issued under the Economic Aid to Hard-Hit Small Businesses, Nonprofits, and Venues Act. The PPP provides for forgiveness of principal subject to various conditions regarding use of funds for allowable expenditures, maintenance of headcount and compensation levels, and the period within which PPP Loan proceeds must be spent. The FSHD Society will account for the PPP2 Loan in accordance with ASC 958-605, Not-for-Profit Entities-Revenue Recognition. The PPP2 Loan is deemed a non-exchange transaction; that is, the government does not receive commensurate value. The non-exchange transaction is conditional, because of the explicit right of return coupled with “barriers” placed upon expenditures for allowable purposes, maintenance of head count and compensation levels, and the period within which the funds must be spent.