

**FACIOSCAPULOHUMERAL (FSH) SOCIETY**

**FINANCIAL STATEMENTS**

*with*

**INDEPENDENT AUDITORS' REPORT**

**YEAR ENDED DECEMBER 31, 2016**

*(With Summarized Comparative Information for 2015)*

Smith  Sullivan  
& Brown PC  
CERTIFIED PUBLIC ACCOUNTANTS

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**FACIOSCAPULOHUMERAL (FSH) SOCIETY**

**REPORT ON FINANCIAL STATEMENTS**

**YEAR ENDED DECEMBER 31, 2016**  
*(With Summarized Comparative Information for 2015)*

**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, 2016  
*(With Summarized Comparative Information for 2015)*

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**INDEPENDENT AUDITORS' REPORT**

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

We have audited the accompanying financial statements of Facioscapulo humeral (FSH) Society (a District of Columbia nonprofit organization), which comprise the statement of financial position as of December 31, 2016, 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 Facioscapulo humeral (FSH) Society as of December 31, 2016, 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.

Facioscapulohumeral (FSH) Society  
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**Report on Summarized Comparative Information**

We have previously audited Facioscapulohumeral (FSH) Society's 2015 financial statements, and our report dated April 5, 2016, 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, 2015, is consistent, in all material respects, with the audited financial statements from which it has been derived.

*Smith, Sullivan & Brown, PC*

Westborough, Massachusetts  
April 4, 2017

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENTS OF FINANCIAL POSITION AS OF DECEMBER 31, 2016 AND 2015

<u>ASSETS</u>	<u>2016</u>	<u>2015</u>
<u>CURRENT ASSETS:</u>		
Cash	\$ 2,295,337	\$ 2,032,766
Contributions Receivable	46,000	129,000
Prepaid Expenses	15,250	4,324
Total Current Assets	<u>2,356,587</u>	<u>2,166,090</u>
<u>NET PROPERTY AND EQUIPMENT</u>		
	<u>23,556</u>	<u>6,758</u>
<u>NON-CURRENT ASSETS:</u>		
Cash Reserves	-	434,712
Contributions Receivable	-	16,000
Deposits	13,977	-
William R. Lewis Family Fund Investments	864,199	658,141
Edward M. Schechter Fund Investments	90,684	85,835
Total Non-Current Assets	<u>968,860</u>	<u>1,194,688</u>
<u>TOTAL ASSETS</u>	<u>\$ 3,349,003</u>	<u>\$ 3,367,536</u>
<u>LIABILITIES AND NET ASSETS</u>		
<u>CURRENT LIABILITIES:</u>		
Grants Payable	\$ 493,751	\$ 381,118
Accounts Payable and Accrued Expenses	61,908	29,246
Accrued Payroll and Related Costs	23,010	14,938
Total Current Liabilities	<u>578,669</u>	<u>425,302</u>
<u>LONG TERM LIABILITIES:</u>		
Long-Term Grants Payable	<u>127,367</u>	<u>-</u>
<u>TOTAL LIABILITIES</u>	<u>706,036</u>	<u>425,302</u>
<u>NET ASSETS:</u>		
Unrestricted Net Assets:		
Undesignated	1,651,540	1,297,466
Board Designated William R. Lewis Family Fund	-	658,141
Total Unrestricted Net Assets	1,651,540	1,955,607
Temporarily Restricted Net Assets	63,348	912,727
Permanently Restricted Net Assets	928,079	73,900
Total Net Assets	<u>2,642,967</u>	<u>2,942,234</u>
<u>TOTAL LIABILITIES AND NET ASSETS</u>	<u>\$ 3,349,003</u>	<u>\$ 3,367,536</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENT OF ACTIVITIES  
FOR THE YEAR ENDED DECEMBER 31, 2016  
*(With Summarized Comparative Totals for 2015)*

	<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>2016</u>	<u>2015</u>
		<u>DESIGNATED</u>					
<b><u>SUPPORT, REVENUES</u></b>							
<b><u>AND RECLASSIFICATIONS:</u></b>							
<i>Support and Revenues:</i>							
Gifts, Grants and Contributions	\$ 1,016,340	\$ -	\$ 1,016,340	\$ 541,409	\$ 196,038	\$ 1,753,787	\$ 1,559,768
Special Events, Net of Direct Costs	161,360	-	161,360	121,028	-	282,388	417,584
Donated Goods and Services	148,569	-	148,569	-	-	148,569	167,127
Total Support and Revenues	<u>1,326,269</u>	<u>-</u>	<u>1,326,269</u>	<u>662,437</u>	<u>196,038</u>	<u>2,184,744</u>	<u>2,144,479</u>
<i>Investment and Other Income:</i>							
Investment Return, Net	644	-	644	55,868	-	56,512	17,354
<i>Reclassification of Net Assets:</i>							
Net Assets Released From Restriction	1,567,684	-	1,567,684	(1,567,684)	-	-	-
Change in Donor Intent	-	(658,141)	(658,141)	-	658,141	-	-
Total Reclassification of Net Assets	<u>1,567,684</u>	<u>(658,141)</u>	<u>909,543</u>	<u>(1,567,684)</u>	<u>658,141</u>	<u>-</u>	<u>-</u>
<b><u>TOTAL SUPPORT, REVENUES</u></b>							
<b><u>AND RECLASSIFICATIONS</u></b>	<b><u>2,894,597</u></b>	<b><u>(658,141)</u></b>	<b><u>2,236,456</u></b>	<b><u>(849,379)</u></b>	<b><u>854,179</u></b>	<b><u>2,241,256</u></b>	<b><u>2,161,833</u></b>
<b><u>FUNCTIONAL EXPENSES:</u></b>							
<i>Program Services:</i>							
Research	1,667,129	-	1,667,129	-	-	1,667,129	1,202,949
Patient Advocacy and Education	486,472	-	486,472	-	-	486,472	451,278
Total Program Services	<u>2,153,601</u>	<u>-</u>	<u>2,153,601</u>	<u>-</u>	<u>-</u>	<u>2,153,601</u>	<u>1,654,227</u>
<i>Supporting Services:</i>							
Administrative	209,103	-	209,103	-	-	209,103	188,236
Fund Raising	177,819	-	177,819	-	-	177,819	121,021
Total Supporting Services	<u>386,922</u>	<u>-</u>	<u>386,922</u>	<u>-</u>	<u>-</u>	<u>386,922</u>	<u>309,257</u>
<b><u>TOTAL FUNCTIONAL EXPENSES</u></b>	<b><u>2,540,523</u></b>	<b><u>-</u></b>	<b><u>2,540,523</u></b>	<b><u>-</u></b>	<b><u>-</u></b>	<b><u>2,540,523</u></b>	<b><u>1,963,484</u></b>
<b><u>CHANGE IN NET ASSETS</u></b>	<b>354,074</b>	<b>(658,141)</b>	<b>(304,067)</b>	<b>(849,379)</b>	<b>854,179</b>	<b>(299,267)</b>	<b>198,349</b>
<b><u>NET ASSETS - BEGINNING OF YEAR</u></b>	<b><u>1,297,466</u></b>	<b><u>658,141</u></b>	<b><u>1,955,607</u></b>	<b><u>912,727</u></b>	<b><u>73,900</u></b>	<b><u>2,942,234</u></b>	<b><u>2,743,885</u></b>
<b><u>NET ASSETS - END OF YEAR</u></b>	<b><u>\$ 1,651,540</u></b>	<b><u>\$ -</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>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENT OF FUNCTIONAL EXPENSES  
FOR THE YEAR ENDED DECEMBER 31, 2016

*(With Summarized Comparative Totals for 2015)*

	<u>RESEARCH</u>	<u>PATIENT ADVOCACY AND EDUCATION</u>	<u>TOTAL PROGRAM SERVICES</u>	<u>ADMINI- STRATIVE</u>	<u>FUND RAISING</u>	<u>FUNCTIONAL EXPENSES 2016</u>	<u>2015</u>
Scientific Advisory Board Grants	\$ 1,383,892	\$ -	\$ 1,383,892	\$ -	\$ -	\$ 1,383,892	\$ 949,221
Salaries and Related Expenses	106,161	277,478	383,639	113,971	61,645	559,255	549,472
Donated Services	66,257	40,303	106,560	22,948	19,060	148,568	167,127
Patient Meetings and Research Conferences	61,293	50,989	112,282	-	-	112,282	64,967
Printing	-	32,199	32,199	2,755	18,514	53,468	36,055
Travel, Lodging and Meals	20,931	14,132	35,063	222	11,913	47,198	2,440
Consultants and Professional Fees	-	-	-	19,296	20,990	40,286	14,293
Office Supplies and Expenses	7,314	19,095	26,409	7,854	3,718	37,981	20,082
Website and Computer Related Expenses	6,285	16,416	22,701	6,753	3,644	33,098	21,269
Bank Service Charges and Credit Card Processing Fees	684	1,787	2,471	3,909	18,512	24,892	24,380
Rent	3,808	9,945	13,753	4,145	2,208	20,106	19,020
Public Awareness	-	17,538	17,538	-	-	17,538	21,467
Fundraising Expenses	-	-	-	-	16,023	16,023	27,378
Accounting, Auditing and Financial Consultants	-	-	-	13,000	-	13,000	11,763
Directors Expenses	465	326	791	6,268	606	7,665	5,052
Scientific Advisory Board Expenses	7,641	-	7,641	-	-	7,641	14,051
Telephone and Communications	1,221	3,189	4,410	1,312	708	6,430	2,705
Postage	1,177	3,075	4,252	1,265	278	5,795	4,826
Insurance	-	-	-	2,950	-	2,950	3,232
Depreciation Expense	-	-	-	2,455	-	2,455	4,684
<b>Total Functional Expenses</b>	<b>\$ 1,667,129</b>	<b>\$ 486,472</b>	<b>\$ 2,153,601</b>	<b>\$ 209,103</b>	<b>\$ 177,819</b>	<b>\$ 2,540,523</b>	<b>\$ 1,963,484</b>



FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENTS OF CASH FLOWS  
FOR THE YEARS ENDED DECEMBER 31, 2016 AND 2015

	<u>2016</u>	<u>2015</u>
<b><u>CASH FLOWS FROM OPERATING ACTIVITIES:</u></b>		
Change in Net Assets	\$ (299,267)	\$ 198,349
<i>Adjustments to Reconcile changes in net assets to net cash Provided by Operating Activities:</i>		
Depreciation Expense	2,455	4,684
Investment Return, Net	(55,869)	(17,354)
<i>Changes in operating assets and liabilities:</i>		
Contributions Receivable - Current and Long-term	99,000	(29,143)
Prepaid Expenses	(10,926)	483
Deposits	(13,977)	-
Grants Payable - Current and Long-term	240,000	94,478
Accounts Payable and Accrued Expenses	32,662	98
Accrued Payroll and Related Costs	8,072	7,765
Net Adjustment	<u>301,417</u>	<u>61,011</u>
<b><u>NET CASH PROVIDED BY OPERATING ACTIVITIES</u></b>	<b><u>2,150</u></b>	<b><u>259,360</u></b>
<b><u>CASH FLOWS FROM INVESTING ACTIVITIES:</u></b>		
Purchase of Leasehold Improvements	(7,100)	(2,448)
Purchase of Furniture and Fixtures	(12,153)	-
Proceeds from Investments	36,000	34,250
Purchase of Investments	(191,038)	(37,153)
Net Cash Flows From Investing Activities	<u>(174,291)</u>	<u>(5,351)</u>
<b><u>NET INCREASE (DECREASE) IN CASH BALANCES</u></b>	<b>(172,141)</b>	<b>254,009</b>
<b><u>CASH BALANCES - BEGINNING OF YEAR</u></b>	<b><u>2,467,478</u></b>	<b><u>2,213,469</u></b>
<b><u>CASH BALANCES - END OF YEAR</u></b>	<b><u>\$ 2,295,337</u></b>	<b><u>\$ 2,467,478</u></b>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016

*(With Summarized Comparative Information for 2015)*

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. Funds are granted for scientific research that is rigorously reviewed by the Society's Scientific Advisory Board (SAB). In addition, the Society advocates for increased government and industry investment in research and therapy development.

***Research***

Organizing and funding research into the causes of FSHD, and, ultimately, developing treatments and a cure, is the Society's core mission. The Society also holds an annual International Research Consortium Conference (IRC). The IRC is attended by scientists, clinicians, researchers, pharmaceutical representatives and FSHD patients from many countries.

***Patient Advocacy and Education***

Through its staff, website, 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. The Society continues to develop, update and disseminate brochures and other written materials, videos, photographs, advertisements, social media postings and nationally broadcast public service announcements depicting what FSHD is and what it is like to live with the disease. The Society also sponsors and operates patient support and education groups throughout the United States.

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.

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.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016

*(With Summarized Comparative Information for 2015)*

*(Continued)*

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.

**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, 2016

*(With Summarized Comparative Information for 2015)*

*(Continued)*

NOTE 2      *(Continued)*

**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. In 2015, unrestricted net assets of the Organization include the William R. Lewis Family Fund, which represents unrestricted resources designated by the Board of Directors as a quasi-endowment. In December of 2016, the William R. Lewis Family Fund was converted from a quasi-endowment to a permanently donor restricted endowment, known as the Lewis Family Fund for FSHD.

*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. In 2015, permanently restricted net assets consist of the Edward M. Schechter Fund for FSHD. In 2016, permanently restricted net assets consist of the Edward M. Schechter Fund for FSHD and the Lewis Family Fund for FSHD.

**Statement of Cash Flows**

For the purpose of the accompanying Statement of Cash Flows for the year ended December 31, 2015, cash includes *Cash Reserves*, which are reported as non-current assets, as management did not intend to draw on these funds within 2016.

**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, 2016

*(With Summarized Comparative Information for 2015)*

*(Continued)*

NOTE 2      *(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 \$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.

**Endowment Funds**

During the years presented, through November 2016, the FSH Society had one donor-restricted endowment fund, the Edward M. Schechter Fund for FSHD, which was established by one donor in August 2011. 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. 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, 2016

*(With Summarized Comparative Information for 2015)*

*(Continued)*

NOTE 2      *(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*<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 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*<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 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.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016

*(With Summarized Comparative Information for 2015)*

*(Continued)*

NOTE 2      *(Continued)*

**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.

**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, 2016 and 2015, total fund raising expenses (including both direct and indirect event expenses) were \$343,231 and \$203,586, respectively.

**Reclassifications**

Certain reclassifications have been made to the 2015 financial statement presentation to correspond to the current year's format. Net assets and changes in net assets are unchanged due to these reclassifications. Employee Benefits of \$40,367 and Payroll Taxes of \$32,387 have been combined with *Salaries and Wages* of \$476,718 in the Statement of Functional Expenses for a total of \$549,472.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016

(With Summarized Comparative Information for 2015)

(Continued)

NOTE 3      PROPERTY AND EQUIPMENT

The following is a summary of property and equipment as of December 31, 2016 and 2015:

<u>Asset Category</u>	<u>Est. Life</u>	<u>Cost</u>	<u>Accumulated Depreciation</u>	<u>Net Book Value</u>	
				<u>2016</u>	<u>2015</u>
Computer, Technology and Office Equipment	3 - 5	\$20,923	\$16,279	\$ 4,644	\$6,758
Furniture and Fixtures	7	12,154	145	12,009	-
Leasehold Improvements	3	<u>7,100</u>	<u>197</u>	<u>6,903</u>	-
Total		<u>\$40,177</u>	<u>\$16,621</u>	<u>\$23,556</u>	<u>\$6,758</u>

During 2016 and 2015, the Organization disposed of fully depreciated equipment with an original cost of \$1,941 and \$40,279, respectively. The disposal of this equipment had no impact on the change in net assets for the years ended December 31, 2016 and 2015.

NOTE 4      INVESTMENTS

As of December 31, 2016 and 2015, investment costs and unrealized gains and losses consisted of the following components:

<u>Investment Type</u>	<u>December 31, 2016</u>					
	<u>Cost</u>	<u>Unrealized</u>	<u>Unrealized</u>	<u>Fair</u>	<u>Fair</u>	<u>Total</u>
	<u>Basis</u>	<u>Gains</u>	<u>Losses</u>	<u>Value</u>	<u>Value</u>	<u>Fair</u>
				<u>Level 1</u>	<u>Level 2</u>	<u>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>

  

<u>Investment Type</u>	<u>December 31, 2015</u>					
	<u>Cost</u>	<u>Unrealized</u>	<u>Unrealized</u>	<u>Fair</u>	<u>Fair</u>	<u>Total</u>
	<u>Basis</u>	<u>Gains</u>	<u>Losses</u>	<u>Value</u>	<u>Value</u>	<u>Fair</u>
				<u>Level 1</u>	<u>Level 2</u>	<u>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>

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.



FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016

*(With Summarized Comparative Information for 2015)*

*(Continued)*

NOTE 4     *(Continued)*

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, 2016 and 2015, is as follows:

<u>Components of Investment Return</u>	<u>2016</u>	<u>2015</u>
Interest and Dividends	\$34,669	\$ 44,162
Unrealized Gains (Losses)	22,036	(32,964)
Realized Gains (Losses)	<u>(193)</u>	<u>6,156</u>
Net Investment Return	<u>\$56,512</u>	<u>\$ 17,354</u>

NOTE 5     DESIGNATIONS AND RESTRICTIONS OF NET ASSETS

**Board Designated Net Assets**

As of December 31, 2015, unrestricted net assets include funds designated by the Board of Directors for the William R. Lewis Family Fund. As discussed in Note 2, this Fund was converted to a Donor Restricted Endowment in December 2016. The schedule on the following page summarizes the changes in Board Designated Net Assets for the years ended December 31, 2016 and 2015.

<u>William R. Lewis Family Fund</u>	<u>Amount</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	658,141
Transfer to Permanently Donor Restricted Fund	<u>(658,141)</u>
Net Assets, December 31, 2016	<u>\$ -</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016

*(With Summarized Comparative Information for 2015)*

*(Continued)*

NOTE 5     *(Continued)*

**Temporarily Restricted Net Assets**

As of December 31, 2016 and 2015, temporarily restricted net assets consisted of the following balances:

<u>Nature of Restriction</u>	<u>2016</u>	<u>2015</u>
Batkin and Younger Family Fund	\$16,000	\$ 52,000
Endowment Appreciation - Edward M. Schechter Fund for FSHD	16,784	11,935
Endowment Appreciation - Lewis Family Fund for FSHD	15,020	-
S&L Marx Foundation	-	30,000
Lincoln and Irene Lai Wellness Fund	-	16,052
Research and Education	<u>15,544</u>	<u>802,740</u>
Total	<u>\$63,348</u>	<u>\$912,727</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>2016</u>	<u>2015</u>
Event Proceeds and Other Donations Designated for Research and Education	\$1,285,312	\$892,353
Clinical Trial Network Registry	121,000	-
Lincoln and Irene Lai Wellness Fund	44,372	-
Batkin and Younger Family Fund	51,000	32,000
S&L Marx Foundation	30,000	41,936
Appropriation of Endowment Appreciation - Edward M. Schechter Fund for FSHD	3,500	4,000
Endowment Appreciation - Lewis Family Fund for FSHD	32,500	-
FSHD Canada Foundation Fund	-	113,046
The Marjorie and Gerald Bronfman Foundation*	-	<u>10,113</u>
Total	<u>\$1,567,684</u>	<u>\$1,093,448</u>

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

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016

(With Summarized Comparative Information for 2015)

(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, 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	11,935	73,900	85,835
Contributions	-	196,038	196,038
Investment Income	33,833	-	33,833
Investment Gains (Losses)	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	<u>\$ 31,804</u>	<u>\$928,079</u>	<u>\$959,883</u>

NOTE 6 **SPECIAL FUND RAISING EVENTS**

The results of fund raising events for the years ended December 31, 2016 and 2015 are summarized below:

<u>Event</u>	<u>Gross</u>	<u>Direct</u>	<u>Net Event Revenues</u>	
	<u>Proceeds</u>	<u>Costs</u>	<u>2016</u>	<u>2015</u>
FSH At The Lake	\$121,028	\$ -	\$121,028	\$217,430
CureFSHD Gala	119,880	76,526	43,354	-
Songs in the Key of Steven Blier	59,844	17,432	42,412	90,846
Ghostly Gala	86,481	45,453	41,028	59,989
Cosie Laurello Memorial Walk	-	-	-	25,502
Musclepalooza	-	-	-	21,592
Golf Tournament	-	-	-	2,225
Other Fund Raising Events	<u>60,567</u>	<u>26,001</u>	<u>34,566</u>	<u>-</u>
Total	<u>\$447,800</u>	<u>\$165,412</u>	<u>\$282,388</u>	<u>\$417,584</u>

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, 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, 2016

*(With Summarized Comparative Information for 2015)*

*(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>2016</u>	<u>2015</u>
Public Relations	\$ 80,607	\$31,348
Scientific Advisory Board Expenses	42,712	70,599
Event Services	11,000	-
Legal	8,850	12,980
Investment Advisory Services	5,400	21,600
Other Professional Advisory Services	-	30,600
Total	<u>\$148,569</u>	<u>\$167,127</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

During 2015 and 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, which includes certain general operating costs and utilities. The following is a schedule of future minimum rental payments as of December 31, 2016:

<u>Year Ending</u>	<u>Amount</u>
December 31, 2017	\$29,422
December 31, 2018	29,422
December 31, 2019	<u>17,163</u>
Total	<u>\$76,007</u>

Rent expense for the year ended December 31, 2016 and 2015 was \$19,887 and \$19,020, respectively.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016

*(With Summarized Comparative Information for 2015)*

*(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.

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 11 COMMITMENTS AND CONTINGENCIES

The Society entered into an employment agreement with its President and Chief Executive Officer effective as of November 1, 2016 and ending on October 31, 2017. The agreement provides for a base salary of \$75,000 beginning November 1, 2016. In addition, it provides for certain benefits, including reimbursement for health insurance in the event group coverage is not available up to \$1,660 per month. The maximum contingency obligation under this arrangement is one year's salary.

In 2012, the Society became party to an offer letter with its current Acting Chief Operating Officer (COO). If the COO is terminated for any reason other than cause, the Society is obligated to pay the COO three months of salary plus benefits. The maximum contingency obligation under this arrangement is approximately \$32,500.

NOTE 12 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, 2016 and 2015, the total employer contributions were \$15,222 and 13,257, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016

*(With Summarized Comparative Information for 2015)*

*(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. 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 (FDIC) up to \$250,000 per institution. 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, 2016 and 2015, cash balances in excess of the FDIC limit were \$50,009 and \$1,691,044, 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.

**Contributions Receivable:**

As of December 31, 2016, 78% of *Contributions Receivable* represented the amounts owed from two donors and as of December 31, 2015, 36% of *Contributions Receivable* was owed from one donor.

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 April 4, 2017 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, 2016, the Society had \$621,118 in expected future disbursements on all research grants awarded to that date. Since then, five research grant awards totaling \$541,134 have been approved and \$485,998 has been paid to recipients. Hence, at April 4, 2017, on all grants awarded to that date, the total expected future disbursements are \$676,254, all of which is payable in 2017 thru 2019.