

**FSHD SOCIETY**

**FINANCIAL STATEMENTS**

*with*

**INDEPENDENT AUDITORS' REPORT**

**YEAR ENDED DECEMBER 31, 2023**

*(With Summarized Comparative Information for 2022)*

Smith  Sullivan  
& Brown PC

CERTIFIED PUBLIC ACCOUNTANTS

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**FSHD SOCIETY**

**REPORT ON FINANCIAL STATEMENTS**

**YEAR ENDED DECEMBER 31, 2023**  
*(With Summarized Comparative Information for 2022)*



**Our Vision**

*A world free of the suffering caused by  
FSH Muscular Dystrophy (FSHD)*

**Mission**

*Find treatments and a cure for FSHD  
while empowering our families*

**Our Strategies**

- 1. Accelerate the development of treatments and a cure for FSHD.*
- 2. Increase, engage, and empower our stakeholders.*
- 3. Aggressively leverage and expand resources to support our mission.*

***[www.fshdsociety.org](http://www.fshdsociety.org)***

FSHD SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2023

*(With Summarized Comparative Information for 2022)*

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# Smith Sullivan & Brown PC

CERTIFIED PUBLIC ACCOUNTANTS

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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, 2023, 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, 2023, 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, 2022 financial statements, and we expressed an unmodified audit opinion on those audited financial statements in our report dated March 14, 2023. In our opinion, the summarized comparative information presented herein as of and for the year ended December 31, 2022, is consistent, in all material respects, with the audited financial statements from which it has been derived.

*Smith, Sullivan & Brown, PC*

Westborough, Massachusetts  
July 16, 2024

FSHD SOCIETY

STATEMENTS OF FINANCIAL POSITION  
AS OF DECEMBER 31, 2023 AND 2022

<u>ASSETS</u>	<u>2023</u>	<u>2022</u>
<u>CURRENT ASSETS:</u>		
Cash and Cash Equivalents	\$ 3,574,002	\$ 3,650,917
Employee Retention Tax Credit Receivable	84,086	162,636
Prepaid Expenses	62,502	58,985
Total Current Assets	<u>3,720,590</u>	<u>3,872,538</u>
 <u>NON-CURRENT ASSETS:</u>		
Deferred Digital Assets	550,000	250,000
Investments	2,150,664	1,956,777
Total Non-Current Assets	<u>2,700,664</u>	<u>2,206,777</u>
 <u>TOTAL ASSETS</u>	 <u>\$ 6,421,254</u>	 <u>\$ 6,079,315</u>
 <u>LIABILITIES AND NET ASSETS</u>		
<u>CURRENT LIABILITIES:</u>		
Grants Payable	\$ 776,214	\$ 966,677
Accounts Payable and Accrued Expenses	320,525	72,281
Total Current Liabilities	<u>1,096,739</u>	<u>1,038,958</u>
 <u>LONG-TERM LIABILITIES:</u>		
Long-Term Deferred Compensation Liability	103,254	72,009
Long-Term Grants Payable	206,578	289,731
Total Long-Term Liabilities	<u>309,832</u>	<u>361,740</u>
 <u>TOTAL LIABILITIES</u>	 <u>1,406,571</u>	 <u>1,400,698</u>
 <u>NET ASSETS:</u>		
Net Assets Without Donor Restrictions	3,828,056	2,724,386
Net Assets With Donor Restrictions	1,186,627	1,954,231
Total Net Assets	<u>5,014,683</u>	<u>4,678,617</u>
 <u>TOTAL LIABILITIES AND NET ASSETS</u>	 <u>\$ 6,421,254</u>	 <u>\$ 6,079,315</u>

FSHD SOCIETY

STATEMENT OF ACTIVITIES  
FOR THE YEAR ENDED DECEMBER 31, 2023  
*(With Summarized Comparative Totals for 2022)*

	<u>WITHOUT</u> <u>DONOR</u> <u>RESTRICTIONS</u>	<u>WITH</u> <u>DONOR</u> <u>RESTRICTIONS</u>	<u>TOTAL ACTIVITIES</u>	
			<u>2023</u>	<u>2022</u>
<b><u>SUPPORT, REVENUES AND RECLASSIFICATIONS</u></b>				
<i>Support and Revenues:</i>				
Gifts, Grants and Contributions	\$ 1,437,857	\$ 1,690,913	\$ 3,128,770	\$ 2,191,362
Gross Special Events Revenue	1,112,243	-	1,112,243	837,995
Less: Cost of Direct Benefits to Donors	(94,852)	-	(94,852)	(98,581)
Donated Goods and Services	339,227	-	339,227	382,791
Program Revenue	157,597	-	157,597	304,466
Total Support and Revenues	<u>2,952,072</u>	<u>1,690,913</u>	<u>4,642,985</u>	<u>3,618,033</u>
<i>Investment and Other Income:</i>				
Return of Grant Funds	1,938	-	1,938	139,274
Investment Return, Net	197,305	143,431	340,736	(335,465)
Other Income (Loss)	700	-	700	500
Total Investment and Other Income	<u>199,943</u>	<u>143,431</u>	<u>343,374</u>	<u>(195,691)</u>
<i>Reclassification of Net Assets:</i>				
Net Assets Released From Restriction	<u>2,601,948</u>	<u>(2,601,948)</u>	<u>-</u>	<u>-</u>
<b><u>TOTAL SUPPORT, REVENUES AND RECLASSIFICATIONS</u></b>	<u>5,753,963</u>	<u>(767,604)</u>	<u>4,986,359</u>	<u>3,422,342</u>
<b><u>EXPENSES:</u></b>				
<i>Program Services:</i>				
Research and Patient Programs	3,682,542	-	3,682,542	4,307,236
<i>Supporting Services:</i>				
Administrative	437,981	-	437,981	359,821
Fund Raising	529,770	-	529,770	429,078
Total Supporting Services	<u>967,751</u>	<u>-</u>	<u>967,751</u>	<u>788,899</u>
<b><u>TOTAL EXPENSES</u></b>	<u>4,650,293</u>	<u>-</u>	<u>4,650,293</u>	<u>5,096,135</u>
<b><u>CHANGE IN NET ASSETS</u></b>	<b><u>1,103,670</u></b>	<b><u>(767,604)</u></b>	<b><u>336,066</u></b>	<b><u>(1,673,793)</u></b>
<b><u>NET ASSETS - BEGINNING OF YEAR</u></b>	<b><u>2,724,386</u></b>	<b><u>1,954,231</u></b>	<b><u>4,678,617</u></b>	<b><u>6,352,410</u></b>
<b><u>NET ASSETS - END OF YEAR</u></b>	<b><u>\$ 3,828,056</u></b>	<b><u>\$ 1,186,627</u></b>	<b><u>\$ 5,014,683</u></b>	<b><u>\$ 4,678,617</u></b>

FSHD SOCIETY

STATEMENT OF FUNCTIONAL EXPENSES  
FOR THE YEAR ENDED DECEMBER 31, 2023  
*(With Summarized Comparative Totals for 2022)*

	<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>2023</u>	<u>2022</u>
Salaries and Related Expenses	\$ 1,710,172	\$ 254,123	\$ 307,887	\$ 2,272,182	\$ 2,016,652
Scientific Grants and Projects	457,183	-	-	457,183	1,408,042
Consultants and Professional Fees	425,467	98,712	8,699	532,878	233,075
Travel, Lodging and Meals	304,056	23,586	36,910	364,552	237,235
Donated Services	335,027	4,200	-	339,227	382,791
Patient Meetings and Research Conferences	158,544	-	-	158,544	303,776
Website and Computer Related Expenses	112,268	14,999	21,505	148,772	194,248
Printing	58,376	-	46,015	104,391	91,957
Bank Service Charges and Credit Card Processing Fees	32,442	10,434	55,954	98,830	90,894
Special Event Costs	-	-	94,852	94,852	59,865
Office Expenses	29,754	4,205	7,586	41,545	36,330
Donor Software and Donor Engagement	-	-	38,422	38,422	60,699
Public Awareness	31,489	-	6,792	38,281	16,551
Chapter and Volunteer Development	25,064	-	-	25,064	24,937
Directors Expenses	-	18,470	-	18,470	17,120
Insurance	2,700	9,252	-	11,952	9,328
Occupancy	-	-	-	-	10,831
Bad Debt Expense	-	-	-	-	385
	<u>          </u>	<u>          </u>	<u>          </u>	<u>          </u>	<u>          </u>
<b>Total Functional Expenses</b>	<b>3,682,542</b>	<b>437,981</b>	<b>624,622</b>	<b>4,745,145</b>	<b>5,194,716</b>
Less: Cost of Direct Benefits to Donors	<u>          </u>	<u>          </u>	<u>(94,852)</u>	<u>(94,852)</u>	<u>(98,581)</u>
<b>Total Expenses Per Statement of Activities</b>	<b><u>\$ 3,682,542</u></b>	<b><u>\$ 437,981</u></b>	<b><u>\$ 529,770</u></b>	<b><u>\$ 4,650,293</u></b>	<b><u>\$ 5,096,135</u></b>



FSHD SOCIETY

STATEMENTS OF CASH FLOWS  
FOR THE YEARS ENDED DECEMBER 31, 2023 AND 2022

	<u>2023</u>	<u>2022</u>
<b><u>CASH FLOWS FROM OPERATING ACTIVITIES:</u></b>		
Change in Net Assets	\$ 336,066	\$(1,673,793)
<i>Adjustments to Reconcile Changes in Net Assets to Net Cash Provided (Used) by Operating Activities:</i>		
Investment Return, Net	(250,642)	334,680
Deferrals to Deferred Compensation Plan	(31,245)	(4,208)
<i>Changes in Operating Assets and Liabilities:</i>		
Employee Retention Tax Credit Receivable	78,550	65,203
Contributions Receivable - Current and Long-Term	-	65,847
Prepaid Expenses	(3,517)	64,694
Grants Payable - Current and Long-Term	(273,616)	89,530
Accounts Payable and Accrued Expenses	248,244	20,551
Net Adjustment	<u>(232,226)</u>	<u>636,297</u>
<b><u>NET CASH PROVIDED (USED) BY OPERATING ACTIVITIES</u></b>	<b><u>103,840</u></b>	<b><u>(1,037,496)</u></b>
<b><u>CASH FLOWS FROM INVESTING ACTIVITIES:</u></b>		
Proceeds from Sale of Donor Advised Fund Investments	88,000	109,000
Purchase of Digital Assets	(300,000)	(250,000)
Refund of Deposits	-	4,477
Net Cash Flows From Investing Activities	<u>(212,000)</u>	<u>(136,523)</u>
<b><u>CASH FLOWS FROM FINANCING ACTIVITIES:</u></b>		
Increase in Long-Term Deferred Compensation Liability	31,245	4,208
Net Cash Flows From Financing Activities	<u>31,245</u>	<u>4,208</u>
<b><u>NET DECREASE IN CASH BALANCES</u></b>	<b>(76,915)</b>	<b>(1,169,811)</b>
<b><u>CASH AND CASH EQUIVALENTS - BEGINNING OF YEAR</u></b>	<b><u>3,650,917</u></b>	<b><u>4,820,728</u></b>
<b><u>CASH AND CASH EQUIVALENTS - END OF YEAR</u></b>	<b><u>\$ 3,574,002</u></b>	<b><u>\$ 3,650,917</u></b>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2023

*(With Summarized Comparative Information for 2022)*

NOTE 1      OPERATIONS AND NONPROFIT STATUS

**Operations:**

The FSHD Society is the world’s largest research-focused patient organization for facioscapulohumeral muscular dystrophy (FSHD), one of the most prevalent forms of muscular dystrophy. We have catalyzed major advancements and are accelerating the development of treatments and a cure to end the pain, disability, and suffering endured by people worldwide who live with FSHD. The FSHD Society has transformed the landscape for FSHD research, and is committed to making sure that no one faces this disease alone.

**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 (“IRC”). Effective October 2, 2019, the Society legally changed its name to FSHD Society. The FSHD Society is not classified as a private foundation under IRC 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, has in management’s opinion, resulted in reliable and consistent financial reporting by the Organization.

**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.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2023

*(With Summarized Comparative Information for 2022)*

*(Continued)*

NOTE 2     *(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:**

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, 2023 and 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.

The accompanying financial statements include certain 2022 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, 2022 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, 2022, from which the summarized information was derived.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2023

*(With Summarized Comparative Information for 2022)*

*(Continued)*

NOTE 2      *(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. 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 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.

**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 software program optimized to facilitate the acquisition, curation, harmonization, and repurposing of disparate electronic health information for research and analytic uses. The Society updated its agreement with IQVIA. 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 in 2024 at which time the total cost will be amortized over the life of the service agreement. Total *Deferred Digital Assets* as of December 31, 2023 and 2022 are \$550,000 and \$250,000, respectively, and are included in accompanying Statements 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 years ended December 31, 2023 and 2022. See *Note 7* for a discussion of future commitments with IQVIA.

**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), certificates of deposits, 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 Statements of Financial Position. Net investment return (loss) is reported in the Statement of Activities and consists of interest and dividend income, realized and unrealized capital gains and losses, less external and direct internal investment expenses. 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.

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

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2023

*(With Summarized Comparative Information for 2022)*

*(Continued)*

NOTE 2      *(Continued)*

**Leases:**

The Organization determines if an arrangement is a lease at inception. When the standards apply, operating leases are included in operating lease right-of-use (“ROU”) assets and operating lease liabilities in the Statements of Financial Position. ROU assets represent the right to use an underlying asset for the lease term and lease liabilities represent the obligation to make lease payments arising from the lease. Operating lease ROU assets and liabilities are recognized at the lease commencement date based on the present value of lease payments over the lease term.

The operating lease ROU asset includes any lease payments made and excludes lease incentives. The lease terms may include options to extend or terminate the lease when it is reasonably certain that the Organization will exercise that option. Lease expense for lease payments is recognized on a straight-line basis over the lease term.

The Organization has elected the short-term lease exemption for all leases with a term of 12 months or less for both existing and ongoing operating leases to not recognize the asset and liability for these leases. Lease payments for short-term leases are recognized on straight-line basis.

For the years presented, there were no arrangements which met the criteria for application of the lease accounting standards.

**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, 2023, and 2022, there were no expenditures for *Property and Equipment* that met the capitalization criteria.

**Donor Advised Funds:**

During the year ended December 31, 2022, The Lewis Family Donor Advised Fund for FSHD was 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 had ultimate variance power over the use of funds; however, the agreement allowed donors to recommend grant recipients subject to the Society’s approval. The Lewis Family Donor Advised Fund for FSHD included 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. In June 2023, the remaining balance in the Lewis Family Donor Advised Fund for FSHD was granted to the Society and designated for spending on research initiatives, including FSHD Therapeutics.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2023

*(With Summarized Comparative Information for 2022)*

*(Continued)*

NOTE 2      *(Continued)*

**Revenue Recognition**

The Organization recognizes revenue from numerous sources as follows:

*Gifts, Grants and Contributions:* The Society is the beneficiary of contributions in the form of grants from other organizations, donations of cash and financial assets from individuals and contributions of nonfinancial assets. Contributions, including promises to give, without donor conditions are recognized as revenue at their estimated fair value at the date of donation and classified as either with or without donor restrictions depending on the donor's stipulations or lack thereof. Unconditional, multi-year commitments are recognized in the year during which the initial commitment is made at the amount that the Organization reasonably expects to collect. 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. Amounts receivable from donors are evaluated yearly for collectability and an allowance for uncollectible pledges is recorded as necessary.

Support that is restricted by the donor is reported as an increase in net assets with donor restrictions until the restrictions are met, at which time the net assets are reclassified to net assets without donor restrictions.

Conditional donations are those that have a measurable performance or other barrier and include a right of return of the assets or right of release of the donor from further obligation if the conditions are not met. Conditional donations are not recognized until the associated barriers are met. Consequently, as of December 31, 2023 and 2022, contributions approximating \$175,000 and \$350,000, respectively, 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 fully met during 2024. Any cash received before the conditions or barriers are met is reported as a refundable grant advance. When the conditions are met the revenue is reported as contributions without donor restrictions unless there are further restrictions over and above those associated with the donor conditions. In such cases, when the conditions and restrictions are met within the same reporting period, the support is recognized as contributions or grants without donor 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, 2023

*(With Summarized Comparative Information for 2022)*

*(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, 2023, *Long-Term Grants Payable* are due in 2025 - 2026.

**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.

NOTE 3     INVESTMENTS

**Investment Components:**

As of December 31, 2023 and 2022, *Investments* on the Statements of Financial Position consist of the following:

<u>Investment Components</u>	<u>2023</u>	<u>2022</u>
Lewis Family Donor Advised Fund for FSHD	\$ -	\$1,734,768
Long-Term Investments	1,897,410	-
Deferred Compensation Investments	<u>103,254</u>	<u>72,009</u>
Total Fair Value Investments	2,000,664	1,806,777
Programmatic Equity Investments	<u>150,000</u>	<u>150,000</u>
Total Investments	<u>\$2,150,664</u>	<u>\$1,956,777</u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2023

(With Summarized Comparative Information for 2022)

(Continued)

NOTE 3 (Continued)

As of December 31, 2023 and 2022, the Organization's investments carried at fair value consisted of the following components:

<u>Investment Type</u>	<u>December 31, 2023</u>		
	<u>Fair Value</u>	<u>Fair Value (Level 1)</u>	<u>Fair Value (Level 2)</u>
Money Market Funds (at Cost)	\$ 42,467	\$ -	\$ -
Mutual Funds – Equity	1,278,797	1,278,797	-
Exchange Traded Funds	148,346	148,346	-
Preferred Stocks and Bonds	31,109	-	31,109
Certificates of Deposit	<u>499,945</u>	<u>499,945</u>	<u>-</u>
Total	<u>\$2,000,664</u>	<u>\$1,927,088</u>	<u>\$31,109</u>
<u>Investment Type</u>	<u>December 31, 2022</u>		
	<u>Fair Value</u>	<u>Fair Value (Level 1)</u>	<u>Fair Value (Level 2)</u>
Money Market Funds (at Cost)	\$ 56,957	\$ -	\$ -
Mutual Funds	1,570,071	1,570,071	-
Exchange Traded Funds	129,582	129,582	-
Preferred Stocks and Bonds	<u>50,167</u>	<u>-</u>	<u>50,167</u>
Total	<u>\$1,806,777</u>	<u>\$1,699,653</u>	<u>\$50,167</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.

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.

Certificates of Deposit: held at market value plus accrued interest.

Components of *Investment Return* for the years ended December 31, 2023 and 2022, is as follows:

<u>Components of Investment Return</u>	<u>2023</u>	<u>2022</u>
Interest and Dividends	\$154,284	\$ 98,205
Unrealized Gains (Losses)	191,718	(469,369)
Realized Gains (Losses)	<u>(5,266)</u>	<u>35,699</u>
Net Investment Return (Loss)	<u>\$340,736</u>	<u>\$(335,465)</u>



FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2023

*(With Summarized Comparative Information for 2022)*

*(Continued)*

NOTE 3      *(Continued)*

**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. 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 and as of December 31, 2023 and 2022, the Society owns 18,944 shares of Common B voting shares in miRecule which represents approximately 1% ownership in miRecule. Accordingly, the Organization accounts for this programmatic investment using the cost method. In management’s opinion, no reserve for impairment loss related to this investment is required for the years ended December 31, 2023 and 2022. The Society’s investment is restricted for research in FSH muscular dystrophy.

NOTE 4      DESIGNATIONS AND RESTRICTIONS OF NET ASSETS

**Net Assets With Donor Restrictions:**

As of December 31, 2023, and 2022, net assets with donor restrictions were designated for research and education and consisted of the following balances:

<u>Nature of Restriction</u>	<u>2023</u>	<u>2022</u>
Lewis Family Donor Advised Fund for FSHD	\$ -	\$1,734,768
FSHD Therapeutics	<u>1,186,627</u>	<u>219,463</u>
Total	<u>\$1,186,627</u>	<u>\$1,954,231</u>

In June 2023, the remaining balance in the Lewis Family Donor Advised Fund for FSHD was granted to the Society and designated for spending on research initiatives, including FSHD Therapeutics.

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>2023</u>	<u>2022</u>
FSHD Therapeutics	\$2,394,430	\$ 729,262
Research and Education	<u>207,518</u>	<u>275,820</u>
Total	<u>\$2,601,948</u>	<u>\$1,005,082</u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2023

*(With Summarized Comparative Information for 2022)*

*(Continued)*

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>2023</u>	<u>2022</u>
Scientific Committees Expenses	\$186,300	\$212,075
Science time for FSHD Connect and Patient Education	75,225	59,925
Public Awareness	58,502	106,591
Event Costs	15,000	-
Investment Advisory Services	<u>4,200</u>	<u>4,200</u>
Total	<u>\$339,227</u>	<u>\$382,791</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*.

During the year ended December 31, 2023, the keynote speaker at the Society's annual Volunteer Leadership Summit provided her time at no charge to the Organization. These event costs were recognized at fair value based on current rates for comparable speaking engagements.

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.

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, 2023 and 2022. The line bears interest at the bank's base rate. As of December 31, 2023, and 2022, the bank's base rate was 8.5% and 8.0%, 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.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2023

*(With Summarized Comparative Information for 2022)*

*(Continued)*

NOTE 7      COMMITMENTS AND CONTINGENCIES

**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 original estimated start date of the work was November 1, 2023, and it is estimated that the work will be completed by July 31, 2024. The total cost of the technology implementation services is \$1,470,000 to be paid as milestones are achieved through July 2024. In addition, the Society is obligated to pay hosting fees of \$300,000 annually from November 1, 2023, through October 31, 2026. The Society did not pay any hosting fees in 2023 because the IHP wasn't operational in 2023. Through December 31, 2023, the Society has incurred \$620,000 in costs related to this project, and \$850,000 remains outstanding and is expected to be paid during 2024.

**Patient Lifestyle and Disease Data Interactium ("Paladin"):**

In October 2023, FSHD Society entered into an agreement to formalize its commitment to the Project Paladin consortium, which is a four-year collaboration between nine organizations who have united under a common goal to overcome obstacles affecting the advancement of treatment, diagnosis, and care of neuromuscular patients worldwide. The four-year project is funded by the European Union (EU) through Horizon Europe / Innovative Health Initiative ("IHI") and has a budget of approximately twenty-one million Euros to develop a new state-of-the-art data collection platform. FSHD Society has committed €4,698,000 (USD 4,986,335), beginning in 2024, which includes €1,600,000 (USD 1,698,198) for the operationalization of the BetterLife Platform, our patient registry platform, which is comprised of €2,261,220 (USD 2,400,000) as a contribution of staff time and €836,780 (USD 888,136) in indirect costs.

**Other Program Service Commitments:**

During 2023, the Society entered into various professional service consulting agreements and venue contracts for 2023 conferences and meetings. Obligations incurred during 2023 under these agreements are approximately \$303,000. Approximately \$215,000 of venue commitments are noncancelable. The program service commitments have not been accrued on the accompanying Statements of Financial Position because the various programs primarily occur in 2024.

NOTE 8      COVID RELIEF FUNDING

The Employee Retention Tax Credit was introduced by the U.S. CARES Act in 2020 and is a refundable tax credit against certain employment taxes. During the year ended December 31, 2021, the Society recorded \$313,636 related to the CARES Employee Retention credit as grant revenue. As of December 31, 2023, the Society has received \$229,550 in payments related to this credit and as of December 31, 2023 and 2022, the Society has \$84,086 and \$162,636 in *Employee Retention Tax Credits Receivable* recorded in the accompanying Statements of Financial Position, respectively.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2023

*(With Summarized Comparative Information for 2022)*

*(Continued)*

NOTE 9    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 2023 and 2022, the Society elected to make safe harbor matches of up to 4% of employees’ earnings.

For the years ended December 31, 2023 and 2022, the total employer contributions to its retirement plan were \$62,411 and \$61,545, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

NOTE 10    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, 2023 and 2022, the Board voted to fund this plan in the amount of \$22,500 and \$20,500, 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, 2023 and 2022 were \$31,245 and \$4,208, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

NOTE 11    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 bank accounts with two financial institutions, including an Insured Cash Sweep account (“ICS account”). After all debit and credit transactions have posted at the end of each business day, excess balances 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, 2023, cash balances in excess of the FDIC limit was \$160,358. The Organization has not experienced any losses on uninsured cash balances.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2023

*(With Summarized Comparative Information for 2022)*

*(Continued)*

NOTE 11 *(Continued)*

**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.

NOTE 12 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, 2023 and 2022:

	<u>2023</u>	<u>2022</u>
Financial Assets at Year End:		
Cash and Cash Equivalents	\$ 3,574,002	\$ 3,650,917
Employee Retention Tax Credit Receivable	84,086	162,636
Investments	<u>2,150,664</u>	<u>1,956,777</u>
Total Financial Assets	<u>5,808,752</u>	<u>5,770,330</u>
Less Amounts Not Available to be Used Within One Year:		
Investments in Donor Advised Fund		
With Donor-Imposed Restrictions	\$ -	\$ (1,734,768)
Programmatic Equity Investment	(150,000)	(150,000)
Deferred Compensation Liability	(103,254)	(72,009)
Grants Payable Due Within One Year	<u>(776,214)</u>	<u>(966,677)</u>
Financial Assets Not Available to be Used Within One Year	<u>(1,029,468)</u>	<u>(2,923,454)</u>
Financial Assets Available to Meet General Expenditures Within One Year	<u>\$ 4,779,284</u>	<u>\$ 2,846,876</u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2023

*(With Summarized Comparative Information for 2022)*

*(Continued)*

NOTE 13 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 July 16, 2024, the date which the financial statements were available for issue.

On July 15, 2024, the Society entered into an agreement with Lumiiio for Phase 1 of the final buildout and implementation of the Integrated Health Platform (IHP) for BetterLife. The cost for this phase is \$234,000, with an annual subscription fee of \$200,000. Additionally, on July 10, 2024, the Society served an official notice of contract termination to IQIVIA for its work on the IHP. Refer to *Note 7* for further disclosure regarding the Society's original contract arrangement with IQIVIA.