FINANCIAL STATEMENTS

with

$\underline{\textbf{INDEPENDENT AUDITORS' REPORT}}$

YEARS ENDED DECEMBER 31, 2014 and 2013



FACIOSCAPULOHUMERAL (FSH) SOCIETY REPORT ON FINANCIAL STATEMENTS YEARS ENDED DECEMBER 31, 2014 AND 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.

REPORT ON FINANCIAL STATEMENTS

YEARS ENDED DECEMBER 31, 2014 AND 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, 2014, 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, 2014, 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 Page Two

Report on Summarized Comparative Information

We have previously audited Facioscapulohumeral (FSH) Society's 2013 financial statements, and our report dated June 12, 2014, 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, 2013, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Westborough, Massachusetts April 15, 2015

Smith, Sullivan , Brown, PC.

STATEMENTS OF FINANCIAL POSITION AS OF DECEMBER 31, 2014 AND 2013

<u>ASSETS</u>		
	<u>2014</u>	<u>2013</u>
<u>CURRENT ASSETS</u> :		
Cash	\$ 2,213,469	\$ 1,810,368
Contributions Receivable	72,857	25,000
Prepaid Expenses	4,807	3,592
Total Current Assets	2,291,133	1,838,960
NET PROPERTY AND EQUIPMENT	8,994	8,973
NON-CURRENT ASSETS:		
Contributions Receivable	43,000	-
Board Designated William R. Lewis Family Fund Investments	634,060	573,134
Edward M. Schechter Fund Investments	89,659	87,915
Total Non-Current Assets	766,719	661,049
TOTAL ASSETS	\$ 3,066,846	\$ 2,508,982
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES:		
Grants Payable	\$ 286,640	\$ 105,866
Accounts Payable and Accrued Expenses	29,148	16,363
Accrued Payroll and Related Costs	7,173	19,178
Total Current Liabilities	322,961	141,407
NET ASSETS: Unrestricted Net Assets:		
Undesignated	1,187,503	782,451
-	634,060	573,134
Board Designated William R. Lewis Family Fund Total Unrestricted Net Assets		
	1,821,563	1,355,585
Temporarily Restricted Net Assets	848,422 73,900	938,090 73,900
Permanently Restricted Net Assets Total Net Assets	2,743,885	2,367,575
Total Net Assets	2,743,003	2,301,313
TOTAL LIABILITIES AND NET ASSETS	\$ 3,066,846	\$ 2,508,982

STATEMENT OF ACTIVITIES

FOR THE YEAR ENDED DECEMBER 31, 2014

(With Summarized Comparative Totals for 2013)

	UNRESTRICTED							
	BOARD		<u>TOTAL</u>	<u>TEMPORARILY</u>	<u>PERMANENTLY</u>	·	<u>CTIVITIES</u>	
	<u>OPERATING</u>	<u>DESIGNATED</u>	UNRESTRICTED	RESTRICTED	<u>RESTRICTED</u>	<u>2014</u>	<u>2013</u>	
SUPPORT, REVENUES								
AND RECLASSIFICATIONS:								
Support and Revenues:								
Gifts, Grants and Contributions	\$ 730,860	\$ 31,000	\$ 761,860	\$ 520,215	\$ -	\$ 1,282,075	\$ 1,007,353	
Special Events, Net of Direct Costs	171,201	-	171,201	426,521	-	597,722	617,876	
Donated Goods and Services	253,791		253,791			253,791	215,474	
Total Support and Revenues	1,155,852	31,000	1,186,852	946,736		2,133,588	1,840,703	
Investment and Other Income:								
Investment Return, Net	243	33,918	34,161	5,995	<u></u>	40,156	102,054	
Reclassification of Net Assets:								
Net Assets Released From Restriction	1,069,589	(27,190)	1,042,399	(1,042,399)	-	-	-	
Board Designated Funds	(23,198)	23,198						
Total Reclassification of Net Assets	1,046,391	(3,992)	1,042,399	(1,042,399)		_		
TOTAL SUPPORT, REVENUES								
AND RECLASSIFICATIONS	2,202,486	60,926	2,263,412	(89,668)	<u> </u>	2,173,744	1,942,757	
FUNCTIONAL EXPENSES:								
Program Services:								
Research	1,069,144	-	1,069,144	-	-	1,069,144	815,716	
Direct Service	264,698	-	264,698	-	-	264,698	302,156	
Education	272,712		272,712			272,712	142,143	
Total Program Services	1,606,554		1,606,554		<u></u>	1,606,554	1,260,015	
Supporting Services:								
Administrative	117,601	-	117,601	-	-	117,601	165,127	
Fund Raising	73,279		73,279		<u></u>	73,279	80,077	
Total Supporting Services	190,880		190,880		<u> </u>	190,880	245,204	
TOTAL FUNCTIONAL EXPENSES	1,797,434	<u> </u>	1,797,434			1,797,434	1,505,219	
CHANGE IN NET ASSETS	405,052	60,926	465,978	(89,668)	-	376,310	437,538	
NET ASSETS - BEGINNING OF YEAR	782,451	573,134	1,355,585	938,090	73,900	2,367,575	1,930,037	
NET ASSETS - END OF YEAR	<u>\$ 1,187,503</u>	\$ 634,060	<u>\$ 1,821,563</u>	\$ 848,422	<u>\$ 73,900</u>	\$ 2,743,885	\$ 2,367,575	

STATEMENT OF FUNCTIONAL EXPENSES

FOR THE YEAR ENDED DECEMBER 31, 2014

(With Summarized Comparative Totals for 2013)

	<u>RESEARCH</u>	<u>DIRECT</u> <u>SERVICE</u>	EDUCATION	TOTAL PROGRAM SERVICES	ADMINI- STRATIVE	<u>FUND</u> <u>RAISING</u>		TAL L EXPENSES 2013
Scientific Advisory Board Grants	\$ 819,261	\$ -	\$ -	\$ 819,261	\$ -	\$ -	\$ 819,261	\$ 661,585
Salaries and Wages	51,788	111,396	93,704	256,888	25,475	21,867	304,230	330,880
Payroll Taxes	3,900	8,388	7,056	19,344	1,918	1,647	22,909	22,351
Employee Benefits	4,670	10,047	8,451	23,168	2,298	1,972	27,438	27,571
Patient Meetings and Conferences	43,845	514	133,991	178,350	-	-	178,350	30,678
Donated Services	105,166	58,402	9,441	173,009	44,448	16,334	233,791	195,474
Scientific Advisory Board Expenses	27,259	-	-	27,259	-	-	27,259	37,849
Directors Expenses	-	7,049	-	7,049	-	-	7,049	3,801
Consultants and Professional Fees	-	-	-	-	8,609	-	8,609	14,081
Fundraising Expenses	-	-	-	-	-	15,217	15,217	21,495
Accounting, Auditing								
and Financial Consultants	-	-	-	-	18,353	-	18,353	45,089
Rent	3,238	6,964	5,858	16,060	1,593	1,367	19,020	20,073
Travel, Lodging and Meals	2,162	453	- -	2,615	-	· -	2,615	7,557
Office Supplies and Expenses	4,018	8,642	7,269	19,929	1,975	1,696	23,600	15,433
Telephone and Communications	309	664	558	1,531	152	130	1,813	2,052
Website and Computer Related Expenses	3,007	6,469	5,441	14,917	1,479	1,270	17,666	5,993
Insurance	75	161	136	372	2,097	39	2,508	2,217
Printing	-	27,006	-	27,006	-	4,469	31,475	34,840
Depreciation Expense	-	-	-	-	5,507	-	5,507	5,569
Postage	446	960	807	2,213	219	188	2,620	2,482
Bank Service Charges and								
Credit Card Processing Fees		17,583		17,583	3,478	7,083	28,144	18,149
Total Functional Expenses	\$ 1,069,144	\$ 264,698	\$ 272,712	\$ 1,606,554	\$ 117,601	\$ 73,279	\$ 1,797,434	\$ 1,505,219

STATEMENTS OF CASH FLOWS FOR THE YEARS ENDED DECEMBER 31, 2014 AND 2013

	<u>2014</u>	<u>2013</u>
<u>CASH FLOWS FROM OPERATING ACTIVITIES</u> :		
Change in Net Assets	\$ 376,310	\$ 437,538
Adjustments to Reconcile the Above to Net Cash		
Provided by Operating Activities:		
Depreciation Expense	5,507	5,569
Investment Return, Net	(40,156)	(102,054)
(Increase) Decrease in Current Assets:		
Contributions Receivable	(47,857)	31,000
Prepaid Expenses	(1,215)	638
Increase (Decrease) in Current Liabilities:		
Grants Payable	180,774	105,866
Accounts Payable and Accrued Expenses	12,785	12,998
Accrued Payroll and Related Costs	(12,005)	5,335
(Increase) Decrease in Non-Current Assets:		
Contributions Receivable	(43,000)	-
Net Adjustment	54,833	59,352
NET CASH PROVIDED BY OPERATING ACTIVITIES	431,143	496,890
CASH FLOWS FROM INVESTING ACTIVITIES:		
Purchase of Equipment	(3,323)	(2,700)
Proceeds from Securities Sold	-	75,150
Acquisition of Securities	(24,719)	(111,419)
Net Cash Flows From Investing Actitivies	(28,042)	(38,969)
NET INCREASE IN CASH BALANCES	403,101	457,921
CASH BALANCES - BEGINNING OF YEAR	1,810,368	1,352,447
CASH BALANCES - END OF YEAR	\$ 2,213,469	\$ 1,810,368

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

NOTE 1 ORGANIZATION

Facioscapulohumeral (FSH) Society ("FSH Society", the "Society" or the "Organization") was incorporated in 1991, under the provisions of the District of Columbia Nonprofit Corporation Act and qualifies as a tax-exempt not-for-profit corporation under Section 501(c)(3) of the Internal Revenue Code. FSH Society is not classified as a private foundation under Section 509(a); accordingly, contributions made to this Organization qualify for the maximum charitable deduction for Federal income tax purposes.

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

NOTE 2 PROGRAM SERVICES

The FSH Society is a world leader in combating facioscapulohumeral muscular dystrophy 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 the most common adult muscular dystrophy with a prevalence of 1:8,333 (it is the third most common muscle disease by incidence). 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 may cause 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. For approximately 860,000 men, women, and children worldwide the major consequence of inheriting this genetic form of muscular dystrophy may be a lifelong progressive loss of all skeletal muscles. FSHD can be a crippling and life shortening disease. 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% of FSHD-affected individuals over age fifty will require the use of a wheelchair. FSHD also has very specific non-muscular manifestations; hearing-loss, vision issues, retinal vasculopathy, respiratory insufficiency and sleep disordered breathing, supraventricular arrhythmias (rare), and cardiac right branch bundle block, 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 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. The severity of FSHD is variable and can range from nonmanifesting/asymptomatic, to mild in presentation in some individuals, to severely crippling and life shortening in individuals with the genetic diagnosis of FSHD.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

(Continued)

NOTE 2 (Continued)

Research

As of March 2015, the FSH Society has provided approximately 5.4 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. The FSH Society offers basic research grants, clinical research, research, pre-doctoral, and post-doctoral 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 fellowships to nearly one hundred junior and senior level researchers, leading to hundreds of 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 was again achieved in 2014 in our understanding of the disease largely due to Society funding of research. The Society made a request for proposals using genomic-engineering techniques and funded two projects using CRISPR/Cas9 and TALEN with the aim of treating the disease. A significant advance in 2014 was that the Society along with two other international FSHD-funding agencies co-funded a "Clinical Trials Readiness" workshop to be held in May 2015, a harbinger that the clinical community is becoming more serious about assets for and conducting clinical trials. 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.

Meetings, symposiums and workshops

The FSH Society organizes meetings, symposiums and workshops. The Society's annual FSHD International Research Consortium symposium for researchers worldwide yields immeasurable gains in our understanding of FSHD. The 2014 FSH Society FSHD International Research Consortium was held in San Diego, California as an ancillary meeting to the American Society of Human Genetics and was attended by 85 scientists, clinicians, and researchers working on FSHD 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. Continued and significant progress was made at the 2014 research consortium and research planning meeting – priorities were set and planning documents again disseminated. 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, more than 7,500 FSHD-affected families committed to working cooperatively. In August 2014, the biennial FSH Society International Patient Researcher Network Day was held in Boston, Massachusetts. More than 200 FSHD patients, families, friends, scientists and researchers gathered at the newly renamed "FSHD Connect" meeting 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 FSHD Connect meeting was improved with significant investment over the previous 2012 meeting and the faculty and talks were greatly expanded. Several noteworthy points were a video keynote by U.S. Senator Elizabeth Warren, a professional film documentary crew doing a documentary, a professional photographer photographing studio quality photos of FSHD, live videobroadcast of the meeting to the patients who could not attend, and the opportunity to be evaluated and give bio-samples to research studies onsite at the meeting.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

(Continued)

NOTE 2 (Continued)

The meeting and FSHD received strong media exposure. The FSH Society also works with the community to foster research planning meetings, research education meetings and patient support groups. In 2014, the FSH Society continued efforts to organize through its "FSHD Champions" work to bring together FSHD-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. A noted advancement over the prior year's meeting was Champions agreeing that the annual research workshop should be considered the focal point for organizing the research meeting. Meetings, symposia, workshops and networking activities are one of the most successful programmatic components of the FSH Society.

Education, Advocacy and Community Action

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 2014, the Society added additional resources to help grow in-person support groups 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 continued to develop materials and assets depicting what FSHD is and what it is to live with the disease in writing, photographs and videos. The Society continued to raise visibility for FSHD through public service announcements on the disease and increased exposure to PSAs were broadcast on 18 stations for a total of 1,821 broadcasts with over 555,000 audience impressions. Through the FSH Society staff and its web site portal at www.fshsociety.org, electronic Yahoo! bulletin board (31,055 messages, 1,052 members), FaceBook pages (2,009 Facebook followers), Twitter, e-mail ListServ (vertical response), and newsletter the "FSH Watch," FSHD patients have found ways to be useful to basic and clinical researchers working on their disease. In 2015, the FSH Society added two full-time staff members, an increase from three, to help with responses to inquiries and requests that we receive. In 2014, the Society completed its new web site with new architecture; migration and updating of content; creation of new forms; testing of e-commerce. The new site was launched on January 10, 2015. The Society continues to receive P.R. and social media marketing/services and expertise donated by the firm SHIFT.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

(Continued)

NOTE 2 (Continued)

In 2014, the Society worked with pharmaceutical companies commencing clinical trials in Europe and potentially the U.S. in 2015, and met with venture capital companies to provide background and education on the disease. In 2014, and continuing in 2015, 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. The FSH Society 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 three times per year, 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 issues associated with FSHD for patients, families, friends and professionals involved with FSHD. In 2014, the FSH Society began to distribute its publication titled "A Guide for Friends and Family" to help friends and family affected with FSHD better navigate the issues of FSHD. Publications, literature, education, patient support, 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 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.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

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

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

(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, 2014, the Organization's non-current contributions were due within three 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, 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.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

(Continued)

NOTE 3 (Continued)

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

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

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

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

(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, 2014 and 2013, *Grants Payable* are expected to be paid in the following year. Conditional commitments are not recognized in the financial statements until the conditions upon which they depend are substantially met.

Donated Goods and Services:

As required by the FASB Accounting Standards CodificationTM, the Organization maintains a policy whereby the value of the donated goods and services which create or enhance nonfinancial assets; require a specialized skill; and/or which would have otherwise been purchased by the Organization are recognized as revenue and expense on the Statement of Activities and are listed as expenses on the Statement of Functional Expenses.

The Society pays for most services requiring specific expertise. However, many individuals volunteer their time and perform a variety of tasks that assist the Society with its meetings and events, peer review of grant applications, research programs, committee assignments and publications. Substantially all of these tasks are performed through donated services.

Functional Expenses:

The Organization allocates its expenses on a functional basis among various programs and support services. Expenses that can be identified with a specific program and support service are allocated directly according to their natural expense classification. Other expenses that are common to several functions are allocated using formulas derived from the nature of related time. Supporting services are those related to operating and managing the Organization and their programs on a day-to-day basis. Supporting services have been sub-classified as follows:

Administrative - includes all activities related to FSH Society's internal management and accounting for program services.

Fund Raising - includes all activities related to maintaining contributor information, writing grant proposals, direct mail solicitation, distribution of materials and other similar projects related to the procurement of funds. Fund raising expenses reported on the Statement of Functional Expenses also include indirect costs of special fund raising events, while direct costs are netted against event proceeds. For the years ended December 31, 2014 and 2013, total fund raising expenses (including both direct and indirect event expenses) were \$237,205 and \$204,006.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

(Continued)

NOTE 3 (Continued)

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 2011, 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, 2014 and 2013:

	Est.		Accumulated	Net Bo	ok Value
Asset Category	<u>Life</u>	Cost	<u>Depreciation</u>	<u>2014</u>	<u>2013</u>
Computer, Technology					
and Office Equipment	3 - 5	\$60,695	<u>\$51,701</u>	<u>\$8,994</u>	\$8,973

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. There were no disposals of equipment in 2014.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

(Continued)

NOTE 5 INVESTMENTS

As of December 31, 2014 and 2013, investment costs and unrealized gains and losses consisted of the following components:

			December	31, 2014		
				Fair	Fair	Total
<u>Investment Type</u>	Cost	Unrealized	Unrealized	Value	Value	Fair
	Basis	Gains	Losses	Level 1	Level 2	Value
Cash and Sweep Accounts	\$ 39,050	\$ -	\$ -	\$ 39,050	\$ -	\$ 39,050
Mutual Funds	434,702	108,498	(5,127)	538,073	-	538,073
Preferred Stocks and Bonds	147,395	1,335	(2,134)		146,596	146,596
Total	<u>\$621,147</u>	<u>\$109,833</u>	<u>\$(7,261</u>)	\$577,123	<u>\$146,596</u>	<u>\$723,719</u>
			December	31, 2013		
				Fair	Fair	Total
Investment Type	Cost	Unrealized	Unrealized	Fair Value	Fair Value	Total Fair
Investment Type	Cost Basis	Unrealized Gains	Unrealized Losses			
Investment Type				Value	Value	Fair
Investment Type Cash and Sweep Accounts				Value	Value	Fair
	Basis	Gains	Losses	Value Level 1	Value Level 2	Fair Value
Cash and Sweep Accounts	Basis \$ 63,173	Gains \$ -	Losses	Value Level 1 \$ 63,173	Value Level 2	Fair Value \$ 63,173

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

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

Preferred Stocks and Bonds: Determined by independent unadjusted market-based prices received from a third-party pricing service that utilizes pricing models that considers standard input factors such as observable market data, benchmark yields, interest rate volatilities, broker/dealer quotes, credit spreads, and new issue data.

Components of *Investment Return* for the years ended December 31, 2014 and 2013, is as follows:

Components of Investment Return	<u>2014</u>	<u>2013</u>
Interest and Dividends	\$46,663	\$ 29,090
Unrealized Gains (Losses)	(6,507)	74,536
Realized Losses	<u> </u>	(1,572)
Net Investment Return	<u>\$40,156</u>	<u>\$102,054</u>

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

(Continued)

NOTE 6 DESIGNATIONS AND RESTRICTIONS OF NET ASSETS

Board Designated Net Assets:

For the years presented, unrestricted net assets includes funds designated by the Board of Directors for the William R. Lewis Family Fund. The following schedule summarizes the changes in Board Designated Net Assets for the years ended December 31, 2014 and 2013:

William R. Lewis Family Fund

	<u>Amount</u>
Net Assets, January 1, 2013	\$471,075
Investment Income	24,149
Investment Gains	67,532
Contributions	32,491
Appropriation for Expenditure	(22,113)
Net Assets, December 31, 2013	573,134
Investment Income	41,686
Investment (Losses)	(7,768)
Contributions	31,000
Board Designated Cash	23,198
Appropriation for Expenditure	<u>(27,190)</u>
Net Assets, December 31, 2014	<u>\$634,060</u>

Temporarily Restricted Net Assets:

As of December 31, 2014 and 2013, temporarily restricted net assets consisted of the following balances:

Nature of Restriction	<u>2014</u>	<u>2013</u>
The Marjorie and Gerald Bronfman Foundation*	\$ 10,113	\$ 45,113
Batkin and Younger Family Fund	65,000	20,000
Endowment Appreciation -		
Edward M. Schechter Fund for FSHD	15,759	14,015
S&L Marx Foundation	11,936	28,311
Lai Fund	5,406	-
Other Donations and Event Proceeds Designated		
for Research and Education	740,208	830,651
Total	<u>\$848,422</u>	<u>\$938,090</u>

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

(Continued)

NOTE 6 (Continued)

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

Nature of Restriction		<u>2014</u>		<u>2013</u>
The Marjorie and Gerald Bronfman Foundation*	\$	35,000	\$	20,000
Batkin and Younger Family Fund		20,000		46,000
FSHD Canada Foundation Fund		62,500		20,000
Lai Fund		-		31,009
Appropriation of Endowment Appreciation -				
Edward M. Schechter Fund for FSHD		4,400		3,600
S&L Marx Foundation		16,375		21,689
Other Donations and Event Proceeds Designated				
for Research and Education		904,124	_5	35,248
Total	\$1.	042,399	\$6	77,546

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

Endowment Net Assets:

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

	Temporarily	Permanently	Total Endowment
	Restricted	Restricted	Net Assets
Endowment Net Assets,			
December 31, 2012	\$ 9,141	\$73,900	\$83,041
Investment Income	3,653	-	3,653
Investment Gains	4,671	-	4,671
Contributions	150	-	150
Appropriation for Expenditure	(3,600)		(3,600)
Endowment Net Assets,			
December 31, 2013	14,015	73,900	87,915
Investment Income	5,126	-	5,126
Investment Gains	1,018	-	1,018
Appropriation for Expenditure	<u>(4,400</u>)		<u>(4,400</u>)
Endowment Net Assets,			
December 31, 2014	<u>\$15,759</u>	<u>\$73,900</u>	<u>\$89,659</u>

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

(Continued)

NOTE 7 SPECIAL FUND RAISING EVENTS

The results of fund raising events to support operations for the years ended December 31, 2014 and 2013 are summarized below:

	<u>Gross</u>	Direct	Net Event Revenues	
<u>Event</u>	<u>Proceeds</u>	<u>Costs</u>	<u>2014</u>	<u>2013</u>
FSH At The Lake	\$152,363	\$20,101*	\$132,262	\$169,860
Friends Supporting Hope	50,674	11,735	38,939	37,928
Total	<u>\$203,037</u>	<u>\$31,836</u>	<u>\$171,201</u>	<u>\$207,788</u>

^{*}For the years presented, direct costs include \$20,000 of donated goods and services.

The results of fund raising events to support specific program activities for the years ended December 31, 2014 and 2013, are summarized below:

	<u>Gross</u>	Direct	Net Event Revenues	
<u>Event</u>	Proceeds	Costs	<u>2014</u>	<u>2013</u>
Festival of Song	\$267,794	\$ 44,811	\$222,983	\$274,498
Golf Tournament	119,050	40,058	78,992	88,471
Celebrity Walkathon	25,207	11,728	13,479	23,492
Songs in the Key of Steven Blier	107,735	29,797	77,938	-
Cosie Laurello Memorial Walk	24,135	1,940	22,195	-
Cape Cod Walk n Roll	-	-	-	14,648
Other Fund Raising Events	14,690	3,756	10,934	8,979
Total	<u>\$558,611</u>	<u>\$132,090</u>	<u>\$426,521</u>	<u>\$410,088</u>

NOTE 8 DONATED GOODS AND SERVICES

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

<u>Description</u>	<u>2014</u>	<u>2013</u>
Scientific Advisory Board Expense	\$107,070	\$ 24,775
Accounting and Auditing	18,100	17,800
Legal	18,160	18,880
Publications and Memberships	31,472	37,247
Executive and Development, Program Services	22,200	53,024
Executive and Development, Administrative	25,495	27,574
Executive and Development, Fundraising	11,294	16,174
Food and Beverage for Special Fundraising Event*	20,000	20,000
Total	\$253,791	\$215,474

^{*} For the years presented, this amount includes \$20,000 in donations reported as direct costs of fund raising events (See Note 7).

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

(Continued)

NOTE 9 FSHD CANADA AGREEMENT

On November 8, 2012, an Agency Agreement was signed between the FSH Society and the FSHD Canada Foundation. FSHD Canada Foundation is registered under the Income Tax Act (Canada) as a "charitable organization." The FSH Society intends to assist the FSHD Canada Foundation in carrying out its charitable purposes and to perform certain activities on behalf of the FSHD Canada Foundation as follows: (1) funding specific FSHD-related scientific and clinical research and development activities in the United States of America as may be specified by the FSHD Canada Foundation from time to time; and (2) performing all other activities in the United States consistent with the furtherance of the FSHD Canada Foundation's charitable object of promoting scientific and clinical research and development of the causes, alleviation of suffering, treatment and cure of facioscapulohumeral muscular dystrophy.

NOTE 10 LEASING ARRANGEMENTS

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 converted 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.

NOTE 11 RELATED PARTY TRANSACTIONS

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

During the year ended December 31, 2013, 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 12 COMMITMENTS AND CONTINGENCIES

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

NOTE 13 RETIREMENT PLAN

FSH Society maintains a SIMPLE IRA retirement plan. The plan allows eligible employees of the Organization to defer a percentage of their earnings from current taxation. For the years presented, employee contributions to the IRA are subject to a 3% employer match. For the years ended December 31, 2014 and 2013, the total employer contributions were \$8,902 and \$8,689, respectively, and are included in *Employee Benefits* in the accompanying Statement of Functional Expenses.

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2014

(Continued)

NOTE 14 CONCENTRATIONS

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

Cash:

The Organization is subject to concentrations in credit risk relating to cash balances. For the years presented, the majority of the Organization's cash deposits were held in three financial institutions. Cash deposits are insured by the Federal Deposit Insurance Corporation up to \$250,000 per institution. As of December 31, 2014 and 2013, cash balances in excess of the FDIC limit were \$1,524,301 and \$1,140,006. The Organization has not experienced any losses on uninsured cash balances.

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, 2014, 60% of *Contributions Receivable* represented the amounts owed from two donors.

As of December 31, 2013, Contributions Receivable represented the amount owed from one Foundation.

NOTE 15 SUBSEQUENT EVENTS

Management is required to consider events subsequent to the financial statement date for potential adjustment to or disclosure in the financial statements. Therefore, Management has evaluated subsequent events through April 15, 2015, the date which the financial statements were available for issue, and noted no events which met the criteria.