

CONSOLIDATED FINANCIAL STATEMENTS AND INDEPENDENT AUDITOR'S REPORT

FSHD SOCIETY AND SUBSIDIARY

December 31, 2025

## TABLE OF CONTENTS

Independent Auditor's Report	3 - 4
Financial Statements	
Consolidated Statement of Financial Position	5
Consolidated Statement of Activities	6
Consolidated Statement of Functional Expenses	7
Consolidated Statement of Cash Flows	8
Notes to Consolidated Financial Statements	9 - 20



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## INDEPENDENT AUDITOR'S REPORT

Board of Directors  
FSHD Society and Subsidiary

### **Opinion**

We have audited the accompanying consolidated financial statements of FSHD Society and Subsidiary (a nonprofit organization) (the "Organization"), which comprise the consolidated statement of financial position as of December 31, 2025, and the related consolidated statements of activities, functional expenses and cash flows for the year then ended, and the related notes to the consolidated financial statements.

In our opinion, the consolidated financial statements referred to above present fairly, in all material respects, the financial position of the Organization as of December 31, 2025, 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 Auditor's Responsibilities for the Audit of the Consolidated Financial Statements section of our report. We are required to be independent of the Organization 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.

### **Prior Period Financial Statements**

The financial statements of FSHD Society and Subsidiary as of December 31, 2024, were audited by other auditors whose report dated April 25, 2025, expressed an unmodified opinion on those financial statements. The summarized comparative information presented herein as of and for the year ended December 31, 2024, is consistent, in all material respects, with the audited financial statements from which it has been derived.

### **Responsibilities of Management for the Consolidated 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 consolidated financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about the Organization's ability to continue as a going concern within one year after the date that the consolidated financial statements are available to be issued.

### **Auditor's Responsibilities for the Audit of the Consolidated Financial Statements**

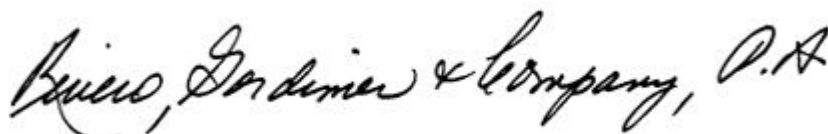
Our objectives are to obtain reasonable assurance about whether the consolidated financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not 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 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.

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 consolidated 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 the Organization'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 consolidated financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about the Organization'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.

Tampa, Florida  
April 30, 2026



FSDH Society and Subsidiary

CONSOLIDATED STATEMENT OF FINANCIAL POSITION

December 31, 2025

(With summarized comparative information for 2024)

	2025	2024
<b>ASSETS</b>		
Cash	\$ 134,456	\$ 1,096,154
Accounts receivable	75,000	259,086
Prepaid expenses	216,430	337,028
Total current assets	425,886	1,692,268
Investments	2,198,373	2,466,091
Intangible assets, net	2,909,493	1,433,832
Total long-term assets	5,107,866	3,899,923
<b>TOTAL ASSETS</b>	<b>\$ 5,533,752</b>	<b>\$ 5,592,191</b>
<b>LIABILITIES AND NET ASSETS</b>		
Grants payable	\$ 305,230	\$ 381,110
Accounts payable and accrued expenses	778,225	343,126
Line of credit	50,000	-
Total current liabilities	1,133,455	724,236
Deferred compensation liability	185,044	142,613
Grants payable	97,125	26,550
Total long-term liabilities	282,169	169,163
<b>TOTAL LIABILITIES</b>	<b>1,415,624</b>	<b>893,399</b>
Net assets without donor restrictions	3,934,966	4,583,881
Net assets with donor restrictions	183,162	114,911
Total net assets	4,118,128	4,698,792
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b>\$ 5,533,752</b>	<b>\$ 5,592,191</b>

The accompanying notes are an integral part of this statement.

FSHD Society and Subsidiary

CONSOLIDATED STATEMENT OF ACTIVITIES

For the year ended December 31, 2025  
(With summarized comparative information for 2024)

	Without Donor Restrictions	With Donor Restrictions	Total	
			2025	2024
<b>PUBLIC SUPPORT AND REVENUE</b>				
Support and revenues				
Contributions and grants	\$ 2,829,838	\$ 560,923	\$ 3,390,761	\$ 3,104,999
Special events, net	1,048,948	-	1,048,948	918,733
Donated goods and services	252,000	-	252,000	317,216
Donated intellectual property	955,000	-	955,000	676,250
Program revenue	318,071	-	318,071	120,198
Total support and revenues	<u>5,403,857</u>	<u>560,923</u>	<u>5,964,780</u>	<u>5,137,396</u>
Investment and other Income				
Investment return, net	317,712	-	317,712	339,205
Other income	2,703	-	2,703	-
Total investment and other income	<u>320,415</u>	<u>-</u>	<u>320,415</u>	<u>339,205</u>
Total revenues	5,724,272	560,923	6,285,195	5,476,601
Net assets released from restriction	<u>492,672</u>	<u>(492,672)</u>	<u>-</u>	<u>-</u>
Total revenues, support and net assets released from restrictions	<u>6,216,944</u>	<u>68,251</u>	<u>6,285,195</u>	<u>5,476,601</u>
<b>EXPENSES</b>				
Program Services				
Research and Patient Programs	<u>5,459,312</u>	<u>-</u>	<u>5,459,312</u>	<u>4,594,470</u>
Supporting Services				
Management and general	696,910	-	696,910	568,150
Development	709,637	-	709,637	629,872
Total supporting services	<u>1,406,547</u>	<u>-</u>	<u>1,406,547</u>	<u>1,198,022</u>
Total expenses	<u>6,865,859</u>	<u>-</u>	<u>6,865,859</u>	<u>5,792,492</u>
Change in net assets	(648,915)	68,251	(580,664)	(315,891)
Net assets, beginning of year	<u>4,583,881</u>	<u>114,911</u>	<u>4,698,792</u>	<u>5,014,683</u>
Net assets, end of year	<u>\$ 3,934,966</u>	<u>\$ 183,162</u>	<u>\$ 4,118,128</u>	<u>\$ 4,698,792</u>

The accompanying notes are an integral part of this statement.

FSHD Society and Subsidiary

CONSOLIDATED STATEMENT OF FUNCTIONAL EXPENSES

For the year ended December 31, 2025  
(With summarized comparative information for 2024)

	Research and Patient Programs	Management and General	Development	Total	
				2025	2024
Salaries and related expenses	\$ 2,086,267	\$ 486,906	\$ 460,784	\$ 3,033,957	\$ 2,701,795
Chapter and volunteer development	3,667	-	41	3,708	3,321
Cloud computing expenses and amortization	230,720	-	-	230,720	102,743
Consultants and professional fees	1,143,910	58,643	-	1,202,553	970,372
Directors expenses	-	37,607	-	37,607	16,348
Donated services	249,140	2,860	-	252,000	317,216
Donor software and donor engagement	-	-	47,863	47,863	49,642
Insurance	2,408	10,518	-	12,926	14,762
Office expenses	66,823	28,448	18,733	114,004	38,620
Patient meetings and research conferences	281,662	-	500	282,162	386,130
Printing	79,481	159	28,180	107,820	97,437
Public awareness	109,853	-	850	110,703	51,056
Research and equipment grants	497,280	-	-	497,280	278,084
Service charges	39,857	19,141	71,129	130,127	121,658
Travel, lodging and meals	375,395	10,670	41,220	427,285	407,713
Website and computer related expenses	292,849	41,958	40,337	375,144	235,595
Total	<u>\$ 5,459,312</u>	<u>\$ 696,910</u>	<u>\$ 709,637</u>	<u>\$ 6,865,859</u>	<u>\$ 5,792,492</u>

The accompanying notes are an integral part of this statement.

FSHD Society and Subsidiary

CONSOLIDATED STATEMENT OF CASH FLOWS

For the year ended December 31, 2025  
(With summarized comparative information for 2024)

	<u>2025</u>	<u>2024</u>
Cash flows from operating activities		
Change in net assets	\$ (580,664)	\$ (315,891)
Adjustments to reconcile changes in net assets to net cash		
Used by operating activities		
Unrealized gain on investments	(143,416)	(276,068)
Contributions to deferred compensation plan	(42,431)	(39,359)
Amortization expense	230,720	36,076
Write off of intangible digital assets, net of settlement	-	125,000
Donated intangible intellectual property	(955,000)	(676,250)
Changes in operating assets and liabilities		
Accounts receivable	184,086	-
Prepaid expenses	120,598	(274,526)
Grants payable	(5,305)	(575,132)
Accounts payable and accrued expenses	435,099	22,601
Total adjustments	<u>(175,649)</u>	<u>(1,657,658)</u>
Net cash used in operating activities	<u>(756,313)</u>	<u>(1,973,549)</u>
Cash flows from investing activities		
Purchase of intangible digital assets	(695,097)	(472,433)
Purchase of intangible website asset	(56,284)	(71,225)
Increase in long-term deferred compensation liability	42,431	39,359
Sale of investments	453,565	-
Net cash used in investing activities	<u>(255,385)</u>	<u>(504,299)</u>
Cash flows from financing activities		
Draw on line of credit	50,000	-
Net decrease in cash balances	(961,698)	(2,477,848)
Cash and cash equivalent balances, beginning of year	<u>1,096,154</u>	<u>3,574,002</u>
Cash and cash equivalents, end of year	<u>\$ 134,456</u>	<u>\$ 1,096,154</u>
Supplemental disclosures of cash flow information		
Cash paid during the year		
Interest	<u>\$ 2,318</u>	<u>\$ -</u>
Income taxes	<u>\$ -</u>	<u>\$ -</u>

The accompanying notes are an integral part of this statement.

## FSHD Society and Subsidiary

### NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS

December 31, 2025

#### NOTE A - DESCRIPTION OF THE ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

##### 1. Nature of the Organization

The FSHD Society (the “Society”) 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.

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.

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.

The financial activities of the Society and Hub, collectively “(the Organization)” have been consolidated in these financial statements. All significant inter-organizational transactions have been eliminated in the accompanying consolidated financial statements.

##### 2. Basis of Accounting

The consolidated financial statements of the Organization 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.

FSHD Society and Subsidiary

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED

December 31, 2025

NOTE A - DESCRIPTION OF THE ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - Continued

3. 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 consolidated financial statements and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates, and those differences could be material.

4. 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 consolidated financial statements is the recurring measurement of investments. There have been no changes to this valuation methodology.

5. 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.

FSHD Society and Subsidiary

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED

December 31, 2025

NOTE A - DESCRIPTION OF THE ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - Continued

- 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. 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. As of December 31, 2025, the Organization has no net assets that are required to be maintained in perpetuity.

6. Intangible Assets

The Organization 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 2025, the Organization capitalized \$2,919,894 in Intangible Assets as further discussed in Note C. Intangible Assets are further classified as amortized or unamortized based on the existence or non-existence of an indefinite useful life.

7. 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 and Subsidiary

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED

December 31, 2025

NOTE A - DESCRIPTION OF THE ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - 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 consolidated statements of financial position. Net investment return (loss) is reported in the consolidated 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 Organization's programmatic investments are accounted for under the cost method of accounting as further discussed in Note B.

8. Revenue Recognition

The Organization recognizes revenue from numerous sources as follows:

*Gifts, Grants and Contributions:* The Organization 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.

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.

FSHD Society and Subsidiary

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED

December 31, 2025

NOTE A - DESCRIPTION OF THE ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - Continued

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.

*Special Event Revenue* is comprised of an exchange element based upon the direct benefits donors receive and a contribution element for the difference. The Organization recognizes special events revenue equal to the fair value of direct benefits to donors when the special event takes place. The Organization 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 Organization 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 Organization recognizes the exchange portion of the sponsorship once the conference or program is held and the contribution portion immediately.

9. Grants Expense, Return of Grant Funds, and Grants Payable

The Organization 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, 2025, 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.

Conditional commitments are not recognized in the financial statements until measurable performance or other barriers have substantially been met. As of December 31, 2025, Long-Term Grants Payable are due in 2027.

10. 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.

FSHD Society and Subsidiary

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED

December 31, 2025

NOTE A - DESCRIPTION OF THE ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES - Continued

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.

11. Concentrations

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

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, 2025, there were no balances in excess of the FDIC limit. The Organization has not experienced any losses on uninsured cash balances.

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 B - INVESTMENTS

As of December 31, 2025, investments consisted of the following:

Long-Term Investments	\$ 1,863,329
Deferred Compensation Investments	185,044
Total Fair Value Investments	<u>2,048,373</u>
Programmatic Equity Investments	<u>150,000</u>
Total Investments	<u>\$ 2,198,373</u>

FSHD Society and Subsidiary

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED

December 31, 2025

NOTE B - INVESTMENTS - Continued

As of December 31, 2025, the Organization's investments carried at fair value consisted of the following components:

	Level 1	Level 2	Level 3	Total
Mutual Funds – Equity	\$ 1,844,633	\$ -	\$ -	\$ 1,844,633
Exchange Traded Funds	170,761	-	-	170,761
Preferred Stocks and Bonds	-	31,577	-	31,577
US Treasury Bills	1,402	-	-	1,402
	<u>1,402</u>	<u>-</u>	<u>-</u>	<u>1,402</u>
Total	<u>\$ 2,016,796</u>	<u>\$ 31,577</u>	<u>\$ -</u>	<u>\$ 2,048,373</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.

As of December 31, 2025, the Organization 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 year ended December 31, 2025. The Society's investment is restricted for research in FSH muscular dystrophy.

FSHD Society and Subsidiary

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED

December 31, 2025

NOTE C - INTANGIBLE ASSETS

As of December 31, 2025, intangible assets consisted of the following:

	<u>Gross Carrying Amount</u>	<u>Accumulated Amortization</u>
Amortized Intangible Assets		
Better Life Digital Platform	\$ 1,169,950	\$ 245,694
Website	118,694	21,102
Work in process	256,395	-
Total Amortized Intangible Assets	<u>1,545,039</u>	<u>266,796</u>
Unamortized Intangible Assets		
Donated Intellectual Property	<u>1,631,250</u>	<u>-</u>
Total Intangible Assets	<u>\$ 3,176,289</u>	<u>\$ 266,796</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. In 2025, the Hub invested in a similar platform. A total of \$1,417,530 in development costs incurred from 2022 through 2025 were capitalized for both projects, of which \$247,580 was included in work in process.

The digital platform is amortized over a useful life of five years. The Better Life platform for the Society was placed in service in 2024, amortization expense of \$209,618 has been included in the financial statements for the year then ended. The Better Life platform for the HUB is still considered to be in process and was not amortized for the year then ended.

Management expects future amortization expense on the existing asset to be as follows:

Year ended December 31,

2026	\$ 232,010
2027	232,010
2028	232,010
2029	<u>228,226</u>
	<u>\$ 924,256</u>

FSHD Society and Subsidiary

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED

December 31, 2025

NOTE C - INTANGIBLE ASSETS - Continued

Website Redesign

The Society initiated a website redesign project to improve user experience, navigation, and mobile optimization. As of December 31, 2025, \$118,694 was capitalized, as implementation costs, while planning and content development costs are expensed as incurred. The website was placed in service during 2025, amortization expense of \$21,102 has been included in the financial statements for the year then ended.

Management expects future amortization expense on the existing asset to be as follows:

<u>Year ended December 31,</u>	
2026	\$ 39,565
2027	39,565
2028	<u>18,463</u>
	<u>\$ 97,593</u>

The Hub had \$8,815 of website redesign in work in process at December 31, 2025.

Donated Intellectual Property

During 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. During 2025, the Society received an additional donation for Phase 2 of this project, independently valued at \$1,002,469 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, 2025, as it met the criteria for unconditional and unrestricted contribution.

As of December 31, 2025, the donated intellectual data package has been recorded as an intangible asset in the Society's Statement of Financial Position, with a total value of \$1,631,250. 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.

FSHD Society and Subsidiary

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED

December 31, 2025

NOTE D - NET ASSETS WITH DONOR RESTRICTIONS

Net assets with donor restrictions were designated for research and education were \$183,162 at December 31, 2025.

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 were \$492,672 for the year ended December 31, 2025.

NOTE E - DONATED GOODS AND SERVICES

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

Scientific Committees Expenses	\$	212,447
Public Awareness		35,953
Investment Advisory Services		<u>3,600</u>
	\$	<u><u>252,000</u></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 F - LINE OF CREDIT

During 2018, the Society entered into a line of credit agreement with a bank for \$250,000. The balance on the line of credit was \$50,000 at December 31, 2025. The line bears interest at the bank's base rate. As of December 31, 2025, the bank's base rate was 8.0%. 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.

## FSHD Society and Subsidiary

### NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED

December 31, 2025

#### NOTE F - LINE OF CREDIT - Continued

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 G - 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.

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 €1,272,488 (\$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 €2,485,912 (\$2,400,000) and €939,600 (\$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, 2025, the Society provided a total in-kind contribution of €3,228,420 (\$3,353,854), which was broken down as follows: Purchases: which include BetterLife Platform: €1,278,825 (\$1,328,511); Travel and Subsistence: €54,010 (\$56,108) and Other Goods and Services: €232,662 (\$241,702), Personnel Costs: €1,017,238 (\$1,056,761), Indirect Costs: €645,684 (\$670,771).

The remaining in-kind commitment as of December 31, 2025, totaled (€1,469,580) \$1,526,678 which will be incurred over the two-year period ending December 31, 2027. The Society has no other remaining financial commitment associated with Paladin as of December 31, 2025.

##### Other Program Service Commitments

As of December 31, 2025, the Society had outstanding commitments of \$177,367 for enhancement features to the BetterLife platform, while the Hub had outstanding commitments of \$500,795 for BetterLife and FOCUS platforms.

FSHD Society and Subsidiary

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED

December 31, 2025

NOTE G - COMMITMENTS AND CONTINGENCIES - Continued

During 2025, the Society entered into various professional service consulting agreements and venue contracts for 2026 conferences and meetings. Obligations incurred during 2025 under these agreements are approximately \$318,889. Approximately \$114,960 and \$116,667 of venue commitments and hosting fees for BetterLife are non-cancelable. These service commitments have not been accrued on the accompanying statement of financial position because the various programs primarily occur in 2026.

NOTE H - RETIREMENT PLAN

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 2025 the Society elected to make safe harbor matches of up to 4% of employees’ earnings.

For the year ended December 31, 2025, the total employer contributions to its retirement plan were \$83,158 and are included in salaries and related expenses in the accompanying statement of functional expenses.

NOTE I - 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, 2025, for employer contributions in the plan to vest, therefore the deferred compensation plan is fully vested as of December 31, 2025.

For the year ended December 31, 2025, the Board voted to fund this plan in the amount of \$23,500. 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 year ended December 31, 2025, was \$42,431, and is included in Salaries and Related Expenses in the accompanying Statement of Functional Expenses.

FSHD Society and Subsidiary

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED

December 31, 2025

NOTE J - LIQUIDITY AND AVAILABILITY

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 as of December 31, 2025:

Financial Assets at Year End	
Cash	\$ 134,456
Investments	<u>2,198,373</u>
Total Financial Assets	<u>2,332,829</u>
Less Amounts Not Available to be Used Within One Year	
Programmatic Equity Investment	(150,000)
Deferred Compensation Liability	(185,044)
Grants Payable Due Within One Year	<u>(305,230)</u>
Financial Assets Not Available to be Used Within One Year	<u>(640,274)</u>
Financial Assets Available to Meet General Expenditures Within One Year	<u>\$ 1,692,555</u>

FSHD Society and Subsidiary

NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS - CONTINUED

December 31, 2025

NOTE K - SUMMARIZED COMPARATIVE INFORMATION

The accompanying financial statements include certain 2024 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, 2024 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, 2024, from which the summarized information was derived.

NOTE L - SUBSEQUENT EVENTS

The Organization has evaluated subsequent events through April 30, 2026, which is the date on which the financial statements were available to be issued.