

FACIOSCAPULOHUMERAL (FSH) SOCIETY

FINANCIAL STATEMENTS

with

INDEPENDENT AUDITORS' REPORT

YEAR ENDED DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

Smith  Sullivan
& Brown PC
CERTIFIED PUBLIC ACCOUNTANTS

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FACIOSCAPULOHUMERAL (FSH) SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

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. Empower: Mobilize patients and communities to take action.*
- 2. Connect and Communicate: Serve as the leading source of information and support for all patients and families with FSHD.*
- 3. Finance: Grow and diversify revenues to invest in research, education, patient support, and operational capacity.*
- 4. Knowledge: Act as a driving force in the development of research directed toward treatment and a cure of FSHD.*

FACIOSCAPULOHUMERAL (FSH) SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2015
(With Summarized Comparative Information for 2014)

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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, 2015, 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, 2015, 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 2014 financial statements, and our report dated April 15, 2015, 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, 2014, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Smith, Sullivan & Brown, PC

Westborough, Massachusetts
April 5, 2016

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENTS OF FINANCIAL POSITION AS OF DECEMBER 31, 2015 AND 2014

<u>ASSETS</u>	<u>2015</u>	<u>2014</u>
<u>CURRENT ASSETS:</u>		
Cash	\$ 2,032,766	\$ 1,846,054
Contributions Receivable	129,000	72,857
Prepaid Expenses	4,324	4,807
Total Current Assets	<u>2,166,090</u>	<u>1,923,718</u>
<u>NET PROPERTY AND EQUIPMENT</u>	<u>6,758</u>	<u>8,994</u>
<u>NON-CURRENT ASSETS:</u>		
Cash Reserves	434,712	367,415
Contributions Receivable	16,000	43,000
Board Designated William R. Lewis Family Fund Investments	658,141	634,060
Edward M. Schechter Fund Investments	85,835	89,659
Total Non-Current Assets	<u>1,194,688</u>	<u>1,134,134</u>
<u>TOTAL ASSETS</u>	<u>\$ 3,367,536</u>	<u>\$ 3,066,846</u>
 <u>LIABILITIES AND NET ASSETS</u> 		
<u>CURRENT LIABILITIES:</u>		
Grants Payable	\$ 381,118	\$ 286,640
Accounts Payable and Accrued Expenses	29,246	29,148
Accrued Payroll and Related Costs	14,938	7,173
Total Current Liabilities	<u>425,302</u>	<u>322,961</u>
<u>NET ASSETS:</u>		
Unrestricted Net Assets:		
Undesignated	1,297,466	1,187,503
Board Designated William R. Lewis Family Fund	658,141	634,060
Total Unrestricted Net Assets	<u>1,955,607</u>	<u>1,821,563</u>
Temporarily Restricted Net Assets	912,727	848,422
Permanently Restricted Net Assets	73,900	73,900
Total Net Assets	<u>2,942,234</u>	<u>2,743,885</u>
<u>TOTAL LIABILITIES AND NET ASSETS</u>	<u>\$ 3,367,536</u>	<u>\$ 3,066,846</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED DECEMBER 31, 2015
(With Summarized Comparative Totals for 2014)

	<u>UNRESTRICTED</u>		<u>TOTAL</u>	<u>TEMPORARILY</u>	<u>PERMANENTLY</u>	<u>TOTAL ACTIVITIES</u>	
	<u>OPERATING</u>	<u>BOARD</u>	<u>UNRESTRICTED</u>	<u>RESTRICTED</u>	<u>RESTRICTED</u>	<u>2015</u>	<u>2014</u>
<u>SUPPORT, REVENUES</u>							
<u>AND RECLASSIFICATIONS:</u>							
<i>Support and Revenues:</i>							
Gifts, Grants and Contributions	\$ 781,775	\$ 38,000	\$ 819,775	\$ 739,993	\$ -	\$ 1,559,768	\$ 1,282,075
Special Events, Net of Direct Costs	-	-	-	417,584	-	417,584	597,722
Donated Goods and Services	167,127	-	167,127	-	-	167,127	253,791
Total Support and Revenues	<u>948,902</u>	<u>38,000</u>	<u>986,902</u>	<u>1,157,577</u>	<u>-</u>	<u>2,144,479</u>	<u>2,133,588</u>
<i>Investment and Other Income:</i>							
Investment Return, Net	847	16,331	17,178	176	-	17,354	40,156
<i>Reclassification of Net Assets:</i>							
Net Assets Released From Restriction	1,093,448	-	1,093,448	(1,093,448)	-	-	-
Board Designated Funds	30,250	(30,250)	-	-	-	-	-
Total Reclassification of Net Assets	<u>1,123,698</u>	<u>(30,250)</u>	<u>1,093,448</u>	<u>(1,093,448)</u>	<u>-</u>	<u>-</u>	<u>-</u>
<u>TOTAL SUPPORT, REVENUES</u>							
<u>AND RECLASSIFICATIONS</u>	<u>2,073,447</u>	<u>24,081</u>	<u>2,097,528</u>	<u>64,305</u>	<u>-</u>	<u>2,161,833</u>	<u>2,173,744</u>
<u>FUNCTIONAL EXPENSES:</u>							
<i>Program Services:</i>							
Research	1,202,949	-	1,202,949	-	-	1,202,949	1,069,144
Direct Service	315,100	-	315,100	-	-	315,100	264,698
Education	136,178	-	136,178	-	-	136,178	272,712
Total Program Services	<u>1,654,227</u>	<u>-</u>	<u>1,654,227</u>	<u>-</u>	<u>-</u>	<u>1,654,227</u>	<u>1,606,554</u>
<i>Supporting Services:</i>							
Administrative	188,236	-	188,236	-	-	188,236	117,601
Fund Raising	121,021	-	121,021	-	-	121,021	73,279
Total Supporting Services	<u>309,257</u>	<u>-</u>	<u>309,257</u>	<u>-</u>	<u>-</u>	<u>309,257</u>	<u>190,880</u>
<u>TOTAL FUNCTIONAL EXPENSES</u>	<u>1,963,484</u>	<u>-</u>	<u>1,963,484</u>	<u>-</u>	<u>-</u>	<u>1,963,484</u>	<u>1,797,434</u>
<u>CHANGE IN NET ASSETS</u>	109,963	24,081	134,044	64,305	-	198,349	376,310
<u>NET ASSETS - BEGINNING OF YEAR</u>	<u>1,187,503</u>	<u>634,060</u>	<u>1,821,563</u>	<u>848,422</u>	<u>73,900</u>	<u>2,743,885</u>	<u>2,367,575</u>
<u>NET ASSETS - END OF YEAR</u>	<u>\$ 1,297,466</u>	<u>\$ 658,141</u>	<u>\$ 1,955,607</u>	<u>\$ 912,727</u>	<u>\$ 73,900</u>	<u>\$ 2,942,234</u>	<u>\$ 2,743,885</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2015

(With Summarized Comparative Totals for 2014)

	<u>RESEARCH</u>	<u>DIRECT SERVICE</u>	<u>EDUCATION</u>	<u>TOTAL PROGRAM SERVICES</u>	<u>ADMINI- STRATIVE</u>	<u>FUND RAISING</u>	<u>TOTAL FUNCTIONAL EXPENSES</u>	
							<u>2015</u>	<u>2014</u>
Scientific Advisory Board Grants	\$ 949,221	\$ -	\$ -	\$ 949,221	\$ -	\$ -	\$ 949,221	\$ 819,261
Salaries and Wages	86,191	171,287	79,281	336,759	85,937	54,022	476,718	304,230
Payroll Taxes	5,856	11,637	5,386	22,879	5,838	3,670	32,387	22,909
Employee Benefits	7,298	14,504	6,714	28,516	7,277	4,574	40,367	27,438
Patient Meetings and Research Conferences	49,246	4,398	11,323	64,967	-	-	64,967	178,350
Public Awareness	-	-	21,467	21,467	-	-	21,467	-
Donated Services	76,844	46,108	-	122,952	26,012	18,163	167,127	233,791
Scientific Advisory Board Expenses	14,051	-	-	14,051	-	-	14,051	27,259
Directors Expenses	-	5,052	-	5,052	-	-	5,052	7,049
Consultants and Professional Fees	-	-	-	-	14,293	-	14,293	8,609
Fundraising Expenses	-	-	-	-	-	27,378	27,378	15,217
Accounting, Auditing and Financial Consultants	-	-	-	-	11,763	-	11,763	18,353
Rent	3,439	6,834	3,163	13,436	3,429	2,155	19,020	19,020
Travel, Lodging and Meals	1,189	1,251	-	2,440	-	-	2,440	2,615
Office Supplies and Expenses	3,631	7,215	3,340	14,186	3,620	2,276	20,082	23,600
Telephone and Communications	489	972	450	1,911	488	306	2,705	1,813
Website and Computer Related Expenses	3,845	7,642	3,537	15,024	3,834	2,411	21,269	17,666
Insurance	90	180	83	353	2,822	57	3,232	2,508
Printing	-	34,923	-	34,923	-	1,132	36,055	31,475
Depreciation Expense	-	-	-	-	4,684	-	4,684	5,507
Postage	873	1,734	803	3,410	870	546	4,826	2,620
Bank Service Charges and Credit Card Processing Fees	686	1,363	631	2,680	17,369	4,331	24,380	28,144
Total Functional Expenses	<u>\$ 1,202,949</u>	<u>\$ 315,100</u>	<u>\$ 136,178</u>	<u>\$ 1,654,227</u>	<u>\$ 188,236</u>	<u>\$ 121,021</u>	<u>\$ 1,963,484</u>	<u>\$ 1,797,434</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENTS OF CASH FLOWS
FOR THE YEARS ENDED DECEMBER 31, 2015 AND 2014

	<u>2015</u>	<u>2014</u>
<u>CASH FLOWS FROM OPERATING ACTIVITIES:</u>		
Change in Net Assets	\$ 198,349	\$ 376,310
<i>Adjustments to Reconcile the Above to Net Cash Provided by Operating Activities:</i>		
Depreciation Expense	4,684	5,507
Investment Return, Net	(17,354)	(40,156)
<i>(Increase) Decrease in Current Assets:</i>		
Contributions Receivable	(56,143)	(47,857)
Prepaid Expenses	483	(1,215)
<i>Increase (Decrease) in Current Liabilities:</i>		
Grants Payable	94,478	180,774
Accounts Payable and Accrued Expenses	98	12,785
Accrued Payroll and Related Costs	7,765	(12,005)
<i>(Increase) Decrease in Non-Current Assets:</i>		
Contributions Receivable	27,000	(43,000)
Net Adjustment	<u>61,011</u>	<u>54,833</u>
<u>NET CASH PROVIDED BY OPERATING ACTIVITIES</u>	<u>259,360</u>	<u>431,143</u>
<u>CASH FLOWS FROM INVESTING ACTIVITIES:</u>		
Purchase of Equipment	(2,448)	(3,323)
Proceeds from Sales of Securities	34,250	31,590
Acquisition of Securities	<u>(37,153)</u>	<u>(56,309)</u>
Net Cash Flows From Investing Activities	<u>(5,351)</u>	<u>(28,042)</u>
<u>NET INCREASE IN CASH BALANCES</u>	<u>254,009</u>	<u>403,101</u>
<u>CASH BALANCES - BEGINNING OF YEAR</u>	<u>2,213,469</u>	<u>1,810,368</u>
<u>CASH BALANCES - END OF YEAR</u>	<u>\$ 2,467,478</u>	<u>\$ 2,213,469</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

NOTE 1 ORGANIZATION

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.

FSH Society is primarily funded by donations from the general public through direct mailings, via the internet, and through various program and fund raising events.

NOTE 2 PROGRAM SERVICES

The FSH Society is a world leader in combating facioscapulohumeral muscular dystrophy (FSH muscular dystrophy or FSHD). The Society helps patients and families through outreach, education and support; funds scientific research that is rigorously reviewed by its Scientific Advisory Board (SAB); and advocates for increased government and industry investment in research and therapy development.

FSHD, a heritable disease, is among the most common forms of muscular dystrophy, affecting approximately 870,000 children and adults of both sexes worldwide. It can affect multiple generations and entire families. FSHD is characterized by the progressive loss of muscle strength. Muscle weakness typically starts at the face, shoulder girdle and upper arms, often progressing to the legs, torso and other muscles. The symptoms can develop at any age. About 4 percent of cases are children under age five. These early-onset patients are at significantly greater risk of having more severe symptoms and added health complications.

The progression of FSHD is highly variable. FSHD has a high burden of disease and can cause significant disability and, in severely affected individuals, premature death, mainly through respiratory failure. Around 20% of affected individuals use a wheelchair or scooter. Besides muscle weakness, FSHD can also have the following manifestations: high-frequency sensorineural hearing loss, respiratory insufficiency, abnormalities of blood vessels in the back of the eye, and non-symptomatic cardiac arrhythmias.

Research

Organizing and funding research into the causes of FSHD, and, ultimately, developing treatments and a cure, is the Society’s core mission. As of February 2016, the Society has funded a cumulative total of around \$6.85 million in grants for basic and translational research. The amount funded has increased year-over-year since 2008. In 2015, the Society awarded 12 new research grants, continued funding five ongoing grants, and issued three travel grants. (For current grant funding, see *Note 15*.)

FSH Society grants have led to hundreds of publications acknowledging Society support in top-tier scientific journals. Research funded in part by the Society has led to the identification of two genes that, together with other factors, cause FSHD. One of the most complex disease-causing genetic mechanisms known to science is at the heart of FSHD. Much has been discovered, yet much still remains to be learned. Discoveries from FSHD could benefit a wide range of other areas of medicine, including cancer and diabetes. Recent Society-funded projects include genomic engineering, developing new methods to measure disease progression, and identifying potential therapeutic targets to interfere with the expression of these genes.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

(Continued)

NOTE 2 *(Continued)*

The FSH Society's world-class SAB provides strategy for FSHD research, therapeutics and clinical trials readiness, recruits researchers, evaluates grant proposals and monitors the progress of research projects. The Society has helped facilitate the production of the world's largest resource for FSHD biomaterials, which are being made available to researchers throughout the world. The Society works with institutions doing clinical research by helping recruit patients for studies and for tissue and blood donation, and facilitates patient travel by covering travel and lodging expenses for those patients who would not otherwise be able to participate.

Meetings, conferences and workshops

Held annually since 1994, the FSH Society's International Research Consortium conference yields immeasurable gains in advancing understanding of FSHD. The 2015 conference was attended by 125 scientists, clinicians, researchers, pharmaceutical representatives and FSHD patients from over 11 countries; great progress was made.

In November 2016, the FSH Society International Patient Researcher Network Day (FSHD CONNECT) will be held in Boston. The Society hopes to have more than 300 patients, family members, friends, scientists and researchers gathered to listen to the latest developments. The main focus is for medical professionals, patients and families to be able to share ideas on the disease in a collegial setting, and to support and inspire each other. This conference has been held biennially since 1997.

The Society also sponsors and operates patient support and education groups in various cities in the US. In addition, in 2015 the Society continued its active role in co-convening "FSHD Champions," an international alliance of FSHD organizations that work together on FSHD research, advocacy and awareness.

Education, advocacy and community action

Through its staff, website www.fshsociety.org, social media and "FSH Watch" newsletter, the FSH Society provides information about FSHD, the science behind it, and practical advice and emotional support on how to live with the disease. The Society responds to inquiries from newly diagnosed patients, their spouses and family members, and medical professionals on a daily basis. The Society continues to develop, update and disseminate brochures and other written materials, videos, photographs, advertisements, social media postings and nationally broadcast PSAs depicting what FSHD is and what it is like to live with the disease. In 2015 and previous years, the Society has been fortunate to receive public relations expertise, and social media and marketing services, generously donated by the firm SHIFT Communications.

In 2015, the Society worked with pharmaceutical companies commencing clinical trials in Europe and, in 2016, in the US. It met with venture capital companies to provide background and education on the disease.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

(Continued)

NOTE 3 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.

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.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

(Continued)

NOTE 3 *(Continued)*

Financial Statement Presentation

As required by the *FASB Accounting Standards Codification*TM, 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 represents 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. In addition, unrestricted net assets of the Organization includes the William R. Lewis Family Fund, which represents unrestricted resources designated by the Board of Directors as a quasi-endowment.

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.

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. For the years presented, permanently restricted net assets consist of the Edward M. Schechter Fund for FSHD.

Statement of Cash Flows

For the purpose of the accompanying Statement of Cash Flows, cash includes *Cash Reserves*, which are reported as non-current assets, as management does not intend to draw on these funds within the next fiscal year.

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, 2015, 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.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

(Continued)

NOTE 3 *(Continued)*

Investments

The Organization maintains an investment portfolio which consists of cash, mutual funds 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 \$1,000), 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 \$1,000) 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.

Endowment Funds

FSH Society has a donor-restricted endowment fund, the Edward M. Schechter Fund for FSHD, which was established by one donor in August 2011. 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

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

(Continued)

NOTE 3 *(Continued)*

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*TM, 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 years). The Organization takes a conservative approach to investing its endowment funds, which are maintained in a diversified portfolio of cash, mutual funds and preferred stocks and bonds.

Contributions, Gifts and Grants

As required by the *FASB Accounting Standards Codification*TM, 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 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. As of December 31, 2015 and 2014, *Grants Payable* are expected to be paid in the following year. Conditional commitments are not recognized in the financial statements until the conditions upon which they depend are substantially met.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

(Continued)

NOTE 3 *(Continued)*

Donated Goods and Services

As required by the *FASB Accounting Standards Codification*TM, the Organization maintains a policy whereby the value of the 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 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. Fund raising expenses reported on the Statement of Functional Expenses also include indirect costs of special fund raising events, while direct costs are netted against event proceeds. For the years ended December 31, 2015 and 2014, total fund raising expenses (including both direct and indirect event expenses) were \$203,586 and \$237,205, respectively.

NOTE 4 PROPERTY AND EQUIPMENT

The following is a summary of property and equipment as of December 31, 2015 and 2014:

<u>Asset Category</u>	<u>Est. Life</u>	<u>Cost</u>	<u>Accumulated Depreciation</u>	<u>Net Book Value</u>	
				<u>2015</u>	<u>2014</u>
Computer, Technology and Office Equipment	3 - 5	<u>\$22,864</u>	<u>\$16,106</u>	<u>\$6,758</u>	<u>\$8,994</u>

During 2015, the Organization disposed of fully depreciated equipment with an original cost of \$40,279. The disposal of this equipment had no impact on the change in net assets for the year ended December 31, 2015.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

(Continued)

NOTE 5 INVESTMENTS

As of December 31, 2015 and 2014, investment costs and unrealized gains and losses consisted of the following components:

<u>Investment Type</u>	<u>December 31, 2015</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	\$ 57,487	\$ -	\$ -	\$ 57,487	\$ -	\$ 57,487
Mutual Funds	480,782	86,121	(16,266)	550,637	-	550,637
Preferred Stocks and Bonds	<u>136,157</u>	<u>2,009</u>	<u>(2,314)</u>	<u>-</u>	<u>135,852</u>	<u>135,852</u>
Total	<u>\$674,426</u>	<u>\$88,130</u>	<u>\$(18,580)</u>	<u>\$608,124</u>	<u>\$135,852</u>	<u>\$743,976</u>

<u>Investment Type</u>	<u>December 31, 2014</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	\$ 39,050	\$ -	\$ -	\$ 39,050	\$ -	\$ 39,050
Mutual Funds	434,702	108,498	(5,127)	538,073	-	538,073
Preferred Stocks and Bonds	<u>147,395</u>	<u>1,335</u>	<u>(2,134)</u>	<u>-</u>	<u>146,596</u>	<u>146,596</u>
Total	<u>\$621,147</u>	<u>\$109,833</u>	<u>\$(7,261)</u>	<u>\$577,123</u>	<u>\$146,596</u>	<u>\$723,719</u>

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

Mutual Funds: Determined by the published net asset value (“NAV”) per unit at the end of the last trading day of the year, which is the basis for transactions at that date. NAV is based on the value of the underlying assets owned by the fund, minus its liabilities and then divided by the number of shares held by the Organization at year end.

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.

Components of *Investment Return* for the years ended December 31, 2015 and 2014, is as follows:

<u>Components of Investment Return</u>	<u>2015</u>	<u>2014</u>
Interest and Dividends	\$ 44,162	\$46,663
Unrealized Gains (Losses)	(32,964)	(6,507)
Realized Gains (Losses)	<u>6,156</u>	<u>-</u>
Net Investment Return	<u>\$ 17,354</u>	<u>\$40,156</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

(Continued)

NOTE 6 DESIGNATIONS AND RESTRICTIONS OF NET ASSETS

Board Designated Net Assets

For the years presented, unrestricted net assets includes funds designated by the Board of Directors for the William R. Lewis Family Fund. The following schedule summarizes the changes in Board Designated Net Assets for the years ended December 31, 2015 and 2014:

<u>William R. Lewis Family Fund</u>		<u>Amount</u>
Net Assets, December 31, 2013		\$573,134
Investment Income		41,686
Investment (Losses)		(7,768)
Contributions		31,000
Board Designated Cash		23,198
Appropriation for Expenditure		<u>(27,190)</u>
Net Assets, December 31, 2014		634,060
Investment Income		37,846
Investment (Losses)		(21,515)
Contributions		38,000
Appropriation for Expenditure		<u>(30,250)</u>
Net Assets, December 31, 2015		<u>\$658,141</u>

Temporarily Restricted Net Assets

As of December 31, 2015 and 2014, temporarily restricted net assets consisted of the following balances:

<u>Nature of Restriction</u>	<u>2015</u>	<u>2014</u>
Batkin and Younger Family Fund	\$ 52,000	\$ 65,000
Endowment Appreciation - Edward M. Schechter Fund for FSHD	11,935	15,759
S&L Marx Foundation	30,000	11,936
Lai Fund	16,052	5,406
The Marjorie and Gerald Bronfman Foundation* Event Proceeds and Other Donations Designated for Research and Education	-	10,113
Total	<u>802,740</u>	<u>740,208</u>
	<u>\$912,727</u>	<u>\$848,422</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

(Continued)

NOTE 6 *(Continued)*

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>2015</u>	<u>2014</u>
Batkin and Younger Family Fund	\$ 32,000	\$ 20,000
FSHD Canada Foundation Fund	113,046	62,500
Appropriation of Endowment Appreciation - Edward M. Schechter Fund for FSHD	4,000	4,400
S&L Marx Foundation	41,936	16,375
The Marjorie and Gerald Bronfman Foundation*	10,113	35,000
Event Proceeds and Other Donations Designated for Research and Education	<u>892,353</u>	<u>904,124</u>
Total	<u>\$1,093,448</u>	<u>\$1,042,399</u>

*As required by the grant agreements, balances are maintained in separate accounts on the books and in separate bank accounts.

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, 2013	\$14,015	\$73,900	\$87,915
Investment Income	5,126	-	5,126
Investment Gains (Losses)	1,018	-	1,018
Appropriation for Expenditure	<u>(4,400)</u>	<u>-</u>	<u>(4,400)</u>
Endowment Net Assets, December 31, 2014	15,759	73,900	89,659
Investment Income	5,469	-	5,469
Investment Gains (Losses)	(5,293)	-	(5,293)
Appropriation for Expenditure	<u>(4,000)</u>	<u>-</u>	<u>(4,000)</u>
Endowment Net Assets, December 31, 2015	<u>\$11,935</u>	<u>\$73,900</u>	<u>\$85,835</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

(Continued)

NOTE 7 SPECIAL FUND RAISING EVENTS

The results of fund raising events for the years ended December 31, 2015 and 2014 are summarized below:

<u>Event</u>	<u>Gross Proceeds</u>	<u>Direct Costs</u>	<u>Net Event Revenues</u>	
			<u>2015</u>	<u>2014</u>
FSH At The Lake	\$218,160	\$ 730	\$217,430	\$132,262
Songs in the Key of Steven Blier	128,085	37,239	90,846	77,938
Festival of Song	-	-	-	222,983
Ghostly Gala	98,429	38,440	59,989	-
Cosie Laurello Memorial Walk	25,502	-	25,502	22,195
Musclepalooza	27,748	6,156	21,592	-
Golf Tournament	2,225	-	2,225	78,992
Celebrity Walkathon	-	-	-	13,479
Friends Supporting Hope	-	-	-	38,939
Other Fund Raising Events	-	-	-	10,934
Total	<u>\$500,149</u>	<u>\$82,565</u>	<u>\$417,584</u>	<u>\$597,722</u>

For the year ended December 31, 2015, a direct mail campaign was conducted in place of the “Festival of Song” fund raising event, and the gross proceeds of \$169,815, received through December 31, 2015, are included as *Gifts, Grants and Contributions* in the accompanying Statement of Activities.

For the year ended December 31, 2015, proceeds from all fund raising events were restricted to research and education program activities. For the year ended December 31, 2014, proceeds from two events, “FSH at the Lake” and “Friends Supporting Hope”, provided unrestricted operational support for the Organization, and all other fundraising event proceeds were restricted to support specific program activities.

NOTE 8 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>2015</u>	<u>2014</u>
Scientific Advisory Board Expenses	\$ 70,599	\$107,070
Accounting and Auditing	-	18,100
Legal	12,980	18,160
Publications and Memberships	22,392	31,472
Executive and Development, Program Services	24,534	22,200
Executive and Development, Administrative	21,704	25,495
Executive and Development, Fundraising	14,918	11,294
Food and Beverage for Special Fundraising Event	-	20,000
Total	<u>\$167,127</u>	<u>\$253,791</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

(Continued)

NOTE 9 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 all 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 10 LEASING ARRANGEMENTS

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

NOTE 11 RELATED PARTY TRANSACTIONS

During the year ended December 31, 2014, the Secretary of the FSH Society provided, as an independent consultant, \$5,475 in grant writing services.

The President and CEO of the Organization is also a member of the Board of Directors, by virtue of holding these offices, but without voting rights.

NOTE 12 COMMITMENTS AND CONTINGENCIES

The Society has an employment agreement with its President and Chief Executive Officer through December 31, 2016. The agreement provides for a base salary of \$150,000 for 2015, with a cost of living adjustment for 2016, equal to the cost of living adjustment (COLA) specified by the United States Social Security Administration for that year. In addition, it provides for certain benefits, including reimbursement for health care expenses not covered by health insurance up to \$5,000. The maximum contingency obligation under this arrangement is one year’s salary.

NOTE 13 RETIREMENT PLAN

FSH Society maintains 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, 2015 and 2014, the total employer contributions were \$13,257 and \$8,902, respectively, and are included in *Employee Benefits* in the accompanying Statement of Functional Expenses.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2015

(With Summarized Comparative Information for 2014)

(Continued)

NOTE 14 CONCENTRATIONS

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

Cash

The Organization is subject to concentrations in credit risk relating to cash balances. For the years presented, the majority of the Organization's cash deposits were held in three financial institutions. Cash deposits are insured by the Federal Deposit Insurance Corporation up to \$250,000 per institution. As of December 31, 2015 and 2014, cash balances in excess of the FDIC limit were \$1,691,044 and \$1,524,301, 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 funds and 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.

Contributions Receivable

As of December 31, 2015, 36% of *Contributions Receivable* was owed from one donor and as of December 31, 2014, 60% of *Contributions Receivable* represented the amounts owed from two donors.

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 April 5, 2016, the date which the financial statements were available for issue, and noted the following event which met the criteria:

Scientific Advisory Board Grants

As of December 31, 2015, the Society had \$381,118 in expected future disbursements on all research grants awarded to that date. Since then, eight research grant awards totaling \$598,242 have been approved and \$430,979 has been paid to recipients. Hence, at April 5, 2016, on all grants awarded to that date, the total expected future disbursements are \$548,381, all of which is payable in 2016 and 2017.