

FSHD SOCIETY
FINANCIAL STATEMENTS
with
INDEPENDENT AUDITORS' REPORT
YEAR ENDED DECEMBER 31, 2024
(With Summarized Comparative Information for 2023)

Smith  Sullivan
& Brown PC

CERTIFIED PUBLIC ACCOUNTANTS

80 Flanders Road, Suite 302  Westborough, Massachusetts 01581
Tel: 508.871.7178 Fax: 508.871.7179 www.ssbcpa.com

FSHD SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2024
(With Summarized Comparative Information for 2023)



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.*

FSHD SOCIETY
REPORT ON FINANCIAL STATEMENTS
YEAR ENDED DECEMBER 31, 2024
(With Summarized Comparative Information for 2023)

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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, 2024, 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, 2024, 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
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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, 2023 financial statements, and we expressed an unmodified audit opinion on those audited financial statements in our report dated July 16, 2024. In our opinion, the summarized comparative information presented herein as of and for the year ended December 31, 2023, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Smith, Sullivan & Brown, PC

Westborough, Massachusetts
April 25, 2025

FSHD SOCIETY

STATEMENTS OF FINANCIAL POSITION
AS OF DECEMBER 31, 2024 AND 2023

	<u>2024</u>	<u>2023</u>
<u>ASSETS</u>		
<u>CURRENT ASSETS:</u>		
Cash	\$ 1,096,154	\$ 3,574,002
Employee Retention Tax Credit Receivable	84,086	84,086
Settlement Agreement Receivable	175,000	-
Prepaid Expenses	337,028	62,502
Total Current Assets	<u>1,692,268</u>	<u>3,720,590</u>
<u>NON-CURRENT ASSETS:</u>		
Investments	2,466,091	2,150,664
Intangible Assets	1,469,908	550,000
Less accumulated amortization	(36,076)	-
Total Non-Current Assets	<u>3,899,923</u>	<u>2,700,664</u>
<u>TOTAL ASSETS</u>	<u>\$ 5,592,191</u>	<u>\$ 6,421,254</u>
<u>LIABILITIES AND NET ASSETS</u>		
<u>CURRENT LIABILITIES:</u>		
Grants Payable	\$ 381,110	\$ 776,214
Accounts Payable and Accrued Expenses	343,126	320,525
Total Current Liabilities	<u>724,236</u>	<u>1,096,739</u>
<u>LONG-TERM LIABILITIES:</u>		
Long-Term Deferred Compensation Liability	142,613	103,254
Long-Term Grants Payable	26,550	206,578
Total Long-Term Liabilities	<u>169,163</u>	<u>309,832</u>
<u>TOTAL LIABILITIES</u>	<u>893,399</u>	<u>1,406,571</u>
<u>NET ASSETS:</u>		
Net Assets Without Donor Restrictions	4,583,881	3,828,056
Net Assets With Donor Restrictions	114,911	1,186,627
Total Net Assets	<u>4,698,792</u>	<u>5,014,683</u>
<u>TOTAL LIABILITIES AND NET ASSETS</u>	<u>\$ 5,592,191</u>	<u>\$ 6,421,254</u>

FSHD SOCIETY

STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED DECEMBER 31, 2024
(With Summarized Comparative Totals for 2023)

	<u>WITHOUT</u> <u>DONOR</u> <u>RESTRICTIONS</u>	<u>WITH</u> <u>DONOR</u> <u>RESTRICTIONS</u>	<u>TOTAL ACTIVITIES</u> <u>2024</u>	<u>2023</u>
<u>SUPPORT, REVENUES AND RECLASSIFICATIONS</u>				
<i>Support and Revenues:</i>				
Gifts, Grants and Contributions	\$ 1,451,398	\$ 1,653,601	\$ 3,104,999	\$ 3,128,770
Gross Special Events Revenue	974,833	6,950	981,783	1,112,243
Less: Cost of Direct Benefits to Donors	(63,050)	-	(63,050)	(94,852)
Donated Goods and Services	317,216	-	317,216	339,227
Donated Intellectual Property (Note 5)	676,250	-	676,250	-
Program Revenue	120,198	-	120,198	157,597
Total Support and Revenues	<u>3,476,845</u>	<u>1,660,551</u>	<u>5,137,396</u>	<u>4,642,985</u>
<i>Investment and Other Income:</i>				
Investment Return, Net	343,704	(4,499)	339,205	340,736
Other Income	-	-	-	2,638
Total Investment and Other Income	<u>343,704</u>	<u>(4,499)</u>	<u>339,205</u>	<u>343,374</u>
<i>Reclassification of Net Assets:</i>				
Net Assets Released From Restriction	<u>2,727,768</u>	<u>(2,727,768)</u>	<u>-</u>	<u>-</u>
<u>TOTAL SUPPORT, REVENUES AND RECLASSIFICATIONS</u>	<u>6,548,317</u>	<u>(1,071,716)</u>	<u>5,476,601</u>	<u>4,986,359</u>
<u>EXPENSES:</u>				
<i>Program Services:</i>				
Research and Patient Programs	4,594,470	-	4,594,470	3,682,542
<i>Supporting Services:</i>				
Administrative	568,150	-	568,150	437,981
Fund Raising	629,872	-	629,872	529,770
Total Supporting Services	<u>1,198,022</u>	<u>-</u>	<u>1,198,022</u>	<u>967,751</u>
<u>TOTAL EXPENSES</u>	<u>5,792,492</u>	<u>-</u>	<u>5,792,492</u>	<u>4,650,293</u>
<u>CHANGE IN NET ASSETS</u>	<u>755,825</u>	<u>(1,071,716)</u>	<u>(315,891)</u>	<u>336,066</u>
<u>NET ASSETS - BEGINNING OF YEAR</u>	<u>3,828,056</u>	<u>1,186,627</u>	<u>5,014,683</u>	<u>4,678,617</u>
<u>NET ASSETS - END OF YEAR</u>	<u>\$ 4,583,881</u>	<u>\$ 114,911</u>	<u>\$ 4,698,792</u>	<u>\$ 5,014,683</u>

FSHD SOCIETY

STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2024
(With Summarized Comparative Totals for 2023)

	<u>RESEARCH AND PATIENT PROGRAMS</u>	<u>ADMINI- STRATIVE</u>	<u>FUND RAISING</u>	<u>TOTAL FUNCTIONAL EXPENSES</u> <u>2024</u>	<u>2023</u>
Salaries and Related Expenses	\$ 1,857,859	\$ 433,599	\$ 410,337	\$ 2,701,795	\$ 2,272,182
Research and Equipment Grants	278,084	-	-	278,084	457,183
Consultants and Professional Fees	926,184	38,384	5,804	970,372	532,878
Travel, Lodging and Meals	358,200	10,181	39,332	407,713	364,552
Donated Services	313,616	3,600	-	317,216	339,227
Patient Meetings and Research Conferences	385,446	-	684	386,130	158,544
Website and Computer Related Expenses	183,913	26,350	25,332	235,595	148,772
Cloud Computing Expenses and Amortization	102,743	-	-	102,743	-
Printing	71,827	144	25,466	97,437	104,391
Service Charges	37,263	17,895	66,500	121,658	98,830
Special Event Costs	-	-	63,050	63,050	94,852
Office Expenses	22,637	9,637	6,346	38,620	41,545
Donor Software and Donor Engagement	-	-	49,642	49,642	38,422
Public Awareness	50,664	-	392	51,056	38,281
Chapter and Volunteer Development	3,284	-	37	3,321	25,064
Directors Expenses	-	16,348	-	16,348	18,470
Insurance	<u>2,750</u>	<u>12,012</u>	<u>-</u>	<u>14,762</u>	<u>11,952</u>
Total Functional Expenses	4,594,470	568,150	692,922	5,855,542	4,745,145
Less: Cost of Direct Benefits to Donors	<u>-</u>	<u>-</u>	<u>(63,050)</u>	<u>(63,050)</u>	<u>(94,852)</u>
Total Expenses Per Statement of Activities	<u>\$ 4,594,470</u>	<u>\$ 568,150</u>	<u>\$ 629,872</u>	<u>\$ 5,792,492</u>	<u>\$ 4,650,293</u>

FSHD SOCIETY

STATEMENTS OF CASH FLOWS

FOR THE YEARS ENDED DECEMBER 31, 2024 AND 2023

	<u>2024</u>	<u>2023</u>
<u>CASH FLOWS FROM OPERATING ACTIVITIES:</u>		
Change in Net Assets	\$ (315,891)	\$ 336,066
<i>Adjustments to Reconcile Changes in Net Assets to Net Cash Provided (Used) by Operating Activities:</i>		
Investment Return, Net	(276,068)	(250,642)
Deferrals to Deferred Compensation Plan	(39,359)	(31,245)
Amortization Expense	36,076	-
Write off of Intangible Digital Assets, Net of Settlement	125,000	-
Donated Intangible Intellectual Property	(676,250)	-
<i>Changes in Operating Assets and Liabilities:</i>		
Employee Retention Tax Credit Receivable	-	78,550
Prepaid Expenses	(274,526)	(3,517)
Grants Payable - Current and Long-Term	(575,132)	(273,616)
Accounts Payable and Accrued Expenses	22,601	248,244
Net Adjustment	<u>(1,657,658)</u>	<u>(232,226)</u>
<u>NET CASH PROVIDED (USED) BY OPERATING ACTIVITIES</u>	<u>(1,973,549)</u>	<u>103,840</u>
<u>CASH FLOWS FROM INVESTING ACTIVITIES:</u>		
Proceeds from Sale of Donor Advised Fund Investments	-	88,000
Purchase of Intangible Digital Assets	(472,433)	(300,000)
Purchase of Intangible Website Asset	(71,225)	-
Net Cash Flows From Investing Activities	<u>(543,658)</u>	<u>(212,000)</u>
<u>CASH FLOWS FROM FINANCING ACTIVITIES:</u>		
Increase in Long-Term Deferred Compensation Liability	39,359	31,245
Net Cash Flows From Financing Activities	<u>39,359</u>	<u>31,245</u>
<u>NET DECREASE IN CASH BALANCES</u>	<u>(2,477,848)</u>	<u>(76,915)</u>
<u>CASH BALANCES - BEGINNING OF YEAR</u>	<u>3,574,002</u>	<u>3,650,917</u>
<u>CASH BALANCES - END OF YEAR</u>	<u>\$ 1,096,154</u>	<u>\$ 3,574,002</u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

NOTE 1 ORGANIZATION AND NATURE OF ACTIVITIES

The FSHD Society (the “Society” or the “Organization”) is a nonprofit patient advocacy organization focused on facioscapulohumeral muscular dystrophy (“FSHD”), one of the most common forms of muscular dystrophy. Founded by individuals affected by FSHD, the Society’s mission is to accelerate the development of treatments and a cure while empowering individuals and families living with the disease. The Society invests in scientific research, fosters collaboration among researchers, clinicians, industry partners, and patients, and provides trusted information and support to the FSHD community.

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.

Global FSHD Innovation Hub, LLC:

In September 2024, the Society established the Global FSHD Innovation Hub, LLC (the “Hub”), a wholly owned limited liability company. For financial reporting purposes, the Hub is treated as a disregarded entity. It was formed to accelerate the development of effective FSHD therapeutics and improve global patient access to clinical trials. The Hub aims to address key challenges in the clinical trial ecosystem, including limited trial site capacity and delayed study start-up timelines.

The Hub is governed by a four-member Board composed of the President and CEO of the FSHD Society, the Society’s Chief Operating Officer, a member of the Society’s Board of Directors, and the President and CEO of FSHD Canada.

As of December 31, 2024, the Hub had no material financial activity to report. Therefore, no amounts are recognized within the accompanying financial statements for this entity.

NOTE 2 SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Basis of Accounting:

The financial statements of the Society have been prepared on the accrual basis of accounting in accordance with generally accepted accounting principles (“GAAP”) and accordingly, reflect all significant receivables, payables, and other liabilities.

Estimates:

The preparation of financial statements, in conformity with 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 Society.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

(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, 2024 and 2023, 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, 2024

(With Summarized Comparative Information for 2023)

(Continued)

NOTE 2 *(Continued)*

The accompanying financial statements include certain 2023 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, 2023 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, 2023, 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. 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.

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, 2024, and 2023, there were no Property and Equipment expenditures that met the capitalization threshold.

Intangible Assets:

The FSHD Society capitalizes intangible assets when the cost or fair value exceeds \$5,000 and the asset is expected to provide future economic benefit. Intangible assets are recorded at cost, if purchased, or at fair value on the date of receipt, if donated. Capitalized costs, such as Website Redesign, Integrated Health Platform (BetterLife) buildout and donated Intellectual Property (Donated IP), are limited to those incurred during the application development phase or fair market value of the property when donated. Costs incurred during the preliminary project stage and post-implementation (such as maintenance and training) are expensed as incurred. In 2024, the Society capitalized \$1,469,909 in *Intangible Assets* as further discussed in Note 5. Intangible Assets are further classified as amortized or unamortized based on the existence or non-existence of an indefinite useful life,

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.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

(Continued)

NOTE 2 *(Continued)*

The Organization maintains an investment portfolio which consists of money market funds, mutual funds, exchange traded funds (ETFs), certificates of deposits, treasury bills 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. Money market funds 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 4.

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.

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 non-financial 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.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

(Continued)

NOTE 2 *(Continued)*

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 contributions provided subject to specific performance milestones or other qualifying conditions. These donations include provisions that allow for the return of assets or the release of the donor from further obligations if the conditions are not met. Consequently, conditional donations are not recognized as revenue until the specified conditions are satisfied.

As of December 31, 2023, approximately \$175,000 in contributions had not been recognized in the accompanying Statement of Activities because the underlying conditions had not been met. The funding was tied to incremental performance milestones, all of which were fully achieved during 2024. As of December 31, 2024, there were no remaining conditional grant commitments.

Any cash received prior to meeting these conditions is reported as a refundable grant advance. Once the conditions are met, the revenue is recorded as contributions without donor restrictions—unless additional restrictions apply beyond the initial donor conditions. In such instances, when both the conditions and any additional restrictions are satisfied 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. As further discussed in Note 5, the Organization received donated Intangible Assets during 2024 which are recognized at fair value.

Special Event Revenue 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.

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 Ad hoc NIH Level Peer Reviewed Study Group and the Society's Therapeutic Accelerator and Research Committee ("TARC"). During the year ended December 31, 2024, the Organization granted mobility equipment to qualifying individuals under a one-time fundraising effort restricted for this purpose. The Society recognizes an expense for *Research and Equipment Grants* at the time the Board of Directors votes to approve the 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.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

(Continued)

NOTE 2 (Continued)

Conditional commitments are not recognized in the financial statements until measurable performance or other barriers have substantially been met. As of December 31, 2024, *Long-Term Grants Payable* are due in 2026.

Functional Expenses:

The Organization allocates its expenses on a functional basis among various programs and support services. *Salaries and Related Expenses* 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 SETTLEMENT AGREEMENT RECEIVABLE

In 2024, the FSHD Society entered into a settlement agreement to resolve a contractual dispute related to services previously rendered under the original master license and services agreement for the implementation of its Integrated Health Platform as further discussed in Note 6. As part of the original contract, the Society made a one-time payment of \$200,000 in July 2023.

Under the terms of the settlement, the Society is entitled to receive a refund of \$175,000, which was received in April 2025, subsequent to year end. As of December 31, 2024, the Society has recorded a *Settlement Agreement Receivable* of \$175,000. The remaining \$25,000, representing the net cost of services not refunded, was recognized as an expense in 2024 and included in *Website and Computer Related Expenses* in the accompanying Statement of Functional Expenses. The receivable is considered fully collectible, and no allowance has been recorded. This settlement constitutes a full and final resolution of all claims between the parties.

NOTE 4 INVESTMENTS

As of December 31, 2024 and 2023, *Investments* on the Statements of Financial Position consist of the following:

<u>Investment Components</u>	<u>2024</u>	<u>2023</u>
Long-Term Investments	\$2,173,478	\$1,897,410
Deferred Compensation Investments	<u>142,613</u>	<u>103,254</u>
Total Fair Value Investments	2,316,091	2,000,664
Programmatic Equity Investments	<u>150,000</u>	<u>150,000</u>
Total Investments	<u>\$2,466,091</u>	<u>\$2,150,664</u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

(Continued)

NOTE 4 (Continued)

As of December 31, 2024 and 2023, the Organization's investments carried at fair value consisted of the following components:

<u>Investment Type</u>	<u>December 31, 2024</u>		
	<u>Fair Value</u>	<u>Fair Value (Level 1)</u>	<u>Fair Value (Level 2)</u>
Mutual Funds – Equity	\$1,592,063	\$1,592,063	\$ -
Exchange Traded Funds	162,400	162,400	-
Preferred Stocks and Bonds	31,850	-	31,850
US Treasury Bills	<u>529,778</u>	<u>529,778</u>	<u>-</u>
Total	<u>\$2,316,091</u>	<u>\$2,284,241</u>	<u>\$31,850</u>

<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>

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.

U.S. Treasury Notes: U.S government obligations are valued by the custodian of the securities using pricing models based on credit quality, time to maturity, stated interest rates, and market-rate assumptions.

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

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

(Continued)

NOTE 4 (Continued)

Components of *Investment Return* for the years ended December 31, 2024 and 2023, is as follows:

<u>Components of Investment Return</u>	<u>2024</u>	<u>2023</u>
Interest and Dividends	\$119,558	\$154,284
Unrealized Gains (Losses)	216,814	191,718
Realized Gains (Losses)	<u>2,833</u>	<u>(5,266)</u>
Net Investment Return (Loss)	<u>\$339,205</u>	<u>\$340,736</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. 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, 2024 and 2023, 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, 2024 and 2023. The Society’s investment is restricted for research in FSH muscular dystrophy.

NOTE 5 INTANGIBLE ASSETS

As of December 31, 2024, and 2023, intangible assets consisted of the following:

	<u>December 31, 2024</u>	
	<u>Gross Carrying Amount</u>	<u>Accumulated Amortization</u>
<u>Amortized Intangible Assets</u>		
Better Life Digital Platform	\$ 722,433	\$36,076
Website	<u>71,225</u>	<u>-</u>
Total Amortized Intangible Assets	<u>793,658</u>	<u>36,076</u>
<u>Unamortized Intangible Assets</u>		
Donated Intellectual Property	<u>676,250</u>	<u>-</u>
Total Intangible Assets	<u>\$1,469,908</u>	<u>\$36,076</u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

(Continued)

NOTE 5 (Continued)

	<u>December 31, 2023</u>	
	<u>Gross Carrying Amount</u>	<u>Accumulated Amortization</u>
<u>Amortized Intangible Assets</u>		
Better Life Digital Platform	<u>\$ 550,000</u>	<u>\$ -</u>

Better Life Digital Platform:

In 2024, the Society completed the implementation of the Better Life digital platform, a cloud-based digital health tool designed to support patient engagement and data collection. A total of \$722,433 in development costs incurred from 2022 through 2024 were capitalized upon the platform entering its useful life. These costs are broken as follows:

Phase 0 - technical assessment and design: \$250,000
Phase 1 - platform customization, dataset finalization, and launch: \$234,000
Phase 1B - development of new features including participant tracking: \$228,533
Clinician Care Connector tool - initial implementation: \$9,900

The digital platform is amortized over a useful life of five years. As the Better Life platform was placed in service in 2024, amortization expense of \$36,076 has been included in the financial statements for the year then ended. As of December 31, 2024, management expects future amortization expense on the existing asset to be as follows:

<u>Year Ended</u>	<u>Amount</u>
December 31, 2025	\$142,507
December 31, 2026	142,507
December 31, 2027	142,507
December 31, 2028	142,507
December 31, 2029	<u>116,329</u>
Total	<u>\$686,357</u>

Website Redesign:

The Society initiated a website redesign project to improve user experience, navigation, and mobile optimization. As of December 31, 2024, \$90,345 in total project costs had been incurred. Of this amount, \$71,225 was capitalized in 2024 as implementation costs, while \$19,120 related to planning and content development was expensed as incurred. The new website had not yet been implemented as of year-end; therefore, no amortization has been recorded for 2024.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

(Continued)

NOTE 5 *(Continued)*

Donated Intellectual Property:

In November 2024, the Society received a donation of an Intellectual Data Package from Fulcrum Therapeutics, Inc., following the discontinuation of its Losmapimod development program for FSHD. This data was independently valued at \$676,250, using both the cost-plus and comparable contract methodologies in accordance with Centers for Medicare & Medicaid Services (CMS) and the Internal Revenue Service (IRS) guidelines. The contribution was recognized as revenue during the year ended December 31, 2024, as it met the criteria for unconditional and unrestricted contribution.

The donated intellectual data package has been recorded as an intangible asset in the Society's Statement of Financial Position as of December 31, 2024. Due to the continuing strategic relevance and absence of legal or contractual expiration, the asset is considered to have an indefinite useful life. As such, the asset is not amortized but will be reviewed for impairment in accordance with FASB ASC 350.

NOTE 6 NET ASSETS WITH DONOR RESTRICTIONS

As of December 31, 2024, and 2023, net assets with donor restrictions were designated for research and education and consisted of the following balances:

<u>Nature of Restriction</u>	<u>2024</u>	<u>2023</u>
Research and Education	\$114,911	\$ -
FSHD Therapeutics	-	1,186,627
Total	<u>\$114,911</u>	<u>\$1,186,627</u>

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>2024</u>	<u>2023</u>
FSHD Therapeutics	\$2,378,335	\$2,394,430
Mobility Equipment Purchases for Patients	146,257	-
Int. Research Congress and Patient Meetings	107,376	63,000
Research and Education	95,800	144,518
Total	<u>\$2,727,768</u>	<u>\$2,601,948</u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

(Continued)

NOTE 7 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>2024</u>	<u>2023</u>
Scientific Committees Expenses	\$150,143	\$186,300
Science time for FSHD Connect and Patient Education	75,650	75,225
Public Awareness	87,823	58,502
Event Costs	-	15,000
Investment Advisory Services	<u>3,600</u>	<u>4,200</u>
Total	<u>\$317,216</u>	<u>\$339,227</u>

Donated science time for Peer-reviewed Study Group and TARC committees and for FSHD Connect and patient education is provided by volunteers who hold either a PhD or an MD. Their donated time helps the Society in fulfilling its fiduciary responsibilities to encourage and finance scientific and clinical research and development on 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.

NOTE 8 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, 2024 and 2023. The line bears interest at the bank's base rate. As of December 31, 2024 and 2023, the bank's base rate was 8.0% and 8.5%, 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.

NOTE 9 COMMITMENTS AND CONTINGENCIES

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

In October 2023, FSHD Society formalized its commitment to the Project Paladin consortium—a four-year collaboration among nine organizations dedicated to overcoming barriers in treatment, diagnosis, and care for neuromuscular patients worldwide. Funded by the European Union through Horizon Europe/Innovative Health Initiative (IHI), the project has a total budget of approximately €21 million (\$22,288,854) aimed at developing a state-of-the-art data collection platform, which includes both grant awards to certain organizations in the consortium combined with in-kind support from the members of the consortium.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

(Continued)

NOTE 9 (Continued)

Although FSHD Society is not receiving direct grant funding as a part of the consortium, the Organization is committed to providing €4,698,000 (\$4,986,335) in in-kind support to the project over the program period.

This commitment includes €1,600,000 (\$1,698,198) specifically allocated for operationalizing the BetterLife Platform, our patient registry platform as a component of Project Paladin. In addition, FSHD Society has committed a contribution of staff time valued at €2,261,220 (\$2,400,000) and €836,780 (\$888,136) in indirect costs. The Society is required to submit documentation of its in-kind support to the granting authority in accordance with the grant agreement.

For the year ending December 31, 2024, the Society provided a total in-kind contribution of €1,294,274 (\$1,339,209), which was broken down as follows: BetterLife Platform: €651,405 (\$672,433), Personnel Costs: €384,014 (\$398,934), Indirect Costs: €258,855 (\$267,842). In addition, FSHD has donated additional research consulting expenses on the project of \$294,022 during the year ended December 31, 2024. Expenses incurred as part of Project Paladin consortium are reported as *Consultants and Professional Fees* in the accompanying Statement of Functional Expenses.

The remaining in-kind commitment as of December 31, 2024, totaled (€3,403,726) \$3,647,126 which will be incurred over the three-year period ending December 31, 2027. The Society has no other remaining financial commitment associated with Paladin as of December 31, 2024.

BetterLife Digital Assets and Other Program Service Commitments:

As of December 31, 2024, the Society had outstanding commitments of \$334,867 for enhancement features to the BetterLife platform and \$19,750 for completion of the Care Connector tool.

During 2024, the Society entered into various professional service consulting agreements and venue contracts for 2025 conferences and meetings. Obligations incurred during 2024 under these agreements are approximately \$337,029. Approximately \$159,253 and \$116,667 of venue commitments and hosting fees for BetterLife are non-cancelable. These service commitments have not been accrued on the accompanying Statements of Financial Position because the various programs primarily occur in 2025.

NOTE 10 COVID RELIEF FUNDING

In 2020, the U.S. CARES Act introduced the Employee Retention Tax Credit—a refundable tax credit designed to offset certain employment taxes. For the year ended December 31, 2021, the Society recognized \$313,636 related to this credit as grant revenue. As of December 31, 2024, the Society has received \$229,550 in payments under this credit. Additionally, the Statements of Financial Position for December 31, 2024 and 2023, each report *Employee Retention Tax Credits Receivable* of \$84,086. Subsequent to year-end, the Society received the remaining \$84,086 in Employee Retention Tax Credit receivables, along with \$10,722 in interest.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

(Continued)

NOTE 11 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 2024 and 2023, the Society elected to make safe harbor matches of up to 4% of employees’ earnings.

For the years ended December 31, 2024 and 2023, the total employer contributions to its retirement plan were \$65,280 and \$62,411, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

NOTE 12 457(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, therefore the deferred compensation plan is fully vested as of December 31, 2024.

For the years ended December 31, 2024 and 2023, the Board voted to fund this plan in the amount of \$23,000 and \$22,500, 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, 2024 and 2023 were \$39,359 and \$31,245, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

NOTE 13 CONCENTRATIONS

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

Cash:

The Organization is subject to concentrations in credit risk relating to cash balances. The Society maintains bank accounts with two financial institutions, including an Insured Cash Sweep account (“ICS account”). After all debit and credit transactions have been 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, 2024 and 2023, cash balances in excess of the FDIC limit was \$20,461 and \$160,358, respectively. The Organization has not experienced any losses on uninsured cash balances.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

(Continued)

NOTE 13 *(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.

NOTE 14 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 expenditure, 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, 2024 and 2023:

	<u>2024</u>	<u>2023</u>
Financial Assets at Year End:		
Cash	\$1,096,154	\$ 3,574,002
Employee Retention Tax Credit Receivable	84,086	84,086
Settlement Agreement Receivable	175,000	-
Investments	<u>2,466,091</u>	<u>2,150,664</u>
Total Financial Assets	<u>3,821,331</u>	<u>5,808,752</u>
Less Amounts Not Available to be Used Within One Year:		
Programmatic Equity Investment	(150,000)	(150,000)
Deferred Compensation Liability	(142,613)	(103,254)
Grants Payable Due Within One Year	<u>(381,110)</u>	<u>(776,214)</u>
Financial Assets Not Available to be Used Within One Year	<u>(673,723)</u>	<u>(1,029,468)</u>
Financial Assets Available to Meet General Expenditures Within One Year	<u>\$3,147,608</u>	<u>\$ 4,779,284</u>

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2024

(With Summarized Comparative Information for 2023)

(Continued)

NOTE 15 SUBSEQUENT EVENTS

Management is required to consider events subsequent to the financial statement date for potential adjustment to or disclosure in the financial statements. Management has evaluated subsequent events through April 25, 2025, the date which the financial statements were available for issue and noted no events that met the recognition and disclosure criteria.