

FSHD SOCIETY
FINANCIAL STATEMENTS
with
INDEPENDENT AUDITORS' REPORT
YEAR ENDED DECEMBER 31, 2022
(With Summarized Comparative Information for 2021)

Smith  Sullivan
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CERTIFIED PUBLIC ACCOUNTANTS

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FSHD SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2022
(With Summarized Comparative Information for 2021)



Our Vision

To deliver treatments and a cure for FSH muscular dystrophy.

Mission

*Be the premier catalyst for connecting all the stakeholders.
Promote research focused on FSHD through thought
leadership, networking, and funding.*

Strategic Imperatives

- 1. To accelerate research and to advance treatments and a cure.*
- 2. To enlarge, to engage, and to empower an active community.*
- 3. To raise and to leverage resources.*
- 4. To ensure organizational capacity to achieve the mission.*

FSHD SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

C O N T E N T S

	<i>Pages</i>
Independent Auditors' Report.....	1 - 2
Statements of Financial Position as of December 31, 2022 and 2021.....	3
Statement of Activities for the Year Ended December 31, 2022..... <i>(With Summarized Comparative Totals for 2021)</i>	4
Statement of Functional Expenses for the Year Ended December 31, 2022..... <i>(With Summarized Comparative Totals for 2021)</i>	5
Statements of Cash Flows for the Years Ended December 31, 2022 and 2021.....	6
Notes to Financial Statements.....	7 - 20

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INDEPENDENT AUDITORS' REPORT

To the Board of Directors
FSHD Society
Randolph, Massachusetts

Opinion

We have audited the accompanying financial statements of FSHD Society (a District of Columbia nonprofit corporation), which comprise the statement of financial position as of December 31, 2022, and the related statements of activities, functional expenses and cash flows for the year then ended, and the related notes to the financial statements.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of FSHD Society as of December 31, 2022, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

Basis for Opinion

We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Our responsibilities under those standards are further described in the Auditors' Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of FSHD Society and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audit. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Responsibilities of Management for the Financial Statements

Management is responsible for the preparation and fair presentation of the financial statements in accordance with accounting principles generally accepted in the United States of America, and for 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.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about FSHD Society's ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

Auditors' Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditors' report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with generally accepted auditing standards will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements, including omissions, are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

To the Board of Directors
FSHD Society
Page Two

In performing an audit in accordance with generally accepted auditing standards, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit 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 FSHD Society's internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about FSHD Society's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control related matters that we identified during the audit.

Report on Summarized Comparative Information

We have previously audited FSHD Society's December 31, 2021 financial statements, and we expressed an unmodified audit opinion on those audited financial statements in our report dated March 15, 2022. In our opinion, the summarized comparative information presented herein as of and for the year ended December 31, 2021, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Smith, Sullivan & Brown, PC

Westborough, Massachusetts
March 14, 2023

FSHD SOCIETY

STATEMENTS OF FINANCIAL POSITION
AS OF DECEMBER 31, 2022 AND 2021

<u>ASSETS</u>	<u>2022</u>	<u>2021</u>
<u>CURRENT ASSETS:</u>		
Cash and Cash Equivalents	\$ 3,650,917	\$ 4,820,728
Employee Retention Tax Credit Receivable	162,636	227,839
Contributions Receivable	-	65,847
Prepaid Expenses	58,985	123,679
Total Current Assets	<u>3,872,538</u>	<u>5,238,093</u>
<u>NON-CURRENT ASSETS:</u>		
Deposits	-	4,477
Deferred Digital Assets	250,000	-
Investments	1,956,777	2,396,249
Total Non-Current Assets	<u>2,206,777</u>	<u>2,400,726</u>
<u>TOTAL ASSETS</u>	<u>\$ 6,079,315</u>	<u>\$ 7,638,819</u>
<u>LIABILITIES AND NET ASSETS</u>		
<u>CURRENT LIABILITIES:</u>		
Grants Payable	\$ 966,677	\$ 669,087
Accounts Payable and Accrued Expenses	72,281	51,730
Total Current Liabilities	<u>1,038,958</u>	<u>720,817</u>
<u>LONG-TERM LIABILITIES:</u>		
Long-Term Deferred Compensation Liability	72,009	67,801
Long-Term Grants Payable	289,731	497,791
Total Long-Term Liabilities	<u>361,740</u>	<u>565,592</u>
<u>TOTAL LIABILITIES</u>	<u>1,400,698</u>	<u>1,286,409</u>
<u>NET ASSETS:</u>		
Net Assets Without Donor Restrictions	2,724,386	3,975,882
Net Assets With Donor Restrictions	1,954,231	2,376,528
Total Net Assets	<u>4,678,617</u>	<u>6,352,410</u>
<u>TOTAL LIABILITIES AND NET ASSETS</u>	<u>\$ 6,079,315</u>	<u>\$ 7,638,819</u>

FSHD SOCIETY

STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED DECEMBER 31, 2022
(With Summarized Comparative Totals for 2021)

	<u>WITHOUT</u> <u>DONOR</u> <u>RESTRICTIONS</u>	<u>WITH</u> <u>DONOR</u> <u>RESTRICTIONS</u>	<u>TOTAL ACTIVITIES</u>	
			<u>2022</u>	<u>2021</u>
<u>SUPPORT, REVENUES AND RECLASSIFICATIONS</u>				
<i>Support and Revenues:</i>				
Gifts, Grants and Contributions	\$ 1,273,653	\$ 917,709	\$ 2,191,362	\$ 4,041,660
Gross Special Events Revenue	837,995	-	837,995	898,796
Less: Cost of Direct Benefits to Donors	(98,581)	-	(98,581)	(80,497)
Donated Goods and Services	382,791	-	382,791	225,200
Program Revenue	<u>304,466</u>	<u>-</u>	<u>304,466</u>	<u>172,014</u>
Total Support and Revenues	<u>2,700,324</u>	<u>917,709</u>	<u>3,618,033</u>	<u>5,257,173</u>
<i>Investment and Other Income:</i>				
Return of Grant Funds	139,274	-	139,274	34,640
Investment Return, Net	(541)	(334,924)	(335,465)	369,528
Other Income (Loss)	<u>500</u>	<u>-</u>	<u>500</u>	<u>424</u>
Total Investment and Other Income	<u>139,233</u>	<u>(334,924)</u>	<u>(195,691)</u>	<u>404,592</u>
<i>Reclassification of Net Assets:</i>				
Net Assets Released From Restriction	<u>1,005,082</u>	<u>(1,005,082)</u>	<u>-</u>	<u>-</u>
<u>TOTAL SUPPORT, REVENUES AND RECLASSIFICATIONS</u>	<u>3,844,639</u>	<u>(422,297)</u>	<u>3,422,342</u>	<u>5,661,765</u>
<u>EXPENSES:</u>				
<i>Program Services:</i>				
Research and Patient Programs	4,307,236	-	4,307,236	4,074,263
<i>Supporting Services:</i>				
Administrative	359,821	-	359,821	332,434
Fund Raising	<u>429,078</u>	<u>-</u>	<u>429,078</u>	<u>436,330</u>
Total Supporting Services	<u>788,899</u>	<u>-</u>	<u>788,899</u>	<u>768,764</u>
<u>TOTAL EXPENSES</u>	<u>5,096,135</u>	<u>-</u>	<u>5,096,135</u>	<u>4,843,027</u>
<u>CHANGE IN NET ASSETS</u>	<u>(1,251,496)</u>	<u>(422,297)</u>	<u>(1,673,793)</u>	<u>818,738</u>
<u>NET ASSETS - BEGINNING OF YEAR</u>	<u>3,975,882</u>	<u>2,376,528</u>	<u>6,352,410</u>	<u>5,533,672</u>
<u>NET ASSETS - END OF YEAR</u>	<u>\$ 2,724,386</u>	<u>\$ 1,954,231</u>	<u>\$ 4,678,617</u>	<u>\$ 6,352,410</u>

FSHD SOCIETY

STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2022
(With Summarized Comparative Totals for 2021)

	<u>RESEARCH</u> <u>AND</u> <u>PATIENT</u> <u>PROGRAMS</u>	<u>ADMINI-</u> <u>STRATIVE</u>	<u>FUND</u> <u>RAISING</u>	<u>TOTAL</u> <u>FUNCTIONAL EXPENSES</u>	
				<u>2022</u>	<u>2021</u>
Salaries and Related Expenses	\$ 1,501,187	262,407	253,058	\$ 2,016,652	\$ 1,637,073
Scientific Grants and Projects	1,408,042	-	-	1,408,042	2,347,464
Travel, Lodging and Meals	193,236	10,350	33,649	237,235	71,432
Consultants and Professional Fees	207,731	7,944	1,400	217,075	60,298
Patient Meetings and Research Conferences	303,776	-	-	303,776	70,593
Website and Computer Related Expenses	162,798	17,962	13,488	194,248	129,347
Donated Services	378,591	4,200	-	382,791	225,200
Printing	46,422	-	45,535	91,957	65,978
Donor Software and Donor Engagement	-	-	60,699	60,699	51,285
Special Event Costs	-	-	59,865	59,865	48,748
Bad Debt Expense	-	385	-	385	2,504
Bank Service Charges and Credit Card Processing Fees	30,828	9,439	50,627	90,894	74,900
Office Expenses	26,804	4,010	5,516	36,330	49,201
Occupancy	7,582	1,733	1,516	10,831	46,814
Chapter and Volunteer Development	24,937	-	-	24,937	4,957
Directors Expenses	-	16,479	641	17,120	5,250
Accounting, Auditing and Financial Consultants	-	16,000	-	16,000	15,500
Insurance	-	8,912	416	9,328	8,314
Depreciation Expense	-	-	-	-	5,097
Public Awareness	15,302	-	1,249	16,551	3,569
	<u>4,307,236</u>	<u>359,821</u>	<u>527,659</u>	<u>5,194,716</u>	<u>4,923,524</u>
Total Functional Expenses					
Less: Cost of Direct Benefits to Donors	<u>-</u>	<u>-</u>	<u>(98,581)</u>	<u>(98,581)</u>	<u>(80,497)</u>
Total Expenses per Statement of Activities	<u>\$ 4,307,236</u>	<u>\$ 359,821</u>	<u>\$ 429,078</u>	<u>\$ 5,096,135</u>	<u>\$ 4,843,027</u>

FSHD SOCIETY

STATEMENTS OF CASH FLOWS
FOR THE YEARS ENDED DECEMBER 31, 2022 AND 2021

	<u>2022</u>	<u>2021</u>
<u>CASH FLOWS FROM OPERATING ACTIVITIES:</u>		
Change in Net Assets	\$ (1,673,793)	\$ 818,738
<i>Adjustments to Reconcile Changes in Net Assets to Net Cash Provided (Used) by Operating Activities:</i>		
Depreciation Expense	-	5,097
Contributions of Mutual Funds to Lewis Family Donor Advised Fund for FSHD	-	(1,008,635)
Investment Return, Net	334,680	(363,022)
Deferrals to Deferred Compensation Plan	(4,208)	(25,923)
<i>Changes in Operating Assets and Liabilities:</i>		
Employee Retention Tax Credit Receivable	65,203	(227,839)
Contributions Receivable - Current and Long-Term	65,847	324,334
Prepaid Expenses	64,694	(62,428)
Grants Payable - Current and Long-Term	89,530	949,949
Accounts Payable and Accrued Expenses	20,551	8,714
Net Adjustment	<u>636,297</u>	<u>(399,753)</u>
<u>NET CASH PROVIDED (USED) BY OPERATING ACTIVITIES</u>	<u>(1,037,496)</u>	<u>418,985</u>
<u>CASH FLOWS FROM INVESTING ACTIVITIES:</u>		
Proceeds from Sale of Donor Advised Fund Investments	109,000	1,095,100
Purchase of Digital Assets	(250,000)	-
Refund of Deposits	4,477	-
Net Cash Flows From Investing Activities	<u>(136,523)</u>	<u>1,095,100</u>
<u>CASH FLOWS FROM FINANCING ACTIVITIES:</u>		
Increase in Long-Term Deferred Compensation Liability	4,208	25,923
Net Cash Flows From Financing Activities	<u>4,208</u>	<u>25,923</u>
<u>NET INCREASE (DECREASE) IN CASH BALANCES</u>	<u>(1,169,811)</u>	<u>1,540,008</u>
<u>CASH AND CASH EQUIVALENTS - BEGINNING OF YEAR</u>	<u>4,820,728</u>	<u>3,280,720</u>
<u>CASH AND CASH EQUIVALENTS - END OF YEAR</u>	<u>\$ 3,650,917</u>	<u>\$ 4,820,728</u>
 <i>Non-Cash Investing and Financing Activities :</i>		
Contributions of Mutual Funds to Lewis Family Donor Advised Fund for FSHD	\$ -	\$ 1,008,635

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

NOTE 1 OPERATIONS AND NONPROFIT STATUS

Operations:

The FSHD Society (the “Society” or the “Organization”) is a world leader in combating facioscapulohumeral muscular dystrophy (FSH muscular dystrophy or FSHD). The Society is the premier catalyst for connecting all stakeholders of FSHD. The Society promotes research focused on FSHD through thought leadership, networking, and funding. Patients and families are aided through patient advocacy and education.

Nonprofit Status:

The Organization was originally incorporated as the Facioscapulohumeral (FSH) Society 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. Effective October 2, 2019, the Society legally changed its name to FSHD Society. The FSHD Society is not classified as a private foundation under Section 509(a); accordingly, contributions made to this Organization qualify for the maximum charitable deduction for Federal income tax purposes.

NOTE 2 SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Basis of Accounting:

The financial statements of the FSHD Society have been prepared on the accrual basis of accounting and accordingly, reflect all significant receivables, payables and other liabilities.

Estimates:

The preparation of financial statements in conformity with generally accepted accounting principles (“GAAP”) 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, as in management’s opinion, resulted in reliable and consistent financial reporting by the Organization.

Cash and Cash Equivalents:

Cash and Cash Equivalents consist of cash and highly liquid financial instruments with original maturities of three months or less, which are neither held for nor restricted by donors for long-term purposes.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

(Continued)

NOTE 2 *(Continued)*

Fair Value of Financial Instruments:

The Organization reports its fair value measures by using a three-level hierarchy that prioritizes the inputs used to measure fair value. This hierarchy, established by generally accepted accounting principles, requires that entities maximize the use of observable inputs and minimize the use of unobservable inputs when measuring fair value.

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

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

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

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

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

Financial Statement Presentation:

The Organization reports information regarding its financial position and activities according to two classes of net assets: net assets without donor restrictions and net assets with donor restrictions. These classifications are related to the existence or absence of donor-imposed restrictions as defined below.

Net Assets Without Donor Restrictions - Net assets without donor restrictions are resources available to support operations and not subject to donor restrictions. In addition, net assets within this classification include funds which represent resources designated by the Board of Directors for specific purposes.

Net Assets With Donor Restrictions - Some restrictions are temporary in nature, such as those that are restricted by a donor for use for a particular purpose or in a particular future period. Other restrictions may be perpetual in nature, such as those that are restricted by a donor that the resources be maintained in perpetuity. As of December 31, 2022, the Organization has no net assets that are required to be maintained in perpetuity. The Organization's unspent contributions are reported in net assets with donor restrictions if the donor limited their use, as are promised contributions that are not yet due. Contributions of property and equipment or cash restricted to acquisition of property and equipment are reported as net assets with donor restrictions if the donor has restricted the use of the property or equipment to a particular program. These restrictions expire when the assets are placed in service.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

(Continued)

NOTE 2 *(Continued)*

The accompanying financial statements include certain 2021 summarized comparative information. With respect to the Statement of Activities, such prior year information is not presented by net class and in the Statement of Functional Expenses, 2021 expenses by line item are in total rather than by functional category which is not a complete financial statement presentation under GAAP. Accordingly, such information should be read in conjunction with the Organization's financial statements for the year ended December 31, 2021, from which the summarized information was derived.

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. Unconditional promises to give that are expected to be collected within one year are reported at net realizable value. Unconditional promises to give due in future years are initially valued at a discounted rate when such amounts are considered material. For each of the years presented, there are no non-current contributions receivable.

Management determines the allowance for uncollectable contributions receivable on historical experience, an assessment of economic conditions, and a review of subsequent collections. *Contributions Receivable* are written off when deemed uncollectable. The following table shows the activity in the allowance for doubtful accounts:

	<u>2022</u>	<u>2021</u>
Balance at Beginning of Period	\$ -	\$50,000
Bad Debt Expense	385	2,504
Write-Off of Uncollectible Accounts	<u>(385)</u>	<u>(52,504)</u>
Balance at End of Period	<u>\$ -</u>	<u>\$ -</u>

Deferred Digital Assets:

In May 2022, the Society entered into an agreement with IQVIA to implement IQVIA's Integrated Health Platform (IHP). IHP is a data-infrastructure optimized to facilitate the acquisition, curation, harmonization, and repurposing of disparate electronic health information for research and analytic uses. In accordance with ASC 350-40, the Society has capitalized all implementation costs incurred in the hosting arrangement to get the hosted service implemented, set-up and ready for use. The Society is still in the implementation phase of the project and anticipates the final build-out will be completed late 2023 at which time the total cost will be amortized over the life of the service agreement. Total *Deferred Digital Assets* as of December 31, 2022 are \$250,000 and are included in accompanying Statement of Financial Position. Preliminary project phase costs of \$70,000 for the year ended December 31, 2022 are included in *Website and Computer Related Expenses* in the accompanying Statement of Functional Expenses. It is also the opinion of management that no reserve for impairment loss is required for the year ended December 31, 2022. See *Note 8* for a discussion of future commitments with IQVIA.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

(Continued)

NOTE 2 *(Continued)*

Investments:

The Organization holds two types of investments: (i) long-term investments made to increase earnings in support of the Society's mission and underlying planned giving agreements; and (ii) programmatic investments made to provide equity capital to directly fund companies to accelerate the development of treatments and a cure for FSH muscular dystrophy.

The Organization maintains an investment portfolio which consists of cash, mutual funds, exchange traded funds (ETFs) and preferred stocks, and bonds. Investment purchases are recorded at cost, or if donated, at fair value on the date of donation. Thereafter, investments are reported at their fair values in the Statement of Financial Position. Net investment return (loss) is reported in the Statement of Activities and consists of interest and dividend income, plus realized and unrealized capital gains and losses, less external and direct internal investment expenses. 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 first in, first out 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. *(See Note 3).*

Programmatic investments are subject to the same accounting standards as similar financial instruments. The Society's programmatic investments are accounted for under the equity or cost method of accounting as further discussed in *Note 3*.

Property and Equipment:

FSHD Society records all property and equipment at cost, if purchased (exceeding \$5,000), or if donated, at fair value on the date of receipt. Expenditures for maintenance, repairs and renewals are charged to expense as incurred, whereas major betterments (exceeding \$5,000) are capitalized as additions to property and equipment. Depreciation of property and equipment is computed using the straight-line method over the estimated useful lives of the assets, as expressed in terms of years. As of December 31, 2022, and 2021, there were no expenditures for *Property and Equipment* that met the capitalization criteria.

Donor Advised Funds:

The Lewis Family Donor Advised Fund for FSHD is restricted by the donor for the purpose of advancing research or therapeutic efforts on behalf of FSHD patients. As a donor advised fund, the FSHD Society has ultimate variance power over the use of funds; however, the agreement allows donors to recommend grant recipients subject to the Society's approval. The Lewis Family Donor Advised Fund for FSHD includes a specification by the donor as to the area of interest they recommend the funds to be spent; therefore, the Society has elected to report these funds as net assets with donor restrictions in the accompanying financial statements.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

(Continued)

NOTE 2 *(Continued)*

Revenue Recognition

The Organization recognizes revenue from numerous sources as follows:

Gifts, Grants and Contributions are recognized when cash, securities or other assets; an unconditional promise to give; or a notification of a beneficial interest is received. Conditional promises to give—that is, those with a measurable performance or other barrier and right of return, are not recognized until the conditions on which they depend have been met. Contributions of assets other than cash are reported at their estimated fair value.

Unconditional, multi-year commitments are recognized in the year during which the initial commitment was made. 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. Consequently, as of December 31, 2022, contributions approximating \$350,000 have not been recognized in the accompanying Statement of Activities because the conditions on which they depend have not been met. The funding is tied to incremental performance milestones which are expected to be met during 2023 and 2024.

Donor-restricted contributions are reported as increases in net assets with donor restrictions, depending on the nature of the restrictions. When a restriction expires, net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the statements of activities as net assets released from restrictions.

Donations of Nonfinancial Assets: Donated services are recognized as contributions if the services (a) create or enhance nonfinancial assets or (b) require specialized skills, are performed by people with those skills, and would otherwise be purchased by the Organization.

Fundraising Event Proceeds is comprised of an exchange element based upon the direct benefits donors receive and a contribution element for the difference. The Society recognizes special events revenue equal to the fair value of direct benefits to donors when the special event takes place. The Society recognizes the contribution element of special event revenue immediately, unless there is a right of return if the special event does not take place.

Program Services: The Society recognizes revenue from patient meeting and conference registrations and other program fees as the meetings and program are held. Sponsorships for these meetings are comprised of an exchange element based on the value of the conference or program benefits provided, and a contribution element for the difference between the total sponsorship paid and the exchange element. The Society recognizes the exchange portion of the sponsorship once the conference or program is held and the contribution portion immediately.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

(Continued)

NOTE 2 *(Continued)*

Grants Expense, Return of Grant Funds, and Grants Payable:

The Society makes grants to eligible applicants after requests for research funding have been reviewed and recommended by the Society's Scientific Advisory Board ("SAB") and the Society's Therapeutic Accelerator and Research Committee ("TARC"). The Society recognizes an expense for *Scientific Grants and Projects* at the time the Board of Directors votes to approve the SAB and TARC recommendations on awards and all significant conditions have been met. *Grants Payable* are classified as current if they are scheduled to be paid within one year, and non-current when they are expected to be paid in more than one year. Conditional commitments are not recognized in the financial statements until measurable performance or other barriers have substantially been met. As of December 31, 2022, *Long-Term Grants Payable* are due in 2024 - 2025.

Functional Expenses:

The Organization allocates its expenses on a functional basis among various programs and support services. Expenses such as *Salaries and Related Expenses, Website and Computer Related Expenses, Office Expenses, and Occupancy*, that are common to several functions are allocated based on salary dollars. Supporting services are those related to operating and managing the Organization and its programs on a day-to-day basis. Supporting services have been sub-classified as follows:

Administrative - includes all activities related to FSHD 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.

Recent Accounting Guidance:

During the year ended December 31, 2022, the Organization adopted ASU 2020-07 *Presentation and Disclosures by Not-for-Profit Entities for Contributed Nonfinancial Assets*. This ASU increases transparency in reporting nonprofit gifts-in-kind in the Organization's financial statements. Although the standard did not change the accounting for contributed nonfinancial assets, the Organization's disclosures have been enhanced to provide qualitative policy information on the techniques and inputs used to determine the valuation of nonfinancial donations. Accordingly, disclosures for the year ended December 31, 2021 were enhanced to be comparative to the 2022 presentation.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

(Continued)

NOTE 3 INVESTMENTS

Investment Components:

As of December 31, 2022 and 2021, Investments on the Statements of Financial Position consist of the following:

<u>Investment Components</u>	<u>2022</u>	<u>2021</u>
Lewis Family Donor Advised Fund for FSHD	\$1,734,768	\$2,178,448
Deferred Compensation Investments	<u>72,009</u>	<u>67,801</u>
Total Fair Value Investments	1,806,777	2,246,249
Programmatic Equity Investments	<u>150,000</u>	<u>150,000</u>
Total Investments	<u>\$1,956,777</u>	<u>\$2,396,249</u>

As of December 31, 2022 and 2021, costs and unrealized gains and losses for the Organization's investments carried at fair value consisted of the following components:

<u>Investment Type</u>	<u>December 31, 2022</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	\$ 56,957	\$ -	\$ -	\$ 56,957	\$ -	\$ 56,957
Mutual Funds	1,624,383	51,750	(106,062)	1,570,071	-	1,570,071
Exchange Traded Funds	106,872	22,710	-	129,582	-	129,582
Preferred Stocks and Bonds	<u>58,055</u>	<u>-</u>	<u>(7,888)</u>	<u>-</u>	<u>50,167</u>	<u>50,167</u>
Total	<u>\$1,846,267</u>	<u>\$74,460</u>	<u>\$(113,950)</u>	<u>\$1,756,610</u>	<u>\$50,167</u>	<u>\$1,806,777</u>

<u>Investment Type</u>	<u>December 31, 2021</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	\$ 4,106	\$ -	\$ -	\$ 4,106	\$ -	\$ 4,106
Mutual Funds	1,564,211	515,546	(131,256)	1,948,501	-	1,948,501
Exchange Traded Funds	106,872	47,306	-	154,178	-	154,178
Preferred Stocks and Bonds	<u>141,992</u>	<u>1,833</u>	<u>(4,361)</u>	<u>-</u>	<u>139,464</u>	<u>139,464</u>
Total	<u>\$1,817,181</u>	<u>\$564,685</u>	<u>\$(135,617)</u>	<u>\$2,106,785</u>	<u>\$139,464</u>	<u>\$2,246,249</u>

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

Mutual Funds and ETFs: Valued at the daily closing prices as reported by the mutual funds and ETFs. The funds held by the Organization are deemed to be actively traded and are valued using Level 1 inputs (See Page 8).

Preferred Stocks and Bonds: Determined by independent unadjusted market-based prices received from a third-party pricing service that utilizes pricing models that consider standard input factors such as observable market data, benchmark yields, interest rate volatilities, broker/dealer quotes, credit spreads, and new issue data. Preferred stocks and bonds are valued using level 2 inputs (See Page 8).

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

(Continued)

NOTE 3 *(Continued)*

Components of *Investment Return* for the years ended December 31, 2022 and 2021, is as follows:

<u>Components of Investment Return</u>	<u>2022</u>	<u>2021</u>
Interest and Dividends	\$ 98,205	\$122,027
Unrealized Gains (Losses)	(469,369)	(51,655)
Realized Gains (Losses)	<u>35,699</u>	<u>299,156</u>
Net Investment Return (Loss)	<u><u>\$ (335,465)</u></u>	<u><u>\$369,528</u></u>

Programmatic Equity Investment:

During 2020, the Organization purchased 13,298 units of InformiR Holdings, LLC (“InformiR”) for a total investment of \$150,000. The primary purpose of the investment is to accelerate research towards a cure for FSH muscular dystrophy. InformiR was incorporated primarily as a temporary vehicle to pool capital from investors to simplify miRecule's application for the Maryland Biotechnology Investment Incentive Tax Credit Program. InformiR used all investment proceeds to purchase Class B Common Stock of miRecule RNA Therapeutics (“miRecule”). MiRecule is an early-stage biotechnology company developing RNA-based therapeutics. MiRecule is applying its platform to a variety of diseases, including cancer and muscular dystrophy. The Society's investment is restricted for research in FSH muscular dystrophy.

Total units issued and outstanding in InformiR as of December 31, 2021 was 31,030; therefore, the Society's ownership was 43% of all units issued and outstanding in InformiR. Accordingly, the organization accounted for this programmatic investment using the equity method in 2021 and through October 2022. It is management's opinion that the profit and loss of InformiR for the year ended December 31, 2021 and the period ended October 2022 was immaterial to the Society. In October of 2022, InformiR received the tax credit from the State of Maryland and subsequently completed a tax-free merger with miRecule. After the merger, the Society owns 18,944 shares of Common B voting shares in miRecule which represents approximately 1.25% ownership in miRecule. Accordingly, the organization accounted for this programmatic investment using the cost method after October 2022. It is also the opinion of management that no reserve for impairment loss is required for the years ended December 31, 2022 and 2021.

NOTE 4 DESIGNATIONS AND RESTRICTIONS OF NET ASSETS

Net Assets With Donor Restrictions:

As of December 31, 2022, and 2021, net assets with donor restrictions were designated for research and education and consisted of the following balances:

<u>Nature of Restriction</u>	<u>2022</u>	<u>2021</u>
Lewis Family Donor Advised Fund for FSHD	\$1,734,768	\$2,178,448
FSHD Therapeutics	<u>219,463</u>	<u>198,080</u>
Total	<u><u>\$1,954,231</u></u>	<u><u>\$2,376,528</u></u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

(Continued)

NOTE 4 (Continued)

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

<u>Nature of Restriction</u>	<u>2022</u>	<u>2021</u>
Lewis Family Donor Advised Fund for FSHD	\$ -	\$1,000,000
FSHD Therapeutics	729,262	471,703
Research and Education	275,820	638,293
Payroll Protection Program	-	285,077
Total	<u>\$1,005,082</u>	<u>\$2,395,073</u>

NOTE 5 DONATED GOODS AND SERVICES

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

<u>Description</u>	<u>2022</u>	<u>2021</u>
Scientific Committees Expenses	\$212,075	\$ 70,300
Science time for FSHD Connect and Patient Education	59,925	40,800
Public Awareness	106,591	109,900
Investment Advisory Services	4,200	4,200
Total	<u>\$382,791</u>	<u>\$225,200</u>

Donated science time for SAB and TARC committees and for FSHD Connect and patient education is provided by volunteers who hold either a PhD or an M.D. Their donated time helps the Society in fulfilling its fiduciary responsibilities to encourage and finance scientific and clinical research and development on facioscapulohumeral muscular dystrophy (FSHD). Their donated services also provide educational services at various conferences such as FSHD Connect, webinars, and 360 conferences. Donated science time is used in program services and is recognized at fair value based on current rates for similar services.

Donated public awareness is provided by *Google Ad Grants* which provides up to \$10,000 worth of ads per month to qualifying nonprofits. Donated public awareness is used in program services and is recognized at fair value based on current rates provided from *Google*.

Donated investment advisory services are provided by investment advisory professionals who advise the Society on investments. Donated investment advisory services are used for administrative activities and are recognized at fair value based on current rates for similar investment advisory services.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

(Continued)

NOTE 6 LINE OF CREDIT

During 2018, the Society entered into a line of credit agreement with a bank for \$250,000. There were no borrowings against the line as of December 31, 2022 and 2021. The line bears interest at the bank's base rate. As of December 31, 2022, and 2021, the bank's base rate was 8.0% and 3.75%, respectively. Under the terms of the line of credit, during each successive twelve-month period of the line of credit, the outstanding principal balance shall be paid in full for a period of thirty consecutive days. The Society is also required to have unencumbered liquidity, as defined, in an amount not less than \$500,000 measured at the end of each fiscal year. On March 10, 2023, Silicon Valley Bank failed (*See Note 14*). As of March 14, 2023, the Society's line of credit is still available for use.

NOTE 7 LEASING ARRANGEMENTS

During the years presented, the Society was party to a three-year lease for 1,835 square feet of office space that was originally scheduled to end in July 2022. The basic rent commencing on August 1, 2019, was \$2,982 and additional amounts were assessed each month for operating costs and utilities. The Society entered into an agreement to terminate the lease effective March 1, 2022.

Rent expense for the years ended December 31, 2022 and 2021 was \$9,530 and \$38,382, respectively, which is included in *Occupancy* in the accompanying Statement of Functional Expenses.

NOTE 8 COMMITMENTS AND CONTINGENCIES

Clinical Trial Research Network Memorandum of Understanding

During 2019, the Society entered a memorandum of understanding ("MOU") with the University of Kansas Medical Center ("KUMC") for the development and management of the FSH Clinical Trial Research Network ("CTRN"). Per the MOU, the Society has agreed to pay KUMC \$180,000 in 2021 contingent upon reasonable determination that KUMC has made sufficient progress in developing the CTRN during the prior calendar year. In the opinion of management, KUMC made sufficient progress in developing the CTRN during 2021. In addition, the Society commits to awarding KUMC up to an additional \$120,000 per year in 2021-2022 for up to four new CTRN members. CTRN expenses for the years ended December 31, 2022 and 2021 were \$120,000 and \$300,000, respectively, which are included in *Scientific Grants and Research Projects* in the accompanying Statement of Functional Expenses.

Deferred Digital Assets:

As discussed in *Note 2*, the Society entered into an agreement with IQVIA to build out Phase 0 of IQVIA's Integrated Health Platform (IHP). On February 3, 2023, the Society entered into an agreement with IQVIA for the final buildout and implementation of the IHP. The estimated start date of the work is April 1, 2023 and it is estimated that the work will be completed by January 4, 2024. The cost of the technology implementation services is \$1,150,000 to be paid as milestones are achieved through January 2024. In addition, the Society is obligated to pay hosting fees of \$300,000 annually from November 1, 2023, through October 31, 2026.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

(Continued)

NOTE 8 *(Continued)*

Other Program Service Commitments:

During 2022, the Society entered into various professional service consulting agreements and venue contracts for 2023 conferences and meetings. Obligations incurred during 2022 under these agreements are approximately \$453,000. Approximately \$373,000 of venue commitments are noncancelable. The program service commitments have not been accrued on the accompanying Statement of Financial Position because the various programs primarily occur in 2023-2024.

NOTE 9 COVID RELIEF FUNDING

On February 8, 2021, the FSHD Society received a second draw of the PPP loan proceeds of \$285,077 (“PPP2 Loan”), issued under the Economic Aid to Hard-Hit Small Businesses, Nonprofits, and Venues Act. The PPP provides for forgiveness of principal subject to various conditions regarding use of funds for allowable expenditures, maintenance of headcount and compensation levels, and the period within which PPP Loan proceeds must be spent. The Society has recognized \$285,077 as grant revenue in the accompanying Statement of Activities for the year ended December 31, 2021. The loan forgiveness application for \$285,077 was approved by the SBA on October 27, 2021.

The CARES Act provides an employee retention credit (“CARES Employee Retention credit”), which is a refundable tax credit against certain employment taxes of up to \$5,000 per employee for eligible employers. The tax credit is equal to 50% of qualified wages paid to employees during a quarter, capped at \$10,000 of qualified wages per employee through December 31, 2020. Additional relief provisions were passed by the United States government, which extend and slightly expand the qualified wage caps on these credits through September 30, 2021. Based on these additional provisions, the tax credit in 2021 is equal to 70% of qualified wages paid to employees during a quarter, and the limit on qualified wages per employee has been increased to \$10,000 of qualified wages per quarter. The Society qualifies for the tax credit under the CARES Act. During the year ended December 31, 2021, the Society recorded \$313,636 related to the CARES Employee Retention credit as grant revenue in the accompanying Statement of Activities. As of December 31, 2022 and 2021, the Society has \$162,636 and \$227,839 in *Employee Retention Tax Credits Receivable* recorded in the accompanying Statement of Financial Position, respectively.

NOTE 10 RETIREMENT PLANS

The Society utilizes a Professional Employer Organization (“PEO”) for its human resource needs, including its 401(k) plan. The PEO 401(k) plan provides that employees who have attained age 21 and completion of three consecutive months of employment may voluntarily contribute their earnings to the plan, up to the maximum allowed by the IRS. Employer contributions are discretionary and are authorized by the Board of Directors each plan year. In 2022 and 2021, the Society elected to make safe harbor matches of up to 4% of employees’ earnings.

For the years ended December 31, 2022 and 2021, the total employer contributions to its retirement plan were \$61,545 and \$49,240, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

(Continued)

NOTE 11 457(b) DEFERRED COMPENSATION PLAN

During 2019, the Society's Board of Directors approved a 457(b) deferred compensation plan that allows eligible employees to defer pretax annual compensation up to certain limitations imposed by the IRS. Eligible employees are determined by the Board of Directors. During the years presented, the only eligible employee is the Society's Chief Executive Officer & President. The Society reports assets and liabilities of equal amounts attributable to the amount deferred, as the Society has opted to set aside amounts contributed to the plan; however, these assets are owned by the Society until a vesting event occurs. Eligible employees must remain employed by the Society until December 31, 2024 for employer contributions in the plan to vest. For the years ended December 31, 2022 and 2021, the Board voted to fund this plan in the amount of \$20,500 and \$19,500, respectively. The assets and liability related to the 457(b) deferred compensation plan are included in *Investments* and *Long-Term Deferred Compensation Liability* in the accompanying Statements of Financial Position and represent the cumulative amount of contributions to the 457(b) deferred compensation plan, as well as accumulated earnings and losses since the plan's inception. The related deferred compensation expense for the years ended December 31, 2022 and 2021 were \$4,208 and 25,923, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

NOTE 12 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. The Society maintains two bank accounts with one financial institution: (1) a Negotiable Order of Withdrawal account ("NOW account") and (2) an Insured Cash Sweep account ("ICS account"). After all debit and credit transactions have posted at the end of each business day, excess balances from the NOW account are automatically moved to the ICS account. ICS account funds are divided into amounts under the standard Federal Deposit Insurance Corporation ("FDIC") maximum and placed with other ICS network members, each an FDIC insured institution. As of December 31, 2022 and 2021, cash balances were not in excess of the FDIC limit. The Organization has not experienced any losses on uninsured cash balances and management considers risk on cash balances to be low.

Investments:

The Organization invests or holds a variety of investment vehicles, including money market funds, mutual fund, ETFs, 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.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

(Continued)

NOTE 13 AVAILABLE RESOURCES AND LIQUIDITY

As part of the Society's liquidity management, it has a policy to structure its financial assets to be available as its general expenditures, liabilities, and other obligations come due. The Society has various sources of liquidity at its disposal, including cash and cash equivalents, marketable debt, and equity securities.

For purposes of analyzing resources available to meet general expenditures over a 12-month period, the Society considers all expenditures related to its ongoing activities of promoting research and patient advocacy and education as well as the conduct of services undertaken to support those activities to be general expenditures. The Society manages its cash available to meet general expenditures following three guiding principles:

- Operating within a prudent range of financial soundness and stability,
- Maintaining adequate liquid assets, and
- Maintaining sufficient reserves to provide reasonable assurance that grant commitments will continue to be met.

The Society strives to maintain year-end financial assets available to meet general expenditures at a level that represents 50% of annual operating expenses plus an amount that represents the next expected payment for semi-annual grant commitments plus all current grants payable approved by the Board.

The table below presents financial assets available for general expenditures within two years as of December 31, 2022 and 2021:

	<u>2022</u>	<u>2021</u>
Financial Assets at Year End:		
Cash and Cash Equivalents	\$ 3,650,917	\$ 4,820,728
Employee Retention Tax Credit Receivable	162,636	227,839
Contributions Receivable	-	65,847
Investments	<u>1,956,777</u>	<u>2,396,249</u>
Total Financial Assets	<u>5,770,330</u>	<u>7,510,663</u>
Less Amounts Not Available to be Used Within One Year:		
Investments in Donor Advised Fund		
With Donor-Imposed Restrictions	\$(1,734,768)	\$(2,178,448)
Programmatic Equity Investment	(150,000)	(150,000)
Deferred Compensation Liability	(72,009)	(67,801)
Contributions Receivable for Restricted Gifts, Net	-	(65,847)
Grants Payable Due Within One Year	(966,677)	(669,087)
Reserves for Bi-Annual International Research and Patient Conference	<u>(163,000)</u>	<u>(352,000)</u>
Financial Assets Not Available to be Used Within One Year	<u>(3,086,454)</u>	<u>(3,482,183)</u>
Financial Assets Available to Meet General Expenditures Within One Year	<u>\$ 2,683,876</u>	<u>\$ 4,027,480</u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2022

(With Summarized Comparative Information for 2021)

(Continued)

NOTE 14 SUBSEQUENT EVENTS

Management is required to consider events subsequent to the financial statement date for potential adjustment to or disclosure in the financial statements. Management has evaluated subsequent events through March 14, 2023, the date which the financial statements were available for issue.

On March 10, 2023, the Society's bank Silicon Valley Bank ("SVB") failed, and the FDIC took over the bank. As noted in *Note 12*, the Society maintains an ICS account and most funds were insured at the date of bank failure. In addition, the FDIC has indicated that it will cover all uninsured funds. It is the opinion of management that the Society will not incur any losses due to SVB's failure. The Society is working on establishing new bank relationships at the date of sign-off. Other than the agreement with IQVIA for the final buildout and implementation of the IHP as discussed in *Note 8*, noted no other events met the disclosure criteria.