

FACIOSCAPULOHUMERAL (FSH) SOCIETY

FINANCIAL STATEMENTS

with

INDEPENDENT AUDITORS' REPORT

YEAR ENDED DECEMBER 31, 2013

Smith  Sullivan
& Brown PC
CERTIFIED PUBLIC ACCOUNTANTS

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FACIOSCAPULOHUMERAL (FSH) SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2013

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, 2013

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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, 2013, 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, 2013, 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.

Smith, Sullivan & Brown, P.C.

Westborough, Massachusetts
June 12, 2014

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENT OF FINANCIAL POSITION AS OF DECEMBER 31, 2013

ASSETS

CURRENT ASSETS:

Cash	\$ 1,840,358
Contributions Receivable	25,000
Prepaid Expenses	3,592
Total Current Assets	<u>1,868,950</u>

NET PROPERTY AND EQUIPMENT

8,973

NON-CURRENT ASSETS:

Board Designated William R. Lewis Family Fund Investments	543,144
Edward M. Schechter Fund Investments	87,915
Total Non-Current Assets	<u>631,059</u>

TOTAL ASSETS

\$ 2,508,982

LIABILITIES AND NET ASSETS

CURRENT LIABILITIES:

Grants Payable	\$ 105,866
Accounts Payable and Accrued Expenses	16,363
Accrued Payroll and Related Costs	19,178
Total Current Liabilities	<u>141,407</u>

NET ASSETS:

Unrestricted Net Assets:	
Undesignated	782,451
Board Designated William R. Lewis Family Fund	573,134
Total Unrestricted Net Assets	<u>1,355,585</u>
Temporarily Restricted Net Assets	938,090
Permanently Restricted Net Assets	73,900
Total Net Assets	<u>2,367,575</u>

TOTAL LIABILITIES AND NET ASSETS

\$ 2,508,982

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED DECEMBER 31, 2013

	<u>UNRESTRICTED</u>	<u>TOTAL</u>	<u>TEMPORARILY</u>	<u>PERMANENTLY</u>	<u>TOTAL</u>	
	<u>OPERATING</u>	<u>BOARD DESIGNATED</u>	<u>UNRESTRICTED</u>	<u>RESTRICTED</u>	<u>RESTRICTED</u>	<u>ACTIVITIES</u>
<u>SUPPORT, REVENUES</u>						
<u>AND RECLASSIFICATIONS:</u>						
<i>Support and Revenues:</i>						
Gifts, Grants and Contributions	\$ 531,235	\$ 32,491	\$ 563,726	\$ 443,627	\$ -	\$ 1,007,353
Special Events, Net of Direct Costs	216,767	-	216,767	401,109	-	617,876
Donated Goods and Services	215,474	-	215,474	-	-	215,474
Total Support and Revenues	963,476	32,491	995,967	844,736	-	1,840,703
<i>Investment and Other Income:</i>						
Investment Return, Net	779	91,681	92,460	9,594	-	102,054
<i>Reclassification of Net Assets:</i>						
Net Assets Released From Restriction	699,659	(22,113)	677,546	(677,546)	-	-
<u>TOTAL SUPPORT, REVENUES</u>						
<u>AND RECLASSIFICATIONS</u>	<u>1,663,914</u>	<u>102,059</u>	<u>1,765,973</u>	<u>176,784</u>	<u>-</u>	<u>1,942,757</u>
<u>FUNCTIONAL EXPENSES:</u>						
<i>Program Services:</i>						
Research	815,716	-	815,716	-	-	815,716
Direct Service	302,156	-	302,156	-	-	302,156
Education	142,143	-	142,143	-	-	142,143
Total Program Services	1,260,015	-	1,260,015	-	-	1,260,015
<i>Supporting Services:</i>						
Administrative	165,127	-	165,127	-	-	165,127
Fund Raising	80,077	-	80,077	-	-	80,077
Total Supporting Services	245,204	-	245,204	-	-	245,204
<u>TOTAL FUNCTIONAL EXPENSES</u>	<u>1,505,219</u>	<u>-</u>	<u>1,505,219</u>	<u>-</u>	<u>-</u>	<u>1,505,219</u>
<u>CHANGE IN NET ASSETS</u>	158,695	102,059	260,754	176,784	-	437,538
<u>NET ASSETS - BEGINNING OF YEAR</u>						
<u>AS RESTATED</u> (Note 6)	<u>623,756</u>	<u>471,075</u>	<u>1,094,831</u>	<u>761,306</u>	<u>73,900</u>	<u>1,930,037</u>
<u>NET ASSETS - END OF YEAR</u>	<u>\$ 782,451</u>	<u>\$ 573,134</u>	<u>\$ 1,355,585</u>	<u>\$ 938,090</u>	<u>\$ 73,900</u>	<u>\$ 2,367,575</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2013

	<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>
Scientific Advisory Board Grants	\$ 661,585	\$ -	\$ -	\$ 661,585	\$ -	\$ -	\$ 661,585
Salaries and Wages	68,762	99,204	108,632	276,598	28,154	26,128	330,880
Payroll Taxes	4,645	6,701	7,338	18,684	1,902	1,765	22,351
Employee Benefits	5,730	8,266	9,052	23,048	2,346	2,177	27,571
Patient Meetings and Conferences	-	30,678	-	30,678	-	-	30,678
Donated Services	24,775	90,271	-	115,046	64,254	16,174	195,474
Scientific Advisory Board Expenses	37,849	-	-	37,849	-	-	37,849
Directors Expenses	-	3,801	-	3,801	-	-	3,801
Consultants and Professional Fees	-	-	-	-	14,081	-	14,081
Fundraising Expenses	-	-	-	-	-	21,495	21,495
Accounting, Auditing and Financial Consultants	-	-	-	-	45,089	-	45,089
Rent	4,171	6,018	6,591	16,780	1,708	1,585	20,073
Travel, Lodging and Meals	1,535	-	-	1,535	-	6,022	7,557
Office Supplies and Expenses	3,207	4,627	5,067	12,901	1,313	1,219	15,433
Telephone and Communications	426	615	674	1,715	175	162	2,052
Website and Computer Related Expenses	1,245	1,797	1,968	5,010	510	473	5,993
Insurance	113	163	178	454	1,720	43	2,217
Printing	-	32,642	-	32,642	-	2,198	34,840
Depreciation Expense	1,157	1,670	1,828	4,655	474	440	5,569
Postage	516	744	815	2,075	211	196	2,482
Bank Service Charges and Credit Card Processing Fees	-	14,959	-	14,959	3,190	-	18,149
Total Functional Expenses	<u>\$ 815,716</u>	<u>\$ 302,156</u>	<u>\$ 142,143</u>	<u>\$ 1,260,015</u>	<u>\$ 165,127</u>	<u>\$ 80,077</u>	<u>\$ 1,505,219</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY
STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED DECEMBER 31, 2013

CASH FLOWS FROM OPERATING ACTIVITIES:

Change in Net Assets	\$ <u>437,538</u>
<i>Adjustments to Reconcile the Above to Net Cash Provided by Operating Activities:</i>	
Depreciation Expense	5,569
Investment Return, Net	(102,054)
Donated Investments	(46,649)
<i>(Increase) Decrease in Current Assets:</i>	
Contributions Receivable	31,000
Prepaid Expenses	638
<i>Increase (Decrease) in Current Liabilities:</i>	
Grants Payable	105,866
Accounts Payable and Accrued Expenses	12,998
Accrued Payroll and Related Costs	<u>5,335</u>
Net Adjustment	<u>12,703</u>

NET CASH PROVIDED BY OPERATING ACTIVITIES **450,241**

CASH FLOWS FROM INVESTING ACTIVITIES:

Purchase of Equipment	(2,700)
Proceeds from Securities Sold	121,799
Acquisition of Securities	<u>(81,429)</u>

NET CASH FLOWS PROVIDED BY INVESTING ACTIVITIES **37,670**

NET INCREASE IN CASH BALANCES **487,911**

CASH BALANCES - BEGINNING OF YEAR **1,352,447**

CASH BALANCES - END OF YEAR **\$ 1,840,358**

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

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 also known as FSH muscular dystrophy and FSHD. The FSH Society’s purpose is to conduct research, increase awareness, understanding and education on FSHD. FSHD is one of the most common adult muscular dystrophies with a prevalence of 1:15,000–1:20,000. For a half-million men, women, and children worldwide the major consequence of inheriting this genetic form of muscular dystrophy is a lifelong progressive loss of all skeletal muscles. FSHD is a crippling and life shortening disease. No one is immune. FSHD is an autosomal dominant muscular dystrophy. It is both genetically and spontaneously transmitted to children. It can affect multiple generations and entire families. With FSHD there is a loss of muscle strength that ranges between one and four percent a year during a lifetime. In terms of functional impairment, 20 percent of FSHD-affected individuals over age fifty will require the use of a wheelchair. FSHD also has very specific non-muscular manifestations; hearing-loss, restrictive lung disease, supraventricular arrhythmias (rare), and retinal vasculopathy. 95% of individuals with FSHD have the FSHD1 (FSHD1A) genetic variation - caused by the contraction of DNA macrosatellite repeat units, termed D4Z4 repeats, on chromosome 4, leading to the release of transcriptional repression of a retrogene (DUX4) believed to be associated with the cause of disease. Of the 5% of FSHD individuals remaining, 80% of those are the FSHD2 (FSHD1B) genetic variation - caused by mutations in the SMCHD1 gene on chromosome 18 that helps to maintain the structure of the D4Z4 repeats on the long arm of chromosome 4.

FSHD is recognizable initially by muscle wasting and weakness in particular muscle groups e.g. (face – facio, shoulders - scapula, and upper arms – humerus), and subsequently by atrophy and wasting in multiple muscle groups such as lower body, legs and torso and all skeletal muscles later in the disease). The disease has a high burden of disease and brings with it significant disability and even premature death in affected individuals. FSHD generally presents outward signs in 95% of affected individuals by the second decade of life for men and the third decade of life for women e.g. FSHD has a phenotypic penetrance of 95% in men by 20 years of age, and in women by 30 years of age. FSHD causes progressive loss, wasting and atrophy of all skeletal muscles. FSHD can have associated respiratory, hearing loss and vision issues. The severity of FSHD is variable and can range from mild in presentation in some individuals, and severely crippling and life shortening in others.

As of March 2014, the FSH Society has provided more than 4.6 million dollars, since the inception of its research fellowships and grants program, in seed funds and grants to pioneering FSHD research areas and education worldwide and created an international collaborative network of patients and researchers. Quantum leaps in our understanding of FSHD have occurred in the past three and a half years. In the last decade alone, we have seen remarkable contributions made by researchers initially funded by the Society. The Society relies entirely on private grants, donations and grassroots philanthropy.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 2 *(Continued)*

The FSH Society offers basic research grants, clinical research, research and postdoctoral fellowships to support research relevant to understanding the molecular genetics and causes of FSHD on an ongoing and ad-hoc basis. The FSH Society Scientific Advisory Board (SAB) diligently carries out its mission of providing strategy for FSHD research, therapeutics and clinical trials readiness, recruiting and attracting qualified researchers and clinician-researchers, selecting research proposals, evaluating research proposals, granting fellowships and monitoring ongoing projects and research opportunities. Since 1997, the FSH Society has funded approximately 4.6 million dollars in \$10,000 to \$125,000 a year grant fellowships to dozens of junior and senior level researchers, leading to more than three hundred publications acknowledging Society support in top-tier scientific journals. Recent advances in understanding the molecular genetics and cellular biology of FSHD have led to the identification of potential therapeutic targets. Impressive scientific progress has been made over the past four years and even in the past few months in our understanding of the disease largely due to Society funding of research. Grant making to FSHD researchers and clinicians located both domestically in the United States and outside the United States is one of the largest programmatic components of the FSH Society.

The FSH Society organizes meetings, symposiums and workshops. The Society's annual FSHD International Research Consortium symposium for researchers worldwide yields measurable gains in our understanding of FSHD. The 2013 FSH Society FSHD International Research Consortium was held in Cambridge, Massachusetts as an ancillary meeting to the American Society of Human Genetics and was attended by a record number of near 100 scientists, clinicians, researchers and FSHD patients. This meeting is a key meeting for the international and worldwide research community for focusing on issues, collaborating, networking, and for filling in missing gaps in the research. Significant progress was made at the 2013 research consortium and research planning meeting – priorities were set and planning documents disseminated. The general discussion of day two covered four major areas. With respect to the first area, called DUX4, the unanimous conclusion of the general discussion was that over-expression of the toxic transcription factor DUX4 is at the root of FSHD1 and FSHD2 and that DUX4 expression is necessary, but not always sufficient, to cause FSHD. Research should focus on upstream and downstream molecular pathways and mechanisms as they form the most plausible intervention targets. The group also discussed needs and priorities in three additional areas: disease models, intervention, clinical studies and trial readiness. The priorities stated for 2014, at the October 21-22, 2013, FSH Society FSHD IRC meetings are as follows:

- The DUX4 interactome
- Understanding DUX4 manifestation and variation
- Additional genetic heterogeneity; non-FSHD1 and FSHD2
- Disease models
- Well documented Natural history with reliable endpoints; modulating mechanisms/genes
- Increasing data depth of patient databases with extensive (follow-up) clinical data
- Prepare for clinical trials: reliable and meaningful outcome measures; with access to discreet patient populations and disease mechanism of action classes.
- Therapy; proof-of-principle experiments
- Focus on translational research; from clinic to bench and back
- Understanding pathophysiology of FSHD: connection to DUX4, heterogeneity, asymmetry, role of inflammation; infiltrates and etiology

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 2 *(Continued)*

Given the recent developments, there is a need to ramp up the preclinical enterprise and build/organize infrastructure needed to conduct clinical trials. Our immediate priorities should be to confirm the new hypotheses and targets. We need to be prepared for this new era in the science of FSHD. Many leading experts are now turning to work on FSHD not only because it is one of the most complicated and challenging problems seen in science, but because it represents the potential for great discoveries, insights into stem cells and transcriptional processes and new ways of thinking about and treating human disease.

In accordance with its primary purpose of serving the FSHD community in the United States and abroad, the FSH Society has brought together through education, patient network meetings, support group meetings, peer-support, and advocacy to more than 6,250 FSHD-affected families committed to working cooperatively. In August 2014, the biennial FSH Society International Patient Researcher Network Day will be held in Boston, Massachusetts. We plan on 200 to 250 FSHD patients, families, friends, scientists and researchers gathering to listen to the latest findings in molecular genetics research and testing and the latest developments in clinical management and therapeutics of FSHD. The main focus is for medical professionals and patients to be able to share ideas on the disease in a collegial setting. The FSH Society also works with the community to foster research planning meetings, research education meetings and patient support groups. In 2012, the FSH Society began efforts to organize funding agencies worldwide to better work together to solve FSHD and to increase rigor, objectivity and transparency in preclinical research to increase the likely of success with clinical trials on FSHD. In 2013, the FSH Society continued a leadership role in convening a monthly meeting for a global group working on FSHD called the "FSHD Champions." FSHD Champions is an informal, international group consisting of fourteen FSHD advocacy and funding organizations, to promote transparency and collaboration in FSHD research. The 2014 FSH Society FSHD International Research Consortium will be held in San Diego, California as an ancillary meeting to the 2014 American Society of Human Genetics meeting and the 2014 FSHD Champions will meet subsequently as an international alliance promoting and funding FSHD research. Meetings, symposia, workshops and networking activities are one of the most successful programmatic components of the FSH Society.

Through the FSH Society staff and its web site portal at www.fshsociety.org, Facebook page, Twitter account, Yahoo! Groups bulletin board, e-mail ListServ (vertical response), and quarterly newsletter the "FSH Watch," FSHD patients have found ways to be useful to one another and to basic and clinical researchers working on their disease. The support patients receive from one another through sharing their common experience is invaluable and immeasurable. The FSH Society acts as a clearinghouse for information on the FSHD disorder and on potential drugs and devices designed to alleviate the effects of the disease. It fosters communication among FSHD patients, their families and caregivers, charitable organizations, government agencies, industry, scientific researchers, and academic institutions. The FSH Society also provides dedicated support, education and outreach services to patients, professionals, researchers and families in need of assistance. The Society responds to numerous inquiries by phone, web and e-mail from newly diagnosed patients, patients, family members and spouses of FSHD patients and professionals each week. In 2013, the Society added additional resources to help grow in-person support group and educational days associated with major clinical and research centers around the United States and many of these meetings were broadcast via internet video-streaming for those having difficulty getting to meetings in person. The Society also embarked on projects to build assets depicting what FSHD is and what it is to live with the disease in writing, photographs and videos. In 2013, the Society began an initiative to raise visibility for FSHD through public service announcements on the disease in seven geographic markets.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 2 *(Continued)*

In 2013, and continuing in 2014, the FSH Society helps educate and recruit patients into research studies headquartered at the U.S. National Institutes of Health University of Massachusetts Medical School Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Center for FSHD, in Worcester, Massachusetts. As a result of the FSH Society serving as the Office of Patient Liaison and Communication to the Wellstone center it has helped facilitate the production of the world's largest resource for FSHD biomaterials that are being made available to all researchers worldwide. The Society hopes that this strategy will help with better reproduction, validation and corroboration of research results by providing the community with a high quality and high number of well controlled FSHD cell lines that multiple research groups can independently access. The FSH Watch is published quarterly, including a more technical and scientific annual research edition, and is distributed in hardcopy by U.S. postal mail, electronically by e-mail and on-line at the Society web site as Adobe PDF files. The FSH Society also designs, develops, publishes and distributes brochures on FSHD and Physical Therapy for patients, families, friends and professionals involved with FSHD. In 2013, the FSH Society continued to promote its publication titled "FSHD: A Guide for Schools" to help teachers and students affected with FSHD better navigate the issues of FSHD in the classroom. The programs and materials are posted on our web site at www.fshsociety.org in perpetuity and read by thousands of more professionals and patients. As of March 2014, our website received over 5,000 unique visits with 16,000 page views per month. In 2013, we embarked on a major upgrade of our web site and will be launching a new site mid-2014 using latest technologies and internet platforms. Publications, literature, education, patient support, advocacy, social networking and research networking combined are the most significant and core programmatic components of the FSH Society.

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. The following policies should be read in conjunction with the accompanying notes to the financial statements.

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.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 3 *(Continued)*

The three levels of inputs used to measure fair value are defined as follows:

- Level 1 - Quoted prices for identical assets or liabilities in active markets to which the Organization has access at the measurement date.

- Level 2 - Inputs other than quoted prices included in Level 1 that are observable for the asset or liability, either directly or indirectly. Level 2 inputs include quoted prices for similar assets or liabilities in active markets; quoted prices for identical or similar assets in markets that are not active; observable inputs other than quoted prices for the asset or liability (for example, interest rate and yield curves); and inputs derived principally from, or corroborated by, observable market data by correlation or by other means.

- Level 3 - Unobservable inputs for the asset or liability. Unobservable inputs should be used to measure the fair value to the extent that observable inputs are not available.

The primary use of fair value measures in the Organization's financial statements is the recurring measurement of investments. There have been no changes to this valuation methodology.

Financial Statement Presentation:

As required by the *FASB Accounting Standards Codification*TM, the Organization 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 may include funds which represent unrestricted resources designated by the Board of Directors for specific purposes.

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.

As of December 31, 2013, permanently restricted net assets consist of the Edward M. Schechter Fund of FSHD.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 3 *(Continued)*

Contributions Receivable:

Contributions Receivable are classified as current if they are scheduled for receipt within one year, and non-current when the expected date of receipt exceeds one year. As of December 31, 2013, all contributions receivable were classified as current. 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, they will be charged to activities at that time. The Organization did not experience any loss on uncollectible receivables for the year presented.

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:

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 3 *(Continued)*

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

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

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 3 *(Continued)*

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 SAB approves awards and all significant conditions have been met. As of December 31, 2013, *Grants Payable* are expected to be paid in 2014. Conditional commitments are not recognized in the financial statements until the conditions upon which they depend are substantially met.

Historically, the Society recognized expenses for grants made as the funds were distributed. Many of the grant agreements contain provisions for disbursement of the grants in installments, subject to continued compliance with the grant terms and satisfactory progress on the particular research project. Accordingly, grants that are awarded in one year may have payments that carry into the subsequent year. In 2013, after considering the history of its grant making, Management determined that in order to more closely align its financial reporting with the Society's intentions to fully fund the grant commitments, it would be more appropriate to recognize the full obligation of the grant at the time of commitment. Therefore, these financial statements include an expense for *Scientific Advisory Board Grants* and a corresponding liability for *Grants Payable* as of December 31, 2013, for commitments totaling \$105,866 that are expected to be paid in the subsequent year. This change in the Society's policy for expense recognition results in a one-time overstatement in *Scientific Advisory Board Grants*.

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 members 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.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 3 *(Continued)*

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 year ended December 31, 2013, total fund raising expenses (including both direct and indirect event expenses) were \$204,006.

Tax Position:

The Organization currently evaluates all tax positions, and makes a determination regarding the likelihood of those positions being upheld under review. The primary tax positions made by the Organization are the nonexistence of Unrelated Business Income Tax and the Organization's status as a tax-exempt organization under Section 501(c)(3) of the Internal Revenue Code. For the years presented, the Organization has not recognized any tax benefits or loss contingencies for uncertain tax positions based on this evaluation. All tax periods prior to 2010 are no longer subject to examination by tax authorities.

NOTE 4 PROPERTY AND EQUIPMENT

The following is a summary of property and equipment as of December 31, 2013:

<u>Asset Category</u>	<u>Est. Life</u>	<u>Cost</u>	<u>Accumulated Depreciation</u>	<u>Net Book Value</u>
Equipment	3 - 5	<u>\$55,167</u>	<u>\$46,194</u>	<u>\$8,973</u>

During 2013, the Organization disposed of fully depreciated equipment with an original cost of \$6,276. The disposal of this equipment had no impact on the change in net assets for the year ended December 31, 2013.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 5 INVESTMENTS

As of December 31, 2013, investment costs and unrealized gains and losses consisted of the following components:

<u>Investment Type</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	\$ 33,183	\$ -	\$ -	\$ 33,183	\$ -	\$ 33,183
Mutual Funds	365,804	115,841	-	481,645	-	481,645
Preferred Stocks and Bonds	<u>122,679</u>	<u>97</u>	<u>(6,545)</u>	<u>-</u>	<u>116,231</u>	<u>116,231</u>
Total	<u>\$521,666</u>	<u>\$115,938</u>	<u>\$(6,545)</u>	<u>\$514,828</u>	<u>\$116,231</u>	<u>\$631,059</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 year ended December 31, 2013, is as follows:

<u>Components of Investment Return</u>	<u>Amount</u>
Interest and Dividends	\$ 29,090
Unrealized Gains	74,536
Realized Losses	<u>(1,572)</u>
Net Investment Return	<u>\$102,054</u>

NOTE 6 RESTATEMENT OF NET ASSETS

Prior to the year ended December 31, 2013, the Organization did not properly report the changes in the fair value of the donor-restricted endowment account as specified by the donor. To retroactively adjust the fair value, the Organization has adjusted its opening temporarily restricted and permanently restricted net assets as of January 1, 2013.

Additionally, Management determined that it should reflect the William R. Lewis Family Fund as Unrestricted and Board Designated as the funds had no donor-imposed restrictions at the time of the initial contribution.

These restatements change the composition within the net asset classifications, but have no effect on total opening net assets.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 6 (Continued)

Management has restated its net assets in the accompanying Statement of Activities as follows:

	<u>Unrestricted and Board Designated</u>	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>
Net Assets as of January 1, 2013	\$ 604,714	\$ 1,242,282	\$83,041
Change in Fair Value of Investments - Edward M. Schechter Fund for FSHD	-	9,141	(9,141)
Change in Fair Value of Investments - William R. Lewis Family Fund	49,032	(49,032)	-
Change in Board Designation - William R. Lewis Family Fund	<u>441,085</u>	<u>(441,085)</u>	<u>-</u>
Net Assets as Restated as of January 1, 2013	<u>\$1,094,831</u>	<u>\$ 761,306</u>	<u>\$73,900</u>

NOTE 7 DESIGNATIONS AND RESTRICTIONS OF NET ASSETS

Board Designated Net Assets:

As of December 31, 2013, unrestricted net assets includes funds which represent unrestricted resources designated by the Board of Directors for the William R. Lewis Family Fund of \$573,134.

The following schedule summarizes the changes in Board Designated Net Assets for the year ended December 31, 2013:

	<u>William R. Lewis Family Fund</u>
Board Designated Net Assets, December 31, 2012 as Restated	\$471,075
Investment Income	24,149
Investment Gains	67,532
Contributions	32,491
Appropriation for Expenditure	<u>(22,113)</u>
Board Designated Net Assets, December 31, 2013	<u>\$573,134</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 7 *(Continued)*

Temporarily Restricted Net Assets:

As of December 31, 2013, temporarily restricted net assets consisted of the following balances:

<u>Nature of Restriction</u>	<u>Amount</u>
The Marjorie and Gerald Bronfman Foundation*	\$ 45,113
Batkin and Younger Family Fund	20,000
Endowment Appreciation - Edward M. Schechter Fund for FSHD	14,015
S&L Marx Foundation	28,311
Other Donations and Event Proceeds Designated for Research and Education	<u>830,651</u>
Total	<u>\$938,090</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 2013 were as follows:

<u>Nature of Restriction</u>	<u>Amount</u>
The Marjorie and Gerald Bronfman Foundation*	\$ 20,000
Batkin and Younger Family Fund	46,000
FSHD Canada Foundation Fund	20,000
Lai Fund	31,009
Appropriation of Endowment Appreciation - Edward M. Schechter Fund for FSHD	3,600
S&L Marx Foundation	21,689
Other Donations and Event Proceeds Designated for Research and Education	<u>535,248</u>
Total	<u>\$677,546</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, 2013

(Continued)

NOTE 7 (Continued)

Endowment Net Assets:

The following schedule summarizes the change in endowment net assets for the year ended December 31, 2013:

	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total Endowment Net Assets</u>
Endowment Net Assets, December 31, 2012 as restated	\$ 9,141	\$73,900	\$83,041
Investment Income	3,653	-	3,653
Investment Gains	4,671	-	4,671
Contributions	150	-	150
Appropriation for Expenditure	<u>(3,600)</u>	<u>-</u>	<u>(3,600)</u>
Endowment Net Assets, December 31, 2013	<u>\$ 14,015</u>	<u>\$73,900</u>	<u>\$87,915</u>

NOTE 8 SPECIAL FUND RAISING EVENTS

The results of unrestricted fund raising events for the year ended December 31, 2013, are summarized below:

<u>Event</u>	<u>Gross Proceeds</u>	<u>Direct Costs</u>	<u>Net Event Revenues</u>
FSH At The Lake	\$189,860	\$20,000*	\$169,860
Dinner Events	<u>56,576</u>	<u>9,669</u>	<u>46,907</u>
Total	<u>\$246,436</u>	<u>\$29,669</u>	<u>\$216,767</u>

*For the year ended December 31, 2013, direct costs include \$20,000 of donated goods and services.

The results of temporarily restricted fund raising events for the year ended December 31, 2013, are summarized below:

<u>Event</u>	<u>Gross Proceeds</u>	<u>Direct Costs</u>	<u>Net Event Revenues</u>
Festival of Song	\$318,850	\$44,352	\$274,498
Golf Tournament	125,606	37,135	88,471
Celebrity Walkathon	35,440	11,948	23,492
Cape Cod Walk n Roll	<u>15,473</u>	<u>825</u>	<u>14,648</u>
Total	<u>\$495,369</u>	<u>\$94,260</u>	<u>\$401,109</u>

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 9 DONATED GOODS AND SERVICES

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

<u>Description</u>	<u>Amount</u>
Scientific Advisory Board Expense	\$ 24,775
Accounting and Auditing	17,800
Legal	18,880
Publications and Memberships	37,247
Executive and Development, Program Services	53,024
Executive and Development, Administrative	27,574
Executive and Development, Fundraising	16,174
Food and Beverage for Special Fundraising Event*	<u>20,000</u>
Total	<u>\$215,474</u>

* For the year ended December 31, 2013, this amount includes \$20,000 in donations reported as direct costs of fund raising events (*See Note 8*).

NOTE 10 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 American 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 11 LEASING ARRANGEMENTS

Through March 2013, the Organization rented 330 net square feet of office space in Watertown, MA. Monthly rent was \$1,800 and the Society was a tenant-at-will. Effective March 2013, the Society entered into a new one-year lease agreement for 973 square feet of office space in Lexington, MA. At the conclusion of the one-year lease, the lease will convert to a tenancy-at-will agreement and the Organization 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. Rent expense for the year ended December 31, 2013, totaled \$20,073. Future minimum lease payments as of December 31, 2013, of \$3,170 are due in 2014.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 12 RELATED PARTY TRANSACTIONS

During the year presented, the Treasurer of the FSH Society was a retired partner of a firm which provided \$23,000 in tax and accounting services. After 22 years of service, this Treasurer retired in February 2014.

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 13 COMMITMENTS AND CONTINGENCIES

Employment Agreement:

The Society has an employment agreement with its President and Chief Executive Officer through December 31, 2014. The agreement provides for a salary of \$120,133 for 2014 and includes an annual cost of living adjustment. In addition, it provides for certain benefits, including health care expenses not covered by health insurance.

State Registrations:

The Organization is currently in the process of determining which states in which FSH solicits funds, will require registration. The FSH Society has engaged the law firm of Copilevitz and Canter, LLC, Kansas City, Missouri to handle all aspects of the national multi-state registration process including initial filings, as well as docketing and preparation of annual renewal registrations/financial reports and seeking extensions. The Organization expects to register in all applicable states to be in compliance with state registration laws and industry best practices. In the event that fees for noncompliance are imposed, the Organization expects that it will be successful in obtaining waivers, and therefore, has not recorded an expense and corresponding liability. In the event that a waiver is denied, the Organization may be required to pay penalties in addition to late fees at the discretion of each state.

NOTE 14 EMPLOYEE BENEFIT 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. In 2013, employee contributions to the IRA are subject to a 3% employer match. For the year ended December 31, 2013, the total employer contributions were \$8,689 and are included in *Employee Benefits* in the accompanying financial statements.

NOTE 15 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 year 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, 2013, cash balances in excess of the FDIC limit were \$1,140,006. The Organization has not experienced any losses on uninsured cash balances.

FACIOSCAPULOHUMERAL (FSH) SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2013

(Continued)

NOTE 15 *(Continued)*

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, 2013, *Contributions Receivable* represented the amount owed from one Foundation.

NOTE 16 SUBSEQUENT EVENTS

Management is required to consider events subsequent to the financial statement date for potential adjustment to or disclosure in the financial statements. Therefore, Management has evaluated subsequent events through June 12, 2014, the date which the financial statements were available for issue, and noted no events which met the criteria.