

**FACIOSCAPULOHUMERAL (FSH) SOCIETY**

**FINANCIAL STATEMENTS**

*with*

**INDEPENDENT AUDITORS' REPORT**

**YEAR ENDED DECEMBER 31, 2017**

*(With Summarized Comparative Information for 2016)*

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](http://www.ssbcpa.com)

**FACIOSCAPULOHUMERAL (FSH) SOCIETY**

**REPORT ON FINANCIAL STATEMENTS**

**YEAR ENDED DECEMBER 31, 2017**  
*(With Summarized Comparative Information for 2016)*

**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.*

FACIOSCAPULOHUMERAL (FSH) SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2017

*(With Summarized Comparative Information for 2016)*

C O N T E N T S

	<i>Pages</i>
Independent Auditors' Report.....	1 - 2
Statements of Financial Position as of December 31, 2017 and 2016.....	3
Statement of Activities for the Year Ended December 31, 2017..... <i>(With Summarized Comparative Totals for 2016)</i>	4
Statement of Functional Expenses for the Year Ended December 31, 2017..... <i>(With Summarized Comparative Totals for 2016)</i>	5
Statements of Cash Flows for the Years Ended December 31, 2017 and 2016.....	6
Notes to Financial Statements.....	7 - 20



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 organization), which comprise the statement of financial position as of December 31, 2017, 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, 2017, 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.

Facioscapulothumeral (FSH) Society  
Page Two

**Report on Summarized Comparative Information**

We have previously audited Facioscapulothumeral (FSH) Society's 2016 financial statements, and our report dated April 4, 2017, 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, 2016, is consistent, in all material respects, with the audited financial statements from which it has been derived.

*Smith, Sullivan & Brown, PC*

Westborough, Massachusetts  
March 20, 2018

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENTS OF FINANCIAL POSITION AS OF DECEMBER 31, 2017 AND 2016

<u>ASSETS</u>	<u>2017</u>	<u>2016</u>
<u>CURRENT ASSETS:</u>		
Cash and Cash Equivalents	\$ 1,993,351	\$ 2,295,337
Contributions Receivable	120,000	46,000
Prepaid Expenses	29,612	15,250
Total Current Assets	<u>2,142,963</u>	<u>2,356,587</u>
<u>NET PROPERTY AND EQUIPMENT</u>	<u>17,858</u>	<u>23,556</u>
<u>NON-CURRENT ASSETS:</u>		
Contributions Receivable	120,000	-
Intangible Asset, Net	28,610	-
Deposits	4,477	13,977
William R. Lewis Family Fund Investments	2,010,380	864,199
Edward M. Schechter Fund Investments	157,841	90,684
Total Non-Current Assets	<u>2,321,308</u>	<u>968,860</u>
<u>TOTAL ASSETS</u>	<u>\$ 4,482,129</u>	<u>\$ 3,349,003</u>
<u>LIABILITIES AND NET ASSETS</u>		
<u>CURRENT LIABILITIES:</u>		
Grants Payable	\$ 771,327	\$ 493,751
Accounts Payable and Accrued Expenses	31,556	61,908
Accrued Payroll and Related Costs	13,834	23,010
Total Current Liabilities	<u>816,717</u>	<u>578,669</u>
<u>LONG TERM LIABILITIES:</u>		
Long-Term Grants Payable	<u>29,100</u>	<u>127,367</u>
<u>TOTAL LIABILITIES</u>	<u>845,817</u>	<u>706,036</u>
<u>NET ASSETS:</u>		
Unrestricted Net Assets	1,279,075	1,651,540
Temporarily Restricted Net Assets	496,921	63,348
Permanently Restricted Net Assets	1,860,316	928,079
Total Net Assets	<u>3,636,312</u>	<u>2,642,967</u>
<u>TOTAL LIABILITIES AND NET ASSETS</u>	<u>\$ 4,482,129</u>	<u>\$ 3,349,003</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENT OF ACTIVITIES  
FOR THE YEAR ENDED DECEMBER 31, 2017  
*(With Summarized Comparative Totals for 2016)*

	<u>UNRESTRICTED</u>	<u>TEMPORARILY RESTRICTED</u>	<u>PERMANENTLY RESTRICTED</u>	<u>TOTAL ACTIVITIES</u>	
				<u>2017</u>	<u>2016</u>
<b><u>SUPPORT, REVENUES AND RECLASSIFICATIONS:</u></b>					
<i>Support and Revenues:</i>					
Gifts, Grants and Contributions	\$ 1,193,902	\$ 820,624	\$ 932,237	\$ 2,946,763	\$ 1,753,787
Special Events, Net of Cost of Direct Benefits to Donors	73,785	2,366	-	76,151	282,388
Donated Goods and Services	167,581	-	-	167,581	148,569
Program Revenue	29,714	-	-	29,714	-
Total Support and Revenues	<u>1,464,982</u>	<u>822,990</u>	<u>932,237</u>	<u>3,220,209</u>	<u>2,184,744</u>
<i>Investment and Other Income:</i>					
Investment Return, Net	736	260,501	-	261,237	56,512
Return of Grant Funds	100,870	-	-	100,870	-
Other Income	1,848	-	-	1,848	-
Total Investment and Other Income	<u>103,454</u>	<u>260,501</u>	<u>-</u>	<u>363,955</u>	<u>56,512</u>
<i>Reclassification of Net Assets:</i>					
Net Assets Released From Restriction	<u>649,918</u>	<u>(649,918)</u>	<u>-</u>	<u>-</u>	<u>-</u>
<b><u>TOTAL SUPPORT, REVENUES AND RECLASSIFICATIONS</u></b>	<b><u>2,218,354</u></b>	<b><u>433,573</u></b>	<b><u>932,237</u></b>	<b><u>3,584,164</u></b>	<b><u>2,241,256</u></b>
<b><u>EXPENSES:</u></b>					
<i>Program Services:</i>					
Research	1,592,275	-	-	1,592,275	1,667,129
Patient Advocacy and Education	373,948	-	-	373,948	486,472
Total Program Services	<u>1,966,223</u>	<u>-</u>	<u>-</u>	<u>1,966,223</u>	<u>2,153,601</u>
<i>Supporting Services:</i>					
Administrative	344,693	-	-	344,693	209,103
Fund Raising	279,903	-	-	279,903	177,819
Total Supporting Services	<u>624,596</u>	<u>-</u>	<u>-</u>	<u>624,596</u>	<u>386,922</u>
<b><u>TOTAL EXPENSES</u></b>	<b><u>2,590,819</u></b>	<b><u>-</u></b>	<b><u>-</u></b>	<b><u>2,590,819</u></b>	<b><u>2,540,523</u></b>
<b><u>CHANGE IN NET ASSETS</u></b>	<b><u>(372,465)</u></b>	<b><u>433,573</u></b>	<b><u>932,237</u></b>	<b><u>993,345</u></b>	<b><u>(299,267)</u></b>
<b><u>NET ASSETS - BEGINNING OF YEAR</u></b>	<b><u>1,651,540</u></b>	<b><u>63,348</u></b>	<b><u>928,079</u></b>	<b><u>2,642,967</u></b>	<b><u>2,942,234</u></b>
<b><u>NET ASSETS - END OF YEAR</u></b>	<b><u>\$ 1,279,075</u></b>	<b><u>\$ 496,921</u></b>	<b><u>\$ 1,860,316</u></b>	<b><u>\$ 3,636,312</u></b>	<b><u>\$ 2,642,967</u></b>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENT OF FUNCTIONAL EXPENSES  
FOR THE YEAR ENDED DECEMBER 31, 2017

*(With Summarized Comparative Totals for 2016)*

	<u>RESEARCH</u>	<u>PATIENT ADVOCACY AND EDUCATION</u>	<u>TOTAL PROGRAM SERVICES</u>	<u>ADMINI- STRATIVE</u>	<u>FUND RAISING</u>	<u>TOTAL FUNCTIONAL EXPENSES</u>	
						<u>2017</u>	<u>2016</u>
Scientific Advisory Board Grants	\$ 1,365,489	\$ -	\$ 1,365,489	\$ -	\$ -	\$ 1,365,489	\$ 1,383,892
Salaries and Related Expenses	105,129	206,019	311,148	183,762	149,725	644,635	559,255
Donated Services	92,863	66,693	159,556	8,025	-	167,581	148,569
Consultants and Professional Fees	-	-	-	81,783	31,066	112,849	66,388
Fundraising Expenses	-	-	-	-	63,219	63,219	135,602
Printing	-	34,780	34,780	-	22,045	56,825	67,132
Travel, Lodging and Meals	3,379	22,629	26,008	4,234	24,128	54,370	51,123
Website and Computer Related Expenses	6,207	12,118	18,325	10,817	14,553	43,695	33,098
Occupancy	5,404	10,551	15,955	9,448	7,664	33,067	20,106
Office Expenses	4,398	8,588	12,986	7,668	6,493	27,147	50,611
Bank Service Charges and Credit Card Processing Fees	740	1,444	2,184	3,791	16,996	22,971	26,628
Accounting, Auditing and Financial Consultants	-	-	-	13,650	-	13,650	13,000
Patient Meetings and Research Conferences	-	10,540	10,540	-	-	10,540	112,282
Depreciation and Amortization Expense	-	-	-	9,274	-	9,274	2,455
Scientific Advisory Board Expenses	8,466	-	8,466	-	-	8,466	7,641
Directors Expenses	200	39	239	6,414	-	6,653	7,665
Insurance	-	-	-	5,447	-	5,447	2,950
Public Awareness	-	547	547	380	-	927	17,538
<b>Total Functional Expenses</b>	<b>1,592,275</b>	<b>373,948</b>	<b>1,966,223</b>	<b>344,693</b>	<b>335,889</b>	<b>2,646,805</b>	<b>2,705,935</b>
Less: Cost of Direct Benefits to Donors	-	-	-	-	(55,986)	(55,986)	(165,412)
<b>Total Expenses per Statement of Activities</b>	<b><u>\$ 1,592,275</u></b>	<b><u>\$ 373,948</u></b>	<b><u>\$ 1,966,223</u></b>	<b><u>\$ 344,693</u></b>	<b><u>\$ 279,903</u></b>	<b><u>\$ 2,590,819</u></b>	<b><u>\$ 2,540,523</u></b>



FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENTS OF CASH FLOWS  
FOR THE YEARS ENDED DECEMBER 31, 2017 AND 2016

	<u>2017</u>	<u>2016</u>
<b><u>CASH FLOWS FROM OPERATING ACTIVITIES:</u></b>		
Change in Net Assets	\$ 993,345	\$ (299,267)
<i>Adjustments to Reconcile Changes in Net Assets to Net Cash Used by Operating Activities:</i>		
Contributions of Mutual Funds to Endowment	(870,542)	-
Contributions Restricted for Endowment	(66,695)	(191,038)
Depreciation and Amortization Expense	9,274	2,455
Investment Return, Net	(260,501)	(55,869)
<i>Changes in Operating Assets and Liabilities:</i>		
Contributions Receivable - Current and Long-term	(194,000)	99,000
Prepaid Expenses	(14,362)	(10,926)
Deposits	9,500	(13,977)
Grants Payable - Current and Long-term	179,309	240,000
Accounts Payable and Accrued Expenses	(30,352)	32,662
Accrued Payroll and Related Costs	(9,176)	8,072
Net Adjustment	<u>(1,247,545)</u>	<u>110,379</u>
<b><u>NET CASH USED FOR OPERATING ACTIVITIES</u></b>	<b><u>(254,200)</u></b>	<b><u>(188,888)</u></b>
<b><u>CASH FLOWS FROM FINANCING ACTIVITIES:</u></b>		
Proceeds from Contributions Restricted for Endowment	<u>66,695</u>	<u>191,038</u>
<b><u>CASH FLOWS FROM INVESTING ACTIVITIES:</u></b>		
Purchase of Leasehold Improvements	-	(7,100)
Purchase of Furniture and Fixtures	-	(12,153)
Website Development	(32,186)	-
Proceeds from Endowment Investments	46,400	36,000
Purchase of Investments	(62,000)	-
Purchase of Endowment Investments	<u>(66,695)</u>	<u>(191,038)</u>
Net Cash Flows From Investing Activities	<u>(114,481)</u>	<u>(174,291)</u>
<b><u>NET DECREASE IN CASH BALANCES</u></b>	<b><u>(301,986)</u></b>	<b><u>(172,141)</u></b>
<b><u>CASH BALANCES - BEGINNING OF YEAR</u></b>	<b><u>2,295,337</u></b>	<b><u>2,467,478</u></b>
<b><u>CASH BALANCES - END OF YEAR</u></b>	<b><u>\$ 1,993,351</u></b>	<b><u>\$ 2,295,337</u></b>
 <i>Non-Cash Investing and Financing Activities :</i>		
Contributions of Mutual Funds to Endowment	<u>\$ 870,542</u>	<u>\$ -</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

*(With Summarized Comparative Information for 2016)*

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.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

*(With Summarized Comparative Information for 2016)*

*(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*<sup>TM</sup>, the Organization reports information regarding its financial position and activities according to three classes of net assets: unrestricted net assets, temporarily restricted net assets, and permanently restricted net assets.

These classifications are related to the existence or absence of donor-imposed restrictions as presented below:

*Unrestricted Net Assets* - consists of assets, public support and program revenues which are available and used for operations and programs. Unrestricted net assets represent the portion of net assets of the Organization that is neither permanently restricted nor temporarily restricted by donor-imposed stipulations. Contributions are considered available for unrestricted use unless specifically restricted by the donor.

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

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

*(With Summarized Comparative Information for 2016)*

*(Continued)*

NOTE 2      *(Continued)*

*Permanently Restricted Net Assets* - includes 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.

**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. As of December 31, 2017, the Organization's non-current contributions were due within two years. 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 specific identification 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.

**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 \$3,576 for the year ended December 31, 2017. The Society expects to recognize future amortization expense as follows:

<u>Year Ending</u>	<u>Amount</u>
December 31, 2018	\$10,729
December 31, 2019	10,729
December 31, 2020	<u>7,152</u>
Total	<u>\$28,610</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

*(With Summarized Comparative Information for 2016)*

*(Continued)*

NOTE 2      *(Continued)*

**Endowment 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 converts the William R. Lewis Board Designated Quasi-Endowment Fund to a Permanent Donor Restricted Endowment Fund known as the Lewis Family Fund for FSHD. See Note 14 for a change in donor wishes subsequent to year-end which in 2018 will convert the Edward M. Schechter permanently restricted Endowment Fund into the temporarily restricted Ed and Betty Jane Schechter Memorial Fund. 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 net appreciation 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

In accordance with generally accepted accounting principles, the Society reports the original fair value of endowment contributions, or original corpus, as permanently restricted net assets. Income and appreciation earned on endowment investments are classified as temporarily restricted 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 which is reported as a permanently restricted net asset. As required by the *FASB Accounting Standards Codification*<sup>TM</sup>, deficiencies of this nature are reported in unrestricted net assets.

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 each 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.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

*(With Summarized Comparative Information for 2016)*

*(Continued)*

NOTE 2      *(Continued)*

**Contributions, Gifts and Grants:**

As required by the *FASB Accounting Standards Codification*<sup>TM</sup>, 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 temporarily or permanently restricted net assets depending on the nature of the restriction until the restriction expires, at which time temporarily restricted net assets are reclassified to unrestricted net assets. 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 approved 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 grants funds that are returned to the Organization by the grantee and is reflected in the accompanying Statement of Activities under *Investment and Other Income*.

**Donated Goods and Services:**

As required by the *FASB Accounting Standards Codification*<sup>TM</sup>, 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.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

*(With Summarized Comparative Information for 2016)*

*(Continued)*

NOTE 2      *(Continued)*

**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 that are common to several functions are allocated using formulas derived from the nature of related time. Supporting services are those related to operating and managing the Organization and their 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, 2017 and 2016, total fund raising expenses (including both direct and indirect event expenses) were \$335,889 and \$343,231, respectively.

**Reclassifications:**

Certain reclassifications have been made to the 2016 financial statement presentation to correspond to the current year's format. Net assets and changes in net assets are unchanged due to these reclassifications. Telephone and Communications of \$6,430 and Postage of \$6,200 have been combined with Office Expenses of \$37,981 in the Statement of Functional Expenses for a total of \$50,611. Cost of Direct Benefits to Donors has been grossed up in the accompanying Statement of Functional Expenses and combined with the following expenses:

	<u>Original Expense</u>	<u>Cost of Direct Benefits to Donors</u>	<u>Reclassified Expense</u>
Printing	\$ 53,468	\$ 13,664	\$ 67,132
Office Expenses	50,204	407	50,611
Travel, Lodging and Meals	47,198	3,925	51,123
Consultants and Professional Fees	40,286	26,102	66,388
Bank Service Charges and Credit Card Processing Fees	24,892	1,736	26,628
Fundraising Expenses	<u>16,024</u>	<u>119,578</u>	<u>135,602</u>
Total	<u>\$232,072</u>	<u>\$165,412</u>	<u>\$397,484</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

(With Summarized Comparative Information for 2016)

(Continued)

NOTE 2 (Continued)

**Recent Accounting Guidance:**

In August 2016, the 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. The new guidance simplifies and improves how not-for-profit entities classify net assets as well as the information presented in financial statements and notes about the function and nature of expenses, liquidity, financial performance, and cash flows. This guidance will be effective for this Organization beginning after December 15, 2017 and is not expected to have a material effect on the Organization's financial position or change in net assets.

NOTE 3 PROPERTY AND EQUIPMENT

The following is a summary of property and equipment as of December 31, 2017 and 2016:

<u>Asset Category</u>	<u>Est. Life</u>	<u>Cost</u>	<u>Accumulated Depreciation</u>	<u>Net Book Value</u>	
				<u>2017</u>	<u>2016</u>
Computer Technology and Office Equipment	3 - 5	\$11,826	\$ 8,777	\$ 3,049	\$ 4,644
Furniture and Fixtures	7	12,154	1,881	10,273	12,009
Leasehold Improvements	3	<u>7,100</u>	<u>2,564</u>	<u>4,536</u>	<u>6,903</u>
Total		<u>\$31,080</u>	<u>\$13,222</u>	<u>\$17,858</u>	<u>\$23,556</u>

During 2017 and 2016, the Organization disposed of fully depreciated equipment with an original cost of \$9,097 and \$1,941, respectively. The disposal of this equipment had no impact on the change in net assets for the years ended December 31, 2017 and 2016.

NOTE 4 INVESTMENTS

As of December 31, 2017 and 2016, investment costs and unrealized gains and losses consisted of the following components:

<u>Investment Type</u>	<u>December 31, 2017</u>					
	<u>Cost Basis</u>	<u>Unrealized Gains</u>	<u>Unrealized Losses</u>	<u>Fair Value (Level 1)</u>	<u>Fair Value (Level 2)</u>	<u>Total Fair Value</u>
Cash and Sweep Accounts	\$ 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	<u>227,073</u>	<u>5,996</u>	<u>(2,104)</u>	<u>-</u>	<u>230,965</u>	<u>230,965</u>
Total	<u>\$1,914,394</u>	<u>\$255,931</u>	<u>\$(2,104)</u>	<u>\$1,937,256</u>	<u>\$230,965</u>	<u>\$2,168,221</u>



FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

(With Summarized Comparative Information for 2016)

(Continued)

NOTE 4 (Continued)

<u>Investment Type</u>	<u>December 31, 2016</u>					
	<u>Cost Basis</u>	<u>Unrealized Gains</u>	<u>Unrealized Losses</u>	<u>Fair Value (Level 1)</u>	<u>Fair Value (Level 2)</u>	<u>Total Fair Value</u>
Cash and Sweep Accounts	\$200,978	\$ -	\$ -	\$200,978	\$ -	\$200,978
Mutual Funds	505,908	102,352	(9,576)	598,684	-	598,684
Preferred Stocks and Bonds	<u>156,410</u>	<u>1,221</u>	<u>(2,410)</u>	<u>-</u>	<u>155,221</u>	<u>155,221</u>
Total	<u>\$863,296</u>	<u>\$103,573</u>	<u>\$(11,986)</u>	<u>\$799,662</u>	<u>\$155,221</u>	<u>\$954,883</u>

As of December 31, 2017, Investments in the Edward M. Schechter Fund include \$62,000 of unrestricted funds, as management does not intend to draw on these funds within the next fiscal year. See Footnote 14 for a change in donor wishes subsequent to year-end which, in 2018, will convert the permanently restricted Edward M. Schechter Endowment Fund into the temporarily restricted Ed and Betty Jane Schechter Memorial Fund.

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 considers 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, 2017 and 2016, is as follows:

<u>Components of Investment Return</u>	<u>2017</u>	<u>2016</u>
Interest and Dividends	\$114,053	\$34,669
Unrealized Gains (Losses)	162,871	22,036
Realized Gains (Losses)	<u>(15,687)</u>	<u>(193)</u>
Net Investment Return	<u>\$261,237</u>	<u>\$56,512</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

*(With Summarized Comparative Information for 2016)*

*(Continued)*

NOTE 5     DESIGNATIONS AND RESTRICTIONS OF NET ASSETS

**Temporarily Restricted Net Assets:**

As of December 31, 2017 and 2016, temporarily restricted net assets consisted of the following balances:

<u>Nature of Restriction</u>	<u>2017</u>	<u>2016</u>
Batkin and Younger Family Fund	\$ -	\$16,000
Endowment Appreciation - Edward M. Schechter Fund for FSHD	21,940	16,784
Endowment Appreciation - Lewis Family Fund for FSHD	223,965	15,020
S&L Marx Foundation	240,000	-
Research and Education	<u>11,016</u>	<u>15,544</u>
Total	<u>\$496,921</u>	<u>\$63,348</u>

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

<u>Nature of Restriction</u>	<u>2017</u>	<u>2016</u>
Event Proceeds and Other Donations Designated for Research and Education	\$340,916	\$1,285,312
Clinical Trial Network Registry	-	121,000
Ed and Betty Jane Schechter Memorial Fund	65,000	-
Lincoln and Irene Lai Wellness Fund	26,622	44,372
Batkin and Younger Family Fund	31,000	51,000
S&L Marx Foundation	120,000	30,000
FSHD Canada Foundation Fund	19,980	-
Appropriation of Endowment Appreciation - Edward M. Schechter Fund for FSHD	3,400	3,500
Endowment Appreciation - Lewis Family Fund for FSHD	<u>43,000</u>	<u>32,500</u>
Total	<u>\$649,918</u>	<u>\$1,567,684</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

(With Summarized Comparative Information for 2016)

(Continued)

NOTE 5 (Continued)

**Endowment Net Assets**

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

	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total Endowment Net Assets</u>
Endowment Net Assets, December 31, 2015	\$ 11,935	\$ 73,900	\$ 85,835
Contributions	-	196,038	196,038
Investment Income	33,833	-	33,833
Investment Gains	22,036	-	22,036
Transfer from Board Designated Fund	-	658,141	658,141
Appropriation for Expenditure	<u>(36,000)</u>	<u>-</u>	<u>(36,000)</u>
Endowment Net Assets, December 31, 2016	31,804	928,079	959,883
Contributions	-	932,237	932,237
Investment Income	112,855	-	112,855
Investment Gains	147,646	-	147,646
Appropriation for Expenditure	<u>(46,400)</u>	<u>-</u>	<u>(46,400)</u>
Endowment Net Assets, December 31, 2017	<u>\$245,905</u>	<u>\$1,860,316</u>	<u>\$2,106,221</u>

NOTE 6 SPECIAL FUND RAISING EVENTS

The results of fund raising events for the years ended December 31, 2017 and 2016 are summarized below:

<u>Event</u>	<u>Gross Proceeds</u>	<u>Direct Costs</u>	<u>Net Event Revenues</u>	
			<u>2017</u>	<u>2016</u>
Songs in the Key of Steven Blier	\$ 63,444	\$41,801	\$21,643	\$ 42,412
FSH At The Lake	-	-	-	121,028
CureFSHD Gala	-	-	-	43,354
Ghostly Gala	-	-	-	41,028
Other Fund Raising Events	<u>68,693</u>	<u>14,185</u>	<u>54,508</u>	<u>34,566</u>
Total	<u>\$132,137</u>	<u>\$55,986</u>	<u>\$76,151</u>	<u>\$282,388</u>

For the year ended December 31, 2017, raffle proceeds of \$2,366 from the Songs in the Key of Steven Blier were restricted to research and education. All other 2017 fund raising event proceeds provided unrestricted operational support for the Society. For the year ended December 31, 2016, proceeds from "FSH at the Lake" were restricted to research and education program activities. All other 2016 fund raising event proceeds provided unrestricted operational support for the Society.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

*(With Summarized Comparative Information for 2016)*

*(Continued)*

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:

<u>Description</u>	<u>2017</u>	<u>2016</u>
Public Relations	\$ 61,643	\$ 80,607
Scientific Advisory Board Expenses	92,863	42,712
Event Services	-	11,000
Legal	4,425	8,850
Investment Advisory Services	3,600	5,400
Other Professional Advisory Services	<u>5,050</u>	<u>-</u>
Total	<u>\$167,581</u>	<u>\$148,569</u>

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      LEASING ARRANGEMENTS

Through November 2016, the Society leased 973 square feet of office space in Lexington, Massachusetts through a tenancy-at-will agreement and could terminate the lease at any time with 120 days written notice. The basic rent was \$1,585 per month, which included certain general operating costs and utilities.

Beginning December 2016, the Society entered into a three-year lease to occupy 1,835 square feet of space at the same location. The basic rent is \$2,452 per month and additional amounts are assessed each month for operating costs and utilities. The following is a schedule of future minimum rental payments as of December 31, 2017:

<u>Year Ending</u>	<u>Amount</u>
December 31, 2018	\$29,422
December 31, 2019	<u>17,163</u>
Total	<u>\$46,585</u>

Rent expense for the year ended December 31, 2017 and 2016 was \$29,422 and \$19,887, respectively.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

*(With Summarized Comparative Information for 2016)*

*(Continued)*

NOTE 10    RELATED PARTY TRANSACTIONS

During the year ended December 31, 2016, the former Secretary of the FSH Society was hired as an employee of the Society. The former Secretary of the FSH Society resigned from the Board on March 20, 2016. She was hired as an employee of the Society during August 2016. Total compensation paid to the employee during 2016 was approximately \$29,500.

NOTE 11    COMMITMENTS AND CONTINGENCIES

The Society entered into a compensation agreement with its Chief Science Officer (CSO) effective as of November 1, 2017 and ending on October 31, 2018. The agreement states that the CSO's employment is at will. The agreement also provides for a 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 \$1,329 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. Obligations during 2018 under these consulting agreements are approximately \$73,000.

NOTE 12    RETIREMENT PLAN

FSH Society has maintained a SIMPLE IRA retirement plan. The plan allows eligible employees of the Organization to defer a percentage of their earnings from current taxation. For the years presented, employee contributions to the IRA are subject to a 3% employer match. For the years ended December 31, 2017 and 2016, the total employer contributions were \$14,863 and \$15,222, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses. Effective December 31, 2017, the Society has terminated its SIMPLE IRA retirement plan. As discussed in Note 14, the Society adopted a defined contribution plan qualified under IRC Section 401(k) in January 2018.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

*(With Summarized Comparative Information for 2016)*

*(Continued)*

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. During 2016, the Society consolidated its bank accounts into two 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, 2017, and 2016, cash balances in excess of the FDIC limit were \$50,012 and \$50,009, 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.

**Gifts, Grants, and Contributions:**

During 2017, a significant portion of the Society's gross support and revenues comes from two donors, 32% and 11% respectively.

**Contributions Receivable:**

As of December 31, 2017, 100% of *Contributions Receivable* represented the amounts owed from one donor and as of December 31, 2016, 78% of *Contributions Receivable* was owed from two donors.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2017

*(With Summarized Comparative Information for 2016)*

*(Continued)*

NOTE 14    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 20, 2018, the date which the financial statements were available for issue, and noted the following events which met the criteria:

**Retirement Plan:**

Effective January 1, 2018, the Society adopted a defined contribution plan qualified under IRC Section 401(k). The 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 has elected to make safe harbor matches of up to 4% of employees' earnings.

**Scientific Advisory Board Grants:**

As of December 31, 2017, the Society had \$800,427 in expected future disbursements on all research grants awarded to that date. Since then, six research grant awards totaling \$634,148 have been approved by the Board and accepted by the grantee. \$871,385 has been paid to recipients. In addition, one grantee returned unused available grant funds of \$26,500. Hence, at March 20, 2018, on all grants awarded to that date, the total expected future disbursements are \$536,690, all of which is payable in 2018 through 2020.

**Edward M. Schecher Fund Investments:**

In March of 2018, a change in donor wishes will convert the permanently restricted Edward M. Schechter Endowment Fund into the temporarily restricted Ed and Betty Jane Schechter Memorial Fund. The Ed and Betty Jane Schechter Memorial Fund will be temporarily restricted to advance the Society's programs in research and travel grants to scientists.