FINANCIAL STATEMENTS

with

INDEPENDENT AUDITORS' REPORT

YEAR ENDED DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)



REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)



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.

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

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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, 2019, 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, 2019, 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 2018 financial statements, and our report dated March 19, 2019, 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, 2018, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Westborough, Massachusetts

Smith, Sullivan , Brown, R.

March 17, 2020

STATEMENTS OF FINANCIAL POSITION AS OF DECEMBER 31, 2019 AND 2018

ASSETS

	ASSE 1S	
	<u>2019</u>	<u>2018</u>
CURRENT ASSETS:		
Cash and Cash Equivalents	\$ 2,617,796	\$ 1,960,102
Contributions Receivable	739,710	120,000
Short-Term Investments	-	498,155
Prepaid Expenses	45,761	32,086
Total Current Assets	3,403,267	2,610,343
NET PROPERTY AND EQUIPMENT	7,108	12,216
NON-CURRENT ASSETS:		
Contributions Receivable	424,566	-
Deposits	4,477	4,477
Investments:		
Lewis Family Donor Advised Fund for FSHD	2,634,048	1,330,771
Deferred Compensation Investments	19,000	
Total Non-Current Assets	3,082,091	1,335,248
TOTAL ASSETS	<u>\$ 6,492,466</u>	\$ 3,957,807
LIABILITIE	ES AND NET ASSETS	
CURRENT LIABILITIES:		
Grants Payable	\$ 418,145	\$ 329,048
Accounts Payable and Accrued Expenses	50,040	48,378
Accrued Payroll and Related Costs	219,938	16,545
Total Current Liabilities	688,123	393,971
LONG TERM LIABILITIES:		
Long-Term Grants Payable	67,905	136,482
Long-Term Deferred Compensation Liability	19,000	
Total Long-term Liabilities	86,905	136,482
TOTAL LIABILITIES	775,028	530,453
NET ASSETS:		
Net Assets Without Donor Restrictions	1,927,614	976,583
Net Assets With Donor Restrictions	3,789,824	2,450,771
Total Net Assets	5,717,438	3,427,354
TOTAL LIABILITIES AND NET ASSETS	<u>\$ 6,492,466</u>	\$ 3,957,807

STATEMENT OF ACTIVITIES

FOR THE YEAR ENDED DECEMBER 31, 2019

(With Summarized Comparative Totals for 2018)

	<u>WITHOUT</u> <u>DONOR</u> RESTRICTIONS	<u>WITH</u> <u>DONOR</u> RESTRICTIONS	TOTAL AC 2019	TIVITIES 2018
SUPPORT, REVENUES AND RECLASSIFICATIONS	<u>112511116110115</u>	<u>ALBSTITUCTION IS</u>	<u>=012</u>	<u> 2010</u>
Support and Revenues:				
Gifts, Grants and Contributions	\$ 1,475,067	\$ 3,073,402	\$ 4,548,469	\$ 2,089,205
Gross special events revenue	443,830	-	443,830	308,114
Less: Cost of Direct Benefits to Donors	(51,017)	-	(51,017)	(59,913)
Donated Goods and Services	80,738	-	80,738	94,338
Program Revenue	191,448	11,000	202,448	194,965
Total Support and Revenues	2,140,066	3,084,402	5,224,468	2,626,709
Investment and Other Income:				
Investment Return, Net	4,800	373,460	378,260	(79,470)
Return of Grant Funds	7,779	-	7,779	27,805
Other Income (Loss)	675	<u> </u>	675	(17,394)
Total Investment and Other Income	13,254	373,460	386,714	(69,059)
Reclassification of Net Assets:				
Net Assets Released From Restriction	2,118,809	(2,118,809)		
TOTAL SUPPORT, REVENUES AND RECLASSIFICATIONS	4,272,129	1,339,053	5,611,182	2,557,650
EXPENSES:				
Program Services:				
Research	1,933,640	-	1,933,640	1,476,690
Patient Advocacy and Education	636,188	<u> </u>	636,188	588,185
Total Program Services	2,569,828	-	2,569,828	2,064,875
Supporting Services:				
Administrative	328,083	-	328,083	331,071
Fund Raising	423,187	-	423,187	370,662
Total Supporting Services	751,270		751,270	701,733
TOTAL EXPENSES	3,321,098		3,321,098	2,766,608
CHANGE IN NET ASSETS	951,031	1,339,053	2,290,084	(208,958)
NET ASSETS - BEGINNING OF YEAR	976,583	2,450,771	3,427,354	3,636,312
NET ASSETS - END OF YEAR	\$ 1,927,614	\$ 3,789,824	\$ 5,717,438	\$ 3,427,354

STATEMENT OF FUNCTIONAL EXPENSES

FOR THE YEAR ENDED DECEMBER 31, 2019

(With Summarized Comparative Totals for 2018)

		<u>PATIENT</u> <u>ADVOCACY</u>	TOTAL			<u>TOT</u>	<u> SAL</u>
		<u>AND</u>	PROGRAM	ADMINI-	<u>FUND</u>	FUNCTIONA	L EXPENSES
	<u>RESEARCH</u>	<u>EDUCATION</u>	<u>SERVICES</u>	<u>STRATIVE</u>	<u>RAISING</u>	<u>2019</u>	<u>2018</u>
Salaries and Related Expenses	\$ 657,440	\$ 342,848	\$ 1,000,288	\$ 213,951	\$ 230,530	\$ 1,444,769	\$ 878,259
Scientific Advisory Board Grants	974,862	-	974,862	-	-	974,862	1,037,579
Travel, Lodging and Meals	76,807	62,815	139,622	14,278	29,695	183,595	110,633
Consultants and Professional Fees	30,252	64,900	95,152	20,190	17,864	133,206	147,734
Patient Meetings and Research Conferences	79,557	23,944	103,501	-	-	103,501	197,940
Website and Computer Related Expenses	28,966	23,831	52,797	13,330	19,945	86,072	63,551
Donated Services	44,413	32,725	77,138	3,600	-	80,738	94,337
Printing	3,578	35,096	38,674	-	38,492	77,166	71,389
Fundraising Expenses	-	-	-	-	66,493	66,493	62,304
Bank Service Charges and							
Credit Card Processing Fees	3,518	2,571	6,089	3,047	49,956	59,092	35,654
Office Expenses	16,543	13,502	30,045	8,167	11,259	49,471	40,430
Occupancy	14,734	11,728	26,462	7,357	7,841	41,660	33,305
Chapter and Volunteer Development	-	19,355	19,355	-	622	19,977	5,553
Directors Expenses	-	-	-	19,216	-	19,216	6,178
Accounting, Auditing							
and Financial Consultants	-	-	-	14,000	-	14,000	14,200
Insurance	2,500	-	2,500	5,839	-	8,339	7,119
Depreciation and Amortization Expense	-	-	-	5,108	-	5,108	16,268
Public Awareness	-	2,873	2,873	-	1,507	4,380	1,851
Scientific Advisory Board Expenses	470		470	-		470	2,237
Total Functional Expenses	1,933,640	636,188	2,569,828	328,083	474,204	3,372,115	2,826,521
Less: Cost of Direct Benefits to Donors					(51,017)	(51,017)	(59,913)
Total Expenses per Statement of Activities	\$ 1,933,640	\$ 636,188	\$ 2,569,828	\$ 328,083	\$ 423,187	\$ 3,321,098	\$ 2,766,608

STATEMENTS OF CASH FLOWS FOR THE YEARS ENDED DECEMBER 31, 2019 AND 2018

	<u>2019</u>	<u>2018</u>	
<u>CASH FLOWS FROM OPERATING ACTIVITIES</u> :			
Change in Net Assets	\$ 2,290,084	\$ (208,958	<u>8</u>)
Adjustments to Reconcile Changes in Net Assets to Net Cash Provided by (Used for) Operating Activities:			
Depreciation and Amortization Expense	5,108	16,268	
Impairment Loss on Intangible Asset	-	17,984	4
Contributions of Mutual Funds to Lewis Family Donor Advised Fund for FSHD	(349,676)	-	
Contributions Restricted for Lewis Family Donor Advised Fund for FSHD	(668,204)	-	
Investment Return, Net	(376,397)	80,573	5
Deferrals to Deferred Compensation Plan	(19,000)	-	
Changes in Operating Assets and Liabilities:			
Contributions Receivable - Current and Long-term	(1,044,276)	120,000	O
Prepaid Expenses	(13,675)	(2,474	
Grants Payable - Current and Long-term	20,520	(334,89	7)
Accounts Payable and Accrued Expenses	1,662	16,822	
Accrued Payroll and Related Costs	203,393	2,71	
Net Adjustment	(2,240,545)	(83,01)	<u>1</u>)
NET CASH PROVIDED BY (USED FOR) OPERATING ACTIVITIES	49,539	(291,969	<u>9</u>)
CASH FLOWS FROM INVESTING ACTIVITIES:			
Proceeds from Investments with Donor Restrictions	-	107,800	0
Proceeds from Donor Advised Fund Grant	589,155	501,845	
Purchase of Investments	(668,204)	(503,000	
Proceeds from Sale of Investments	-	152,073	
Net Cash Flows From Investing Actitivies	(79,049)	258,720	
CASH FLOWS FROM FINANCING ACTIVITIES:			
Proceeds from Contributions Restricted for Lewis Family Donor Advised Fund for FSHD	668,204		
Increase in Long-Term Deferred Compensation Liability	19,000	-	
Net Cash Flows From Financing Actitivies	687,204		-
Net Cash Flows From Financing Actitivies	007,204		_
NET INCREASE (DECREASE) IN CASH BALANCES	657,694	(33,249	9)
CASH BALANCES - BEGINNING OF YEAR	1,960,102	1,993,35	<u>1</u>
CASH BALANCES - END OF YEAR	<u>\$ 2,617,796</u>	<u>\$ 1,960,102</u>	<u>2</u>
Non-Cash Investing and Financing Activities: Contributions of Mutual Funds to Lewis Family Donor Advised Fund for FSHD	\$ 349,676	\$ <u> </u>	
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NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

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.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

(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 of the income derived from the donated assets.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

(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. Management believes that these receivables are collectible, and therefore, no allowance for doubtful amounts has been established. If a receivable is determined to be uncollectible in subsequent periods, a provision will be established at that time. The Organization did not experience any loss on uncollectible receivables for the years presented.

Investments:

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 CodificationTM, 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.

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.

Intangibles:

The Society deferred costs totaling \$32,186 associated with the development and upgrade of its website. The intangible assets were originally amortized over 36 months, and amortization expense was \$10,626 for the year ended December 31, 2018. Intangible assets subject to amortization are reviewed for impairment whenever events or changes in circumstances indicate that a carrying value of an asset may not be recoverable. During December 2018, after a communication and marketing audit, the Society determined that a new website was required, which was developed during the first quarter of 2019, the costs of which are not material to these financial statements. As such, the Society determined that the carrying value of the intangible asset exceeded the fair value of the intangible asset as of December 31, 2018. An impairment loss of \$17,984 is included in *Other Income (Loss)* in the accompanying Statement of Activities for the year ended December 31, 2018.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

(Continued)

NOTE 2 (Continued)

Endowment and Donor Advised Funds:

In November 2018, the Lewis Family signed a gift agreement to convert the Endowment Fund known as the Lewis Family Fund for FSHD into a non-endowed donor advised fund known as the Lewis Family Donor Advised Fund for FSHD. 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.

In March of 2018, a change in donor wishes converted the Edward M. Schechter Endowment Fund into a non-endowed fund known as the Ed and Betty Jane Schechter Memorial Fund. The Ed and Betty Jane Schechter Memorial Fund is restricted by the donor for the purpose of advancing the Society's programs in research and travel grants to scientists.

Contributions, Gifts and Grants:

As required by the FASB Accounting Standards CodificationTM, 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. Contributions may include gifts of cash, securities, collection items or promises to give.

Contributions, including unconditional promises to give, are recognized as revenues in the period 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. 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 restriction expires, at which time the assets are reclassified to net assets without donor restrictions. Contributions are considered available for unrestricted use unless specifically restricted by the donor.

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 the conditions upon which they depend are substantially 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*.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

(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/or 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 of 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.

Recent Accounting Guidance:

Recently Implemented Standards

In May 2014, the FASB issued ASC Update No. 2014-09, (Topic 606) *Revenue from Contracts with Customers*. This ASU is a comprehensive new revenue recognition model that requires an organization to recognize revenue to depict the transfer of goods or services to a customer at an amount that reflects the consideration it expects to receive in exchange for those goods or services. This updated guidance impacts not-for-profit entities that have revenue transactions other than contributions. In August 2015, the FASB deferred the effective date of ASC Update No. 2014-09 by one year when it issued ASC Update No. 2015-14, (Topic 606) *Revenue from Contracts with Customers*. This standard was adopted by the Organization effective January 1, 2019. The adoption of this standard did not result in a material change to the Organization's revenue balances.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

(Continued)

NOTE 2 (Continued)

In June 2018, the FASB issued ASC Update No. 2018-08, (Topic 958) Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made. This ASU provides a more robust framework for determining whether a transaction should be accounted for as a contribution or as an exchange transaction. The ASU also provides additional guidance to help determine whether a contribution is conditional or unconditional. This standard was adopted by the Organization effective January 1, 2019. This ASU provides organizations with the option of applying the clarified guidance in the initial year of implementation on a prospective basis; therefore, the Organization has not restated its 2018 revenue balances or opening net assets for the years presented.

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. The Organization received \$100,000 and \$150,000 during 2019 and 2018, respectively, in accordance with the original grant agreement. The remaining installment of \$100,000 to be received in 2020 is conditioned upon receipt and review of reports demonstrating that a fundraising goal of \$567,233 per year has been met, and project milestones are reached. In accordance with generally accepted accounting principles, conditional promises to give are not recognized until they become unconditional, that is, at the time when the conditions on which they depend are substantially met.

NOTE 4 PROPERTY AND EQUIPMENT

The following is a summary of property and equipment as of December 31, 2019 and 2018:

	Est.		<u>Accumulated</u>	Net Boo	ok Value
Asset Category	<u>Life</u>	Cost	<u>Depreciation</u>	<u>2019</u>	<u>2018</u>
Computer, Technology					
And Office Equipment	3 - 5	\$ 7,976	\$ 7,689	\$ 287	\$ 1,468
Furniture and Fixtures	7	12,154	5,333	6,821	8,544
Leasehold Improvements	3	7,100	7,100		2,204
Total		<u>\$27,230</u>	<u>\$20,122</u>	<u>\$7,108</u>	\$12,216

During 2018, the Organization disposed of fully depreciated equipment with an original cost of \$3,850. The disposal of this equipment had no impact on the change in net assets for the year ended December 31, 2018.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

(Continued)

NOTE 5 INVESTMENTS

As of December 31, 2019 and 2018, investment costs and unrealized gains and losses consisted of the following components:

_	December 31, 2019					
	Cost	Unrealized	Unrealized	Fair Value	Fair Value	Total
<u>Investment Type</u>	Basis	Gains	Losses	(Level 1)	(Level 2)	Fair Value
Cash and Sweep Accounts S	\$ 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	208,043	5,208	(2,377)		210,874	210,874
Total	\$2,375,115	<u>\$282,047</u>	<u>\$(4,114)</u>	\$2,442,174	<u>\$210,874</u>	\$2,653,048
_			Decer	nber 31, 2018		
	Cost	Unrealized	Unrealized	Fair Value	Fair Value	Total
Investment Type	Basis	Gains	Losses	(Level 1)	(Level 2)	Fair Value
Cash and Sweep Accounts	\$ 10,422	\$ -	\$ -	\$ 10,422	\$ -	\$ 10,422
Mutual Funds	1,519,201	82,309	(56,438)	1,545,072	-	1,545,072
Exchange Traded Funds			(0.001)	0.4.67.4		04.674
Exchange Traded Funds	97,005	-	(2,331)	94,674	-	94,674
Preferred Stocks and Bonds	,		(2,331) (8,588)	94,674	178,758	94,674 178,758

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).

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

(Continued)

NOTE 5 (Continued)

Components of *Investment Return* for the years ended December 31, 2019 and 2018, is as follows:

Components of Investment Return	<u>2019</u>	<u>2018</u>
Interest and Dividends	\$ 93,131	\$ 137,366
Unrealized Gains (Losses)	261,928	(238,437)
Realized Gains (Losses)	23,201	21,601
Net Investment Return	<u>\$378,260</u>	<u>\$ (79,470)</u>

NOTE 6 DESIGNATIONS AND RESTRICTIONS OF NET ASSETS

Net Assets With Donor Restrictions:

As of December 31, 2019, and 2018, net assets with donor restrictions were designated for research and education and consisted of the following balances:

Nature of Restriction	<u>2019</u>	<u>2018</u>
Lewis Family Donor Advised Fund for FSHD	\$2,639,048	\$1,330,771
FSHD Theraputics	815,869	1,000,000
S&L Marx Foundation	-	120,000
Research and Education	334,907	
Total	<u>\$3,789,824</u>	\$2,450,771

As of December 31, 2019 and 2018, investments and cash and cash equivalents in the Lewis Family Donor Advised Fund for FSHD include \$2,639,048 and \$1,330,771, respectively, of funds that management does not intend to draw on within the next fiscal year. As of December 31, 2018, investments also include \$498,155 of short-term investments designated for FSHD Therapeutic initiatives during the next fiscal year. For the years presented, components of FSHD Therapeutics include the following:

	<u>2019</u>	<u>2018</u>
Contributions Receivable-		
Current and Long-Term	\$815,869	\$ -
Cash and Cash Equivalents	-	501,845
Short-Term Investments	_	498,155
Total	<u>\$815,869</u>	\$1,000,000

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

(Continued)

NOTE 6 (Continued)

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:

Nature of Restriction	<u>2019</u>	<u>2018</u>
Donations Designated for FSDH Therapeutics:		
Grant From Lewis Family Donor Advised Fund for FSHD	\$1,000,000	\$ -
Helen Younger Memorial Fund	94,957	-
Other	462,107	-
Clinical Trial Research Network:		
Tides Foundation	100,000	150,000
Donations Designated for Research and Education:		
Ed and Betty Jane Schechter Memorial Fund	-	148,383
S&L Marx Foundation	120,000	120,000
Lincoln and Irene Lai Wellness Fund	1,000	22,964
Helen Younger Memorial Fund	-	8,340
Appropriation from Lewis Fund:		
Donor Advised Fund from FSHD	91,000	-
Other	249,745	169,573
Appropriation of Endowment Appreciation:		
Edward M. Schechter Endowment Fund for FSHD	-	7,800
Lewis Family Endowment Fund for FSHD		100,000
Total	\$2,118,809	\$727,060

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>2019</u>	<u>2018</u>
Scientific Advisory Board Expenses	\$44,413	\$57,588
Science time for FSHD Connect and Family Days	32,725	33,150
Investment Advisory Services	3,600	3,600
Total	\$80,738	\$94,338

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.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

(Continued)

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, 2019 and 2018. The line bears interest at the bank's base rate. At December 31, 2019 and 2018, the bank's base rate was 5.25% and 5.75%, 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.

NOTE 10 LEASING ARRANGEMENTS

During 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 are 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 is \$2,982 and additional amounts are assessed each month for operating costs and utilities. The basic annual rent increases each August 1st thru 2021 by \$1.00 per square foot. The following is a schedule of future minimum rental payments as of December 31, 2019:

Fiscal Year
Ending Amount
\$36,547
38,382
23,014
<u>\$97,943</u>

Rent expense for the years ended December 31, 2019 and 2018 was \$32,072 and \$29,422, respectively, which is included in *Occupancy* in the accompanying statement of functional expenses.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

(Continued)

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 supercedes 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.

In 2012, the Society became party to an offer letter with its current Chief Strategic Programs Officer (CSPO). If the CSPO is terminated for any reason other than cause, the Society is obligated to pay the CSPO three months of salary plus benefits. The maximum contingency obligation under this arrangement was approximately \$32,500. In December 2019, due to a reorganization, the Society and the CSPO signed a new offer letter which supercedes the 2012 offer letter. The 2019 offer letter does not contain a separation contingency.

Program Service Commitments:

During 2019, the Society entered into 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 both 2020 and 2021 contingent upon reasonable determination that KUMC has made sufficient progess 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 2020-2022 for up to four new CTRN members.

During 2019, the Society entered into various professional service consulting agreements and venue contracts for 2020 conferences and meetings. Obligations during 2020 under these agreements are approximately \$306,000.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

(Continued)

NOTE 12 RETIREMENT PLAN

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 2019 and 2018, the Society elected to make safe harbor matches of up to 4% of employees' earnings.

For the years ended December 31, 2019 and 2018, the total employer contributions to each of the retirement plans outlined above were \$36,867 and \$25,589, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

NOTE 13 457(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 2019, 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 year ended December 31, 2019, the Board voted to fund this plan in the amount of \$19,000. The long-term deferred compensation liability, and related expense, as of, and for the year ended, December 31, 2019 is \$19,000 and is included in the accompanying Statement of Financial Position and is also included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

NOTE 14 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 FDIC maximum and placed with other ICS network members, each an FDIC insured institution. As of December 31, 2019, and 2018, cash balances in excess of the FDIC limit were \$132,392 and \$49,937, respectively. The Organization has not experienced any losses on uninsured cash balances and management considers risk on cash balances to be low.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

(Continued)

NOTE 14 (Continued)

Investments:

The Organization invests or holds a variety of investment vehicles, including money market funds, mutual fund, 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 represents 18% of the Society's gross support and revenues. During 2018, there are no significant donors that meet the requirement for disclosure.

Contributions Receivable:

As of December 31, 2018, 100% of *Contributions Receivable* represent the amounts owed from one donor. As of December 31, 2019, 59% of *Contributions Receivable* was owed from three donors.

NOTE 15 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. In addition, during 2018, the Society has a contingent obligation due to the former Chief Science Officer (CSO) of approximately \$150,000 (see Note 11). It is the Society's policy to reserve for this contingent liability in full. It is also the Society's policy to reserve annually for its bi-annual international research and patient meeting.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2019

(With Summarized Comparative Information for 2018)

(Continued)

NOTE 15 (Continued)

The table below presents financial assets available for general expenditures within two years as of December 31, 2019 and 2018:

,	2019	2018
Financial Assets at Year End:	· 	
Cash and Cash Equivalents	\$ 2,617,796	\$ 1,960,102
Contributions Receivable	739,710	120,000
Investments	2,653,048	1,828,926
Total Financial Assets	6,010,554	3,909,028
Less Amounts Not Available to be Used Within One Year:		
Investments in Donor Advised Fund		
With Donor-Imposed Restrictions	(2,639,048)	(1,330,771)
Contributions Receivable for Restricted Gifts, Net	(739,710)	(120,000)
Grants Payable Due Within One Year	(466,145)	(603,986)
Maximum Contingency Obligation to CSO	-	(150,000)
Severance Liability	(206,787)	-
Deferred Compensation Liability	(19,000)	-
Reserves for Bi-Annual International Research and		
Patient Conference	(157,000)	(115,000)
Financial Assets Not Available to be Used Within One Year	(4,227,690)	(2,319,757)
Financial Assets Available to Meet General Expenditures		
Within One Year	<u>\$ 1,782,864</u>	<u>\$ 1,589,271</u>

NOTE 16 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 17, 2020, the date which the financial statements were available for issue, and noted the following events which met the criteria:

2020 Coronavirus Pandemic:

Subsequent to year end, the global economies have been impacted by the Coronavirus pandemic. This has led to large market swings impacting the daily value of the Society's long-term investments. It is the opinion of management that market volatility will not hinder daily operations of the FSHD Society. Investments are considered long-term by management. Therefore, investments are not factored into financial assets available to meet general expenditures within one year (see Footnote 15).

Scientific Advisory Board Grants:

As of December 31, 2019, the Society had \$486,050 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, one research grant awards totaling \$48,000 has been approved by the Board and accepted by the grantee, \$91,905 has been paid to recipients. Hence, at March 17, 2020, on all grants awarded to that date, the total expected future disbursements are \$442,146 all of which is payable in 2020 through 2021.