FACIOSCAPULOHUMERAL (FSH) SOCIETY

FINANCIAL STATEMENTS

with

INDEPENDENT AUDITORS' REPORT

YEAR ENDED DECEMBER 31, 2018

(With Summarized Comparative Information for 2017)

Smith Sullivan & Brown PC
CERTIFIED PUBLIC ACCOUNTANTS

80 Flanders Road, Suite 200 Westborough, Massachusetts 01581
Tel: 508.871.7178 Fax: 508.871.7179 www.ssbcpa.com

FACIOSCAPULOHUMERAL (FSH) SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2018

(With Summarized Comparative Information for 2017)

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.*

www.fshsociety.org

FACIOSCAPULOHUMERAL (FSH) SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2018

(With Summarized Comparative Information for 2017)

C O N T E N T S

Smith Sullivan & Brown PC
CERTIFIED PUBLIC ACCOUNTANTS

80 Flanders Road, Suite 200 Westborough, Massachusetts 01581
Tel: 508.871.7178 Fax: 508.871.7179 www.ssbcpa.com

INDEPENDENT AUDITORS' REPORT

To the Board of Directors
Facioscapulohumeral (FSH) Society
Lexington, Massachusetts

We have audited the accompanying financial statements of Facioscapulohumeral (FSH) Society (a District of Columbia nonprofit corporation), which comprise the statement of financial position as of December 31, 2018, 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 Facioscapulohumeral (FSH) Society as of December 31, 2018, 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 Facioscapulohumeral (FSH) Society's 2017 financial statements, and our report dated March 20, 2018, 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, 2017, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Smith, Sullivan & Brown, P.C.

Westborough, Massachusetts
March 19, 2019

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENTS OF FINANCIAL POSITION AS OF DECEMBER 31, 2018 AND 2017

ASSETS

	2018	2017
CURRENT ASSETS:		
Cash and Cash Equivalents	$ 1,960,102	$ 1,993,351
Contributions Receivable	120,000	120,000
Short-Term Investments	498,155	-
Prepaid Expenses	32,086	29,612
Total Current Assets	2,610,343	2,142,963
NET PROPERTY AND EQUIPMENT	12,216	17,858
NON-CURRENT ASSETS:		
Contributions Receivable	-	120,000
Intangible Asset, Net	-	28,610
Deposits	4,477	4,477
Investments:		
Lewis Family Donor Advised Fund for FSHD	1,330,771	-
Lewis Family Fund for FSHD	-	2,010,380
Edward M. Schechter Fund Investments	-	157,841
Total Non-Current Assets	1,335,248	2,321,308
TOTAL ASSETS	$ 3,957,807	$ 4,482,129

LIABILITIES AND NET ASSETS

	2018	2017
CURRENT LIABILITIES:		
Grants Payable	$ 329,048	$ 771,327
Accounts Payable and Accrued Expenses	48,378	31,556
Accrued Payroll and Related Costs	16,545	13,834
Total Current Liabilities	393,971	816,717
LONG TERM LIABILITIES:		
Long-Term Grants Payable	136,482	29,100
TOTAL LIABILITIES	530,453	845,817
NET ASSETS:		
Net Assets Without Donor Restrictions	976,583	1,279,075
Net Assets With Donor Restrictions	2,450,771	2,357,237
Total Net Assets	3,427,354	3,636,312
TOTAL LIABILITIES AND NET ASSETS	$ 3,957,807	$ 4,482,129

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED DECEMBER 31, 2018
(With Summarized Comparative Totals for 2017)

	WITHOUT DONOR RESTRICTIONS	WITH DONOR RESTRICTIONS	TOTAL ACTIVITIES 2018	TOTAL ACTIVITIES 2017
SUPPORT, REVENUES AND RECLASSIFICATIONS				
Support and Revenues:				
Gifts, Grants and Contributions	$ 1,189,745	$ 899,460	$ 2,089,205	$ 2,946,763
Gross special events revenue	307,414	700	308,114	132,137
Less: Cost of Direct Benefits to Donors	(59,913)	-	(59,913)	(55,986)
Donated Goods and Services	94,338	-	94,338	167,581
Program Revenue	194,965	-	194,965	29,714
Total Support and Revenues	1,726,549	900,160	2,626,709	3,220,209
Investment and Other Income:				
Investment Return, Net	96	(79,566)	(79,470)	261,237
Return of Grant Funds	27,805	-	27,805	100,870
Other Income (Loss)	(17,394)	-	(17,394)	1,848
Total Investment and Other Income	10,507	(79,566)	(69,059)	363,955
Reclassification of Net Assets:				
Net Assets Released From Restriction	727,060	(727,060)	-	-
TOTAL SUPPORT, REVENUES AND RECLASSIFICATIONS	**2,464,116**	**93,534**	**2,557,650**	**3,584,164**
EXPENSES:				
Program Services:				
Research	1,476,690	-	1,476,690	1,592,275
Patient Advocacy and Education	588,185	-	588,185	373,948
Total Program Services	2,064,875	-	2,064,875	1,966,223
Supporting Services:				
Administrative	331,071	-	331,071	344,693
Fund Raising	370,662	-	370,662	279,903
Total Supporting Services	701,733	-	701,733	624,596
TOTAL EXPENSES	**2,766,608**	**-**	**2,766,608**	**2,590,819**
CHANGE IN NET ASSETS	**(302,492)**	**93,534**	**(208,958)**	**993,345**
NET ASSETS - BEGINNING OF YEAR	**1,279,075**	**2,357,237**	**3,636,312**	**2,642,967**
NET ASSETS - END OF YEAR	**$ 976,583**	**$ 2,450,771**	**$ 3,427,354**	**$ 3,636,312**

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2018
(With Summarized Comparative Totals for 2017)

	RESEARCH	PATIENT ADVOCACY AND EDUCATION	TOTAL PROGRAM SERVICES	ADMINI-STRATIVE	FUND RAISING	TOTAL FUNCTIONAL EXPENSES 2018	TOTAL FUNCTIONAL EXPENSES 2017
Scientific Advisory Board Grants	$ 1,037,579	$ -	$ 1,037,579	$ -	$ -	$ 1,037,579	$ 1,365,489
Salaries and Related Expenses	226,529	287,909	514,438	189,263	174,558	878,259	644,635
Patient Meetings and Research Conferences	63,788	134,152	197,940	-	-	197,940	10,540
Consultants and Professional Fees	16,726	-	16,726	55,983	75,025	147,734	112,849
Travel, Lodging and Meals	35,393	52,827	88,220	2,362	20,051	110,633	54,370
Donated Services	57,587	33,150	90,737	3,600	-	94,337	167,581
Printing	1,465	30,941	32,406	-	38,983	71,389	56,825
Website and Computer Related Expenses	15,039	19,457	34,496	17,267	11,788	63,551	43,695
Fundraising Expenses	-	-	-	-	62,304	62,304	63,219
Office Expenses	10,316	12,817	23,133	8,512	8,785	40,430	27,147
Bank Service Charges and Credit Card Processing Fees	1,452	1,850	3,302	3,136	29,216	35,654	22,971
Occupancy	8,579	10,914	19,493	7,183	6,629	33,305	33,067
Depreciation and Amortization Expense	-	-	-	16,268	-	16,268	9,274
Accounting, Auditing and Financial Consultants	-	-	-	14,200	-	14,200	13,650
Insurance	-	-	-	7,119	-	7,119	5,447
Directors Expenses	-	-	-	6,178	-	6,178	6,653
Chapter and Volunteer Development	-	2,630	2,630	-	2,923	5,553	-
Scientific Advisory Board Expenses	2,237	-	2,237	-	-	2,237	8,466
Public Awareness	-	1,538	1,538	-	313	1,851	927
Total Functional Expenses	**1,476,690**	**588,185**	**2,064,875**	**331,071**	**430,575**	**2,826,521**	**2,646,805**
Less: Cost of Direct Benefits to Donors	-	-	-	-	(59,913)	(59,913)	(55,986)
Total Expenses per Statement of Activities	**$ 1,476,690**	**$ 588,185**	**$ 2,064,875**	**$ 331,071**	**$ 370,662**	**$ 2,766,608**	**$ 2,590,819**

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENTS OF CASH FLOWS
FOR THE YEARS ENDED DECEMBER 31, 2018 AND 2017

	2018	2017
CASH FLOWS FROM OPERATING ACTIVITIES:		
Change in Net Assets	$ (208,958)	$ 993,345
Adjustments to Reconcile Changes in Net Assets to Net Cash Used for Operating Activities:		
Depreciation and Amortization Expense	16,268	9,274
Impairment Loss on Intangible Asset	17,984	-
Contributions of Mutual Funds to Endowment	-	(870,542)
Contributions Restricted for Endowment	-	(66,695)
Investment Return, Net	80,575	(260,501)
Changes in Operating Assets and Liabilities:		
Contributions Receivable - Current and Long-term	120,000	(194,000)
Prepaid Expenses	(2,474)	(14,362)
Deposits	-	9,500
Grants Payable - Current and Long-term	(334,897)	179,309
Accounts Payable and Accrued Expenses	16,822	(30,352)
Accrued Payroll and Related Costs	2,711	(9,176)
Net Adjustment	(83,011)	(1,247,545)
NET CASH USED FOR OPERATING ACTIVITIES	**(291,969)**	**(254,200)**
CASH FLOWS FROM INVESTING ACTIVITIES:		
Website Development	-	(32,186)
Proceeds from Endowment Investments	107,800	46,400
Proceeds from Donor Advised Fund Grant	501,845	-
Purchase of Investments	(503,000)	(62,000)
Proceeds from Sale of Investments	152,075	-
Purchase of Endowment Investments	-	(66,695)
Net Cash Flows From Investing Actitivies	258,720	(114,481)
CASH FLOWS FROM FINANCING ACTIVITIES:		
Proceeds from Contributions Restricted for Endowment	-	66,695
NET DECREASE IN CASH BALANCES	**(33,249)**	**(301,986)**
CASH BALANCES - BEGINNING OF YEAR	**1,993,351**	**2,295,337**
CASH BALANCES - END OF YEAR	**$ 1,960,102**	**$ 1,993,351**
Non-Cash Investing and Financing Activities:		
Contributions of Mutual Funds to Endowment	*$ -*	*$ 870,542*

NOTE 1 OPERATIONS AND NONPROFIT STATUS

Operations:

The FSH Society 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:

Facioscapulohumeral (FSH) Society ("FSH Society", the "Society" or the "Organization") was incorporated 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. FSH 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.

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*™, 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.

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. As of December 31, 2017, the Organization's non-current contributions were due within two years. As of December 31, 2018, the Organization has no non-current contributions outstanding. 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 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 6.

Property and Equipment:

FSH 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 during the year ended December 31, 2017. The intangible assets are amortized over 36 months and presented net of accumulated amortization on the accompanying Statements of Financial Position. Amortization expense was $10,626 and $3,576, respectively, for the years ended December 31, 2018 and 2017. 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 is required. The new website will be developed during the first quarter of 2019. As such, the Society determined that the carrying value of the intangible asset exceeded the fair value of the intangible asset. 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.

NOTE 2 *(Continued)*

Endowment and Donor Advised Funds:

In December 2016, the Board voted to authorize a gift agreement between Duncan and William R. Lewis, Sr. and the Society. The executed gift agreement converted the William R. Lewis Board Designated Quasi-Endowment Fund to a Permanent Donor Restricted Endowment Fund known as the Lewis Family Fund for FSHD. In November 2018, the Lewis Family signed a gift agreement to convert the Permanent Donor Restricted 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 FSH 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 permanently restricted 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.

When the Society holds endowed funds, as required by the Commonwealth of Massachusetts, the Organization follows the guidance of the Uniform Prudent Management of Institutional Funds Act ("UPMIFA"). UPMIFA establishes law for the management of investment of donor-restricted endowment funds.

The Board of Director's interpretation of state law is that the Organization, absent explicit donor stipulations to the contrary, may appropriate as much of the endowed fund as is prudent considering the Organization's long and short-term needs, present and anticipated financial requirements, expected total return on its investments, price-level trends, and general economic conditions.

In accordance with UPMIFA, the Organization considers the following factors in making a determination of whether to invest or appropriate donor-restricted endowment funds:

- The duration and preservation of the fund
- The purposes of the Organization and the donor-restricted endowment fund
- General economic conditions
- The possible effect of inflation and deflation
- The expected total return from income and the appreciation of investments
- Other resources of the Organization
- The investment policies of the Organization

NOTE 2 *(Continued)*

In accordance with generally accepted accounting principles, the Society reports the original fair value of permanent endowment contributions, or original corpus, as part of net assets with donor restrictions. Income and appreciation earned on endowment investments are also classified part of net assets with donor restrictions until appropriated for expenditure by the Board of Directors based on the above factors. From time to time, the fair value of assets associated with individual donor-restricted endowment funds may fall below the level of the original corpus. As required by the *FASB Accounting Standards Codification*™, deficiencies of this nature are reported in net assets with donor restrictions.

The Organization has a spending policy of appropriating for distribution each year the endowment income to supplement operating income an amount equal to not more than five percent of the average value of the fund (as determined by the value on the last day of the preceding fiscal year). The Organization takes a conservative approach to investing its endowment funds, which are maintained in a diversified portfolio of cash, mutual funds, ETFs, and preferred stocks and bonds.

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. 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 are not recognized until they become unconditional, that is, at the time when the conditions on which they depend are substantially 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.*

NOTE 2 *(Continued)*

Donated Goods and Services:

As required by the *FASB Accounting Standards Codification*™, 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 FSH 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. For the years ended December 31, 2018 and 2017, total fund raising expenses (including both direct and indirect event expenses) were $430,575 and $335,889, respectively.

Recent Accounting Guidance:

Recently Implemented Standards

In August 2016, the Financial Accounting Standards Board ("FASB") issued ASC Update No. 2016-14, (Topic 958) *Presentation of Financial Statements of Not-for-Profit Entities*, with the goal of improving not-for-profit financial statements to provide more useful information to donors, grantors, creditors, and other financial statement users. This ASU modified the current guidance over several criteria, of which the following affected the Organization's financial statements:

NOTE 2 *(Continued)*

- The Organization's net assets are segregated into two categories, "with donor restrictions" and "without donor restrictions" as opposed to the previous requirement of three classes of net assets.
- The Organization provided qualitative and quantitative information relating to management of liquidity and the availability of financial assets to cover short-term cash needs within one year from the statement of financial position date.
- The Organization provided a more in-depth explanation of the methods used to allocate costs among program and supporting functions.

In accordance with this ASU, the Organization has applied a modified retrospective application of the above standard, and as a result, is not presenting a liquidity and availability disclosure for the year ended December 31, 2017. See Footnote 14 for available resources and liquidity as of December 31, 2018.

Recently Issued 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 is effective for this Organization in financial statements issued for fiscal years beginning January 1, 2019. The adoption of this ASU is not expected to have a material effect on the Organization's financial position or change in net assets.

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 is effective for this Organization in financial statements issued for fiscal years beginning January 1, 2019. The adoption of this ASU is not expected to have a material effect on the Organization's financial position or change in net assets.

In February 2016, the FASB issued ASC Update No. 2016-02, (Topic 842) *Leases* which establishes a comprehensive new lease accounting model. The new standard clarifies the definition of a lease and causes lessees to recognize leases on the balance sheet as a lease liability with a corresponding right-of-use asset for leases with a lease term of more than one year. This standard is effective for this Organization in financial statements issued for fiscal years beginning January 1, 2020. The new standard requires a modified retrospective transition for capital or operating leases existing at or entered into after the beginning of the earliest comparative period presented in the financial statements, but it does not require transition accounting for leases that expire prior to the date of initial application. The adoption of this ASU is not expected to have a material effect on the Organization's financial position or change in net assets.

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. $150,000 was received during 2018. The remaining installments of $100,000 in 2019 and 2020 are 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, 2018 and 2017:

Asset Category	Est. Life	Cost	Accumulated Depreciation	Net Book Value 2018	Net Book Value 2017
Computer Technology and Office Equipment	3 - 5	$7,976	$ 6,508	$ 1,468	$ 3,049
Furniture and Fixtures	7	12,154	3,610	8,544	10,273
Leasehold Improvements	3	7,100	4,896	2,204	4,536
Total		$27,230	$15,014	$12,216	$17,858

During 2018 and 2017, the Organization disposed of fully depreciated equipment with an original cost of $3,850 and $9,097, respectively. The disposal of this equipment had no impact on the change in net assets for the years ended December 31, 2018 and 2017.

NOTE 5 INVESTMENTS

As of December 31, 2018 and 2017, investment costs and unrealized gains and losses consisted of the following components:

	December 31, 2018					
Investment Type	Cost Basis	Unrealized Gains	Unrealized Losses	Fair Value (Level 1)	Fair Value (Level 2)	Total 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	97,005	-	(2,331)	94,674	-	94,674
Preferred Stocks and Bonds	186,269	1,077	(8,588)	-	178,758	178,758
Total	$1,812,897	$83,386	$(67,357)	$1,650,168	$178,758	$1,828,926

NOTE 5 *(Continued)*

	December 31, 2017					
Investment Type	Cost Basis	Unrealized Gains	Unrealized Losses	Fair Value (Level 1)	Fair Value (Level 2)	Total Fair Value
Cash and Sweep Accounts	$ 11,748	$ -	$ -	$ 11,748	$ -	$ 11,748
Mutual Funds	1,578,568	240,419	-	1,818,987	-	1,818,987
Exchange Traded Funds	97,005	9,516	-	106,521	-	106,521
Preferred Stocks and Bonds	227,073	5,996	(2,104)	-	230,965	230,965
Total	$1,914,394	$255,931	$(2,104)	$1,937,256	$230,965	$2,168,221

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, 2018 and 2017, is as follows:

Components of Investment Return	2018	2017
Interest and Dividends	$ 137,366	$114,053
Unrealized Gains (Losses)	(238,437)	162,871
Realized Gains (Losses)	21,601	(15,687)
Net Investment Return	$ (79,470)	$261,237

NOTE 6 DESIGNATIONS AND RESTRICTIONS OF NET ASSETS

Net Assets With Donor Restrictions:

As of December 31, 2018, and 2017, net assets with donor restrictions were designated for research and education and consisted of the following balances:

Nature of Restriction	2018	2017
Lewis Family Donor Advised Fund for FSHD	$1,330,771	$ -
Lewis Family Endowment Fund for FSHD	-	2,010,381
FSHD Theraputics	1,000,000	-
S&L Marx Foundation	120,000	240,000
Edward M. Schechter Endowment Fund for FSHD	-	95,840
Research and Education	-	11,016
Total	$2,450,771	$2,357,237

NOTE 6 *(Continued)*

As of December 31, 2018, investments in the Lewis Family Donor Advised Fund for FSHD includes $1,330,771 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. As of December 31, 2018, components of FSHD Therapeutics include the following:

Cash and Cash Equivalents	$ 501,845
Short-Term Investments	498,155
Total	$1,000,000

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	2018	2017
Donations designated for Research and Education:		
Ed and Betty Jane Schechter Memorial Fund	$148,383	$ 65,000
S&L Marx Foundation	120,000	120,000
Lincoln and Irene Lai Wellness Fund	22,964	26,622
Helen Younger Memorial Fund	8,340	31,000
Other	169,573	360,896
Appropriation of Endowment Appreciation:		
Edward M. Schechter Endowment Fund for FSHD	7,800	3,400
Lewis Family Endowment Fund for FSHD	100,000	43,000
Clinical Trial Research Network:		
Tides Foundation	150,000	-
Total	$727,060	$649,918

Endowment Net Assets

The following schedule summarizes the change in endowment net assets for the years presented:

Endowment Net Assets, December 31, 2016	$ 959,883
Contributions	932,237
Investment Income	112,855
Investment Gains (Losses)	147,646
Appropriation for Expenditure	(46,400)
Endowment Net Assets, December 31, 2017	2,106,221
Contributions	-
Investment Income	21,415
Investment Gains (Losses)	(25,460)
Appropriation for Expenditure	(107,800)
Change in Donor Intent	(1,994,376)
Endowment Net Assets, December 31, 2018	$ -

NOTE 7 DONATED GOODS AND SERVICES

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

Description	2018	2017
Scientific Advisory Board Expenses	$57,588	$ 92,863
Science time for FSHD Connect and Family Days	33,150	-
Public Relations	-	61,643
Other Professional Services	-	5,050
Legal	-	4,425
Investment Advisory Services	3,600	3,600
Total	$94,338	$167,581

NOTE 8 FSHD CANADA AGREEMENT

On November 8, 2012, an Agency Agreement was signed between the FSH Society and the FSHD Canada Foundation. FSHD Canada Foundation is registered under the Income Tax Act (Canada) as a "charitable Organization." The FSH 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 at December 31, 2018. The line bears interest at the bank's base rate. At December 31, 2018, the bank's base rate was 5.75%. 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 2017 and through July 31, 2019, the Society is a party to a 3-year lease agreement to occupy 1,835 square feet of office space in Lexington, Massachusetts. The basic rent is $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, 2018:

Fiscal Year Ending	Amount
December 31, 2019	$ 32,072
December 31, 2020	36,547
December 31, 2021	38,382
December 31, 2022	23,014
Total	$130,015

Rent expense for the years ended December 31, 2018 and 2017 was $29,422 which is included in *Occupancy* in the accompanying statement of functional expenses.

NOTE 11 COMMITMENTS AND CONTINGENCIES

The Society entered into a compensation agreement with its Chief Science Officer (CSO) effective as of November 1, 2017. The agreement states that the 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 is two times the annual salary.

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 is approximately $32,500.

During 2017, the Society entered into various professional service consulting agreements and venue contracts for 2019 conferences and meetings. Obligations during 2019 under these agreements are approximately $76,000.

NOTE 12 RETIREMENT PLAN

Through December 2017, FSH Society maintained a SIMPLE IRA retirement plan. The IRA plan allowed eligible employees of the Organization to defer a percentage of their earnings from current taxation. For the year ended December 31, 2017, employee contributions to the IRA were subject to a 3% employer match. Effective January 1, 2018, the Society adopted 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 2018, the Society elected to make safe harbor matches of up to 4% of employees' earnings.

For the years ended December 31, 2018 and 2017, the total employer contributions to each of the retirement plans outlined above were $25,589 and $14,863, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

NOTE 13 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, 2018, and 2017, cash balances in excess of the FDIC limit were $49,937 and $50,012, 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, 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.

NOTE 13 *(Continued)*

Gifts, Grants, and Contributions:

During 2017, a significant portion of the Society's gross support and revenues came from two donors, 32% and 11% respectively. During 2018, there are no significant donors that meet the requirement for disclosure.

Contributions Receivable:

As of December 31, 2018, and 2017, 100% of *Contributions Receivable* represent the amounts owed from one donor.

NOTE 14 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, the Society has a contingent obligation due to the 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.

NOTE 14 *(Continued)*

The table below presents financial assets available for general expenditures within one year as of December 31, 2018:

Financial assets at year end:	
Cash and cash equivalents	$1,960,102
Contributions receivable	120,000
Investments	1,828,926
Total Financial Assets	3,909,028
Less amounts not available to be used within one year:	
Investements in endowments with donor-imposed restrictions,	
Less annual endowment draw	(1,330,771)
Contributions receivable for restricted gifts, net	(120,000)
Grants payable due within one year	(603,986)
Maximum contingency obligation to CSO	(150,000)
Reserves for bi-annual international research and patient conference	(115,000)
Financial assets not available to be used within one year	(2,319,757)
Financial assets available to meet general expenditures within one year	$1,589,271

NOTE 15 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 19, 2019, 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, 2018, the Society had $465,530 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, three research grant awards totaling $332,906 have been approved by the Board and accepted by the grantee, $242,535 has been paid to recipients. Hence, at March 19, 2019, on all grants awarded to that date, the total expected future disbursements are $555,901 all of which is payable in 2019 through 2020.