

FSHD SOCIETY
FINANCIAL STATEMENTS

with

INDEPENDENT AUDITORS' REPORT

YEAR ENDED DECEMBER 31, 2021
(With Summarized Comparative Information for 2020)

Smith  Sullivan
& Brown PC
CERTIFIED PUBLIC ACCOUNTANTS

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FSHD SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2021
(With Summarized Comparative Information for 2020)



Our Vision

To deliver treatments and a cure for FSH muscular dystrophy.

Mission

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

Strategic Imperatives

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

FSHD SOCIETY

REPORT ON FINANCIAL STATEMENTS

YEAR ENDED DECEMBER 31, 2021

(With Summarized Comparative Information for 2020)

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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, 2021, 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, 2021, 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, 2020 financial statements, and we expressed an unmodified audit opinion on those audited financial statements in our report dated March 16, 2021. In our opinion, the summarized comparative information presented herein as of and for the year ended December 31, 2020, is consistent, in all material respects, with the audited financial statements from which it has been derived.

Smith, Sullivan & Brown, PC

Westborough, Massachusetts
March 15, 2022

FSHD SOCIETY

STATEMENTS OF FINANCIAL POSITION
AS OF DECEMBER 31, 2021 AND 2020

| <u>ASSETS</u> | <u>2021</u> | <u>2020</u> |
|---|---------------------|---------------------|
| <u>CURRENT ASSETS:</u> | | |
| Cash and Cash Equivalents | \$ 4,820,728 | \$ 3,280,720 |
| Employee Retention Tax Credit Receivable | 227,839 | - |
| Contributions Receivable | 65,847 | 340,181 |
| Prepaid Expenses | <u>123,679</u> | <u>61,251</u> |
| Total Current Assets | <u>5,238,093</u> | <u>3,682,152</u> |
| <u>NET PROPERTY AND EQUIPMENT</u> | <u>-</u> | <u>5,097</u> |
| <u>NON-CURRENT ASSETS:</u> | | |
| Contributions Receivable | - | 50,000 |
| Deposits | 4,477 | 4,477 |
| Investments | <u>2,396,249</u> | <u>2,093,769</u> |
| Total Non-Current Assets | <u>2,400,726</u> | <u>2,148,246</u> |
| <u>TOTAL ASSETS</u> | <u>\$ 7,638,819</u> | <u>\$ 5,835,495</u> |
| <u>LIABILITIES AND NET ASSETS</u> | | |
| <u>CURRENT LIABILITIES:</u> | | |
| Grants Payable | \$ 669,087 | \$ 216,929 |
| Accounts Payable and Accrued Expenses | <u>51,730</u> | <u>43,016</u> |
| Total Current Liabilities | <u>720,817</u> | <u>259,945</u> |
| <u>LONG-TERM LIABILITIES:</u> | | |
| Long-Term Deferred Compensation Liability | 67,801 | 41,878 |
| Long-Term Grants Payable | <u>497,791</u> | <u>-</u> |
| Total Long-Term Liabilities | <u>565,592</u> | <u>41,878</u> |
| <u>TOTAL LIABILITIES</u> | <u>1,286,409</u> | <u>301,823</u> |
| <u>NET ASSETS:</u> | | |
| Net Assets Without Donor Restrictions | 3,975,882 | 3,007,424 |
| Net Assets With Donor Restrictions | <u>2,376,528</u> | <u>2,526,248</u> |
| Total Net Assets | <u>6,352,410</u> | <u>5,533,672</u> |
| <u>TOTAL LIABILITIES AND NET ASSETS</u> | <u>\$ 7,638,819</u> | <u>\$ 5,835,495</u> |

FSHD SOCIETY
STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED DECEMBER 31, 2021
(With Summarized Comparative Totals for 2020)

| | <u>WITHOUT DONOR RESTRICTIONS</u> | <u>WITH DONOR RESTRICTIONS</u> | <u>TOTAL ACTIVITIES</u> | |
|---|---|--|----------------------------|----------------------------|
| | | | <u>2021</u> | <u>2020</u> |
| <u>SUPPORT, REVENUES AND RECLASSIFICATIONS</u> | | | | |
| <i>Support and Revenues:</i> | | | | |
| Gifts, Grants and Contributions | \$ 2,196,683 | \$ 1,844,977 | \$ 4,041,660 | \$ 1,748,962 |
| Gross Special Events Revenue | 861,126 | 37,670 | 898,796 | 541,907 |
| Less: Cost of Direct Benefits to Donors | (80,497) | - | (80,497) | (18,698) |
| Donated Goods and Services | 225,200 | - | 225,200 | 76,075 |
| Program Revenue | 172,014 | - | 172,014 | 158,395 |
| Total Support and Revenues | <u>3,374,526</u> | <u>1,882,647</u> | <u>5,257,173</u> | <u>2,506,641</u> |
| <i>Investment and Other Income:</i> | | | | |
| Return of Grant Funds | 34,640 | - | 34,640 | - |
| Investment Return, Net | 6,822 | 362,706 | 369,528 | 399,879 |
| Other Income (Loss) | 424 | - | 424 | 527 |
| Total Investment and Other Income | <u>41,886</u> | <u>362,706</u> | <u>404,592</u> | <u>400,406</u> |
| <i>Reclassification of Net Assets:</i> | | | | |
| Net Assets Released From Restriction | <u>2,395,073</u> | <u>(2,395,073)</u> | <u>-</u> | <u>-</u> |
| <u>TOTAL SUPPORT, REVENUES AND RECLASSIFICATIONS</u> | <u>5,811,485</u> | <u>(149,720)</u> | <u>5,661,765</u> | <u>2,907,047</u> |
| <u>EXPENSES:</u> | | | | |
| <i>Program Services:</i> | | | | |
| Research | 3,036,600 | - | 3,036,600 | 1,364,207 |
| Patient Advocacy and Education | 1,037,663 | - | 1,037,663 | 820,896 |
| Total Program Services | <u>4,074,263</u> | <u>-</u> | <u>4,074,263</u> | <u>2,185,103</u> |
| <i>Supporting Services:</i> | | | | |
| Administrative | 332,434 | - | 332,434 | 366,401 |
| Fund Raising | 436,330 | - | 436,330 | 439,375 |
| Total Supporting Services | <u>768,764</u> | <u>-</u> | <u>768,764</u> | <u>805,776</u> |
| <u>TOTAL EXPENSES</u> | <u>4,843,027</u> | <u>-</u> | <u>4,843,027</u> | <u>2,990,879</u> |
| <u>CHANGE IN NET ASSETS BEFORE OTHER CHANGES</u> | 968,458 | (149,720) | 818,738 | (83,832) |
| <u>OTHER CHANGE IN NET ASSETS:</u> | | | | |
| Other Loss (See Note 11) | - | - | - | (99,934) |
| <u>TOTAL CHANGES IN NET ASSETS</u> | 968,458 | (149,720) | 818,738 | (183,766) |
| <u>NET ASSETS - BEGINNING OF YEAR</u> | <u>3,007,424</u> | <u>2,526,248</u> | <u>5,533,672</u> | <u>5,717,438</u> |
| <u>NET ASSETS - END OF YEAR</u> | <u>\$ 3,975,882</u> | <u>\$ 2,376,528</u> | <u>\$ 6,352,410</u> | <u>\$ 5,533,672</u> |

FSHD SOCIETY

STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2021
(With Summarized Comparative Totals for 2020)

| | <u>RESEARCH</u> | <u>PATIENT ADVOCACY AND EDUCATION</u> | <u>TOTAL PROGRAM SERVICES</u> | <u>ADMINI- STRATIVE</u> | <u>FUND RAISING</u> | <u>TOTAL FUNCTIONAL EXPENSES</u> | |
|---|----------------------------|---|---------------------------------------|-----------------------------|--------------------------|--------------------------------------|----------------------------|
| | | | | | | <u>2021</u> | <u>2020</u> |
| Salaries and Related Expenses | \$ 450,740 | \$ 661,330 | \$ 1,112,070 | \$ 245,583 | \$ 279,420 | \$ 1,637,073 | \$ 1,622,282 |
| Scientific Grants and Projects | 2,347,464 | - | 2,347,464 | - | - | 2,347,464 | 625,018 |
| Travel, Lodging and Meals | 11,589 | 39,049 | 50,638 | 871 | 19,923 | 71,432 | 46,622 |
| Consultants and Professional Fees | 17,240 | 35,342 | 52,582 | 7,716 | - | 60,298 | 73,139 |
| Patient Meetings and Research Conferences | 63,071 | 7,522 | 70,593 | - | - | 70,593 | 90,452 |
| Website and Computer Related Expenses | 41,772 | 54,420 | 96,192 | 14,571 | 18,584 | 129,347 | 117,458 |
| Donated Services | 70,300 | 150,700 | 221,000 | 4,200 | - | 225,200 | 76,075 |
| Printing | 490 | 33,112 | 33,602 | - | 32,376 | 65,978 | 72,235 |
| Fundraising Expenses | - | - | - | - | 100,033 | 100,033 | 53,774 |
| Bad Debt Expense | - | - | - | 2,504 | - | 2,504 | 50,000 |
| Bank Service Charges and Credit Card Processing Fees | 9,461 | 13,182 | 22,643 | 8,765 | 43,492 | 74,900 | 42,039 |
| Office Expenses | 11,615 | 17,922 | 29,537 | 6,197 | 13,467 | 49,201 | 37,732 |
| Occupancy | 12,658 | 18,324 | 30,982 | 7,971 | 7,861 | 46,814 | 44,185 |
| Chapter and Volunteer Development | - | 4,887 | 4,887 | - | 70 | 4,957 | 22,207 |
| Directors Expenses | - | - | - | 5,250 | - | 5,250 | 5,268 |
| Accounting, Auditing and Financial Consultants | - | - | - | 15,500 | - | 15,500 | 15,500 |
| Insurance | - | 105 | 105 | 8,209 | - | 8,314 | 7,137 |
| Depreciation Expense | - | - | - | 5,097 | - | 5,097 | 2,011 |
| Public Awareness | 200 | 1,768 | 1,968 | - | 1,601 | 3,569 | 6,443 |
| Total Functional Expenses | 3,036,600 | 1,037,663 | 4,074,263 | 332,434 | 516,827 | 4,923,524 | 3,009,577 |
| Less: Cost of Direct Benefits to Donors | - | - | - | - | (80,497) | (80,497) | (18,698) |
| Total Expenses per Statement of Activities | <u>\$ 3,036,600</u> | <u>\$ 1,037,663</u> | <u>\$ 4,074,263</u> | <u>\$ 332,434</u> | <u>\$ 436,330</u> | <u>\$ 4,843,027</u> | <u>\$ 2,990,879</u> |

FSHD SOCIETY

STATEMENTS OF CASH FLOWS
FOR THE YEARS ENDED DECEMBER 31, 2021 AND 2020

| | <u>2021</u> | <u>2020</u> |
|--|----------------------------|----------------------------|
| <u>CASH FLOWS FROM OPERATING ACTIVITIES:</u> | | |
| Change in Net Assets | \$ 818,738 | \$ (183,766) |
| <i>Adjustments to Reconcile Changes in Net Assets to Net Cash Provided (Used) by Operating Activities:</i> | | |
| Depreciation Expense | 5,097 | 2,011 |
| Contributions of Mutual Funds to Lewis Family Donor Advised Fund for FSHD | (1,008,635) | - |
| Contributions Restricted for Lewis Family Donor Advised Fund for FSHD | - | (7,500) |
| Investment Return, Net | (363,022) | (392,343) |
| Deferrals to Deferred Compensation Plan | (25,923) | (22,878) |
| <i>Changes in Operating Assets and Liabilities:</i> | | |
| Employee Retention Tax Credit Receivable | (227,839) | - |
| Contributions Receivable - Current and Long-Term | 324,334 | 774,095 |
| Prepaid Expenses | (62,428) | (15,490) |
| Grants Payable - Current and Long-Term | 949,949 | (269,121) |
| Accounts Payable and Accrued Expenses | 8,714 | (7,024) |
| Accrued Payroll and Related Costs | - | (219,938) |
| Net Adjustment | <u>(399,753)</u> | <u>(158,188)</u> |
| <u>NET CASH PROVIDED (USED) BY OPERATING ACTIVITIES</u> | <u>418,985</u> | <u>(341,954)</u> |
| <u>CASH FLOWS FROM INVESTING ACTIVITIES:</u> | | |
| Proceeds from Sale of Donor Advised Fund Investments | 1,095,100 | 1,132,000 |
| Purchase of Investments | - | (150,000) |
| Net Cash Flows From Investing Activities | <u>1,095,100</u> | <u>982,000</u> |
| <u>CASH FLOWS FROM FINANCING ACTIVITIES:</u> | | |
| Increase in Long-Term Deferred Compensation Liability | 25,923 | 22,878 |
| Net Cash Flows From Financing Activities | <u>25,923</u> | <u>22,878</u> |
| <u>NET INCREASE IN CASH BALANCES</u> | <u>1,540,008</u> | <u>662,924</u> |
| <u>CASH AND CASH EQUIVALENTS - BEGINNING OF YEAR</u> | <u>3,280,720</u> | <u>2,617,796</u> |
| <u>CASH AND CASH EQUIVALENTS - END OF YEAR</u> | <u>\$ 4,820,728</u> | <u>\$ 3,280,720</u> |
| <i>Non-Cash Investing and Financing Activities :</i> | | |
| Contributions of Mutual Funds to Lewis Family Donor Advised Fund for FSHD | <u>\$ 1,008,635</u> | <u>\$ -</u> |

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2021

(With Summarized Comparative Information for 2020)

NOTE 1 OPERATIONS AND NONPROFIT STATUS

Operations:

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

Nonprofit Status:

The Organization was originally incorporated as the Facioscapulohumeral (FSH) Society in 1991, under the provisions of the District of Columbia Nonprofit Corporation Act and qualifies as a tax-exempt not-for-profit corporation under Section 501(c)(3) of the Internal Revenue Code. Effective October 2, 2019, the Society legally changed its name to FSHD Society. The FSHD Society is not classified as a private foundation under Section 509(a); accordingly, contributions made to this Organization qualify for the maximum charitable deduction for Federal income tax purposes.

NOTE 2 SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

The accounting policies which affect significant elements of the Organization’s financial statements are described below to enhance the usefulness of the financial statements to the reader. The preparation of financial statements in conformity with generally accepted accounting principles requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates; however, adherence to generally accepted accounting principles has, in management’s opinion, resulted in reliable and consistent financial reporting by the Organization.

Basis of Accounting:

The Organization’s policy is to maintain its books and prepare its financial statements on the accrual basis of accounting in accordance with generally accepted accounting principles. Consequently, revenues and gains are recognized when earned and expenses and losses are recognized when a liability has been incurred.

Cash and Cash Equivalents:

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

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2021

(With Summarized Comparative Information for 2020)

(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:

As required by the *FASB Accounting Standards Codification*TM, the Organization classifies its net assets based on the existence or absence of donor or grantor-imposed restrictions. Accordingly, net assets and changes in net assets therein are classified and reported as follows:

Net Assets Without Donor Restrictions - consists of assets, public support and program revenues which are available and used for activities and programs. Net assets without donor restrictions represents the portion of net assets of the Organization that is not restricted by donor-imposed stipulations. Contributions are considered without restriction unless specifically restricted by the donor. In addition, net assets without donor restrictions may include funds which represent unrestricted resources designated by the Board of Directors for specific purposes.

Net Assets With Donor Restrictions - includes funds with donor-imposed restrictions which permit the donee organization to expend the assets as specified and are satisfied either by the passage of time or by actions of the Organization. Resources of this nature originate from gifts, grants, bequests, and contracts, and may include investment income earned on restricted funds.

These may also include resources which have a permanent donor-imposed restriction which stipulates that the assets are to be maintained permanently but permits the Organization to expend part or all the income derived from the donated assets.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2021

(With Summarized Comparative Information for 2020)

(Continued)

NOTE 2 *(Continued)*

Contributions Receivable:

Contributions Receivable are classified as current if they are scheduled for receipt within one year and non-current when the expected date of receipt exceeds one year. Unconditional promises to give that are expected to be collected within one year are reported at net realizable value. Unconditional promises to give due in future years are initially valued at a discounted rate when such amounts are considered material. For each of the years presented, non-current contributions receivable were due within five years. Management determines the allowance for uncollectable contributions receivable on historical experience, an assessment of economic conditions, and a review of subsequent collections. Contributions receivable are written off when deemed uncollectable. The following table shows the activity in the allowance for doubtful accounts:

| | <u>2021</u> | <u>2020</u> |
|-------------------------------------|-----------------|-----------------|
| Balance at Beginning of Period | \$ 50,000 | \$ - |
| Bad Debt Expense | 2,504 | 50,000 |
| Write-Off of Uncollectible Accounts | <u>(52,504)</u> | <u>-</u> |
| Balance at End of Period | <u>\$ -</u> | <u>\$50,000</u> |

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 a cure for FSH muscular dystrophy.

The Organization maintains an investment portfolio which consists of cash, mutual funds, exchange traded funds (ETFs) and preferred stocks and bonds. As required by the FASB Accounting Standards Codification™, investment purchases are recorded at cost, or if donated, at fair value on the date of donation. Thereafter, investments are reported at their fair values in the Statement of Financial Position. Net investment return (loss) is reported in the Statement of Activities and consists of interest and dividend income, realized and unrealized capital gains and losses, less external and direct internal investment expenses. Purchases and sales of securities are recorded on the trade date. In determining the gains (losses) realized on the sales of securities, the cost of the securities sold has been determined on a first in, first out basis. Cash held in brokerage accounts is reported as investments for purposes of these financial statements. Investments are classified as either short-term or long-term depending on the underlying intentions. *See Footnote 4.*

Programmatic investments are subject to the same accounting standards as similar financial instruments. The Society's programmatic investments are accounted for under the equity method of accounting as further discussed in Note 4.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2021

(With Summarized Comparative Information for 2020)

(Continued)

NOTE 2 *(Continued)*

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.

Donor Advised Funds:

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

Contributions, Gifts and Grants:

As required by the FASB Accounting Standards Codification™, contributions are required to be recorded as receivables and revenues, and the Organization is required to distinguish between contributions received for each net asset category in accordance with donor-imposed restrictions.

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

Multi-year, unconditional commitments are recognized in the year during which the initial commitment was made. Contributions to be received after one year are discounted at an appropriate discount rate commensurate with the risk involved, when such amounts are considered material.

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

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2021

(With Summarized Comparative Information for 2020)

(Continued)

NOTE 2 *(Continued)*

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

The Society makes grants to eligible applicants after requests for research funding have been reviewed and recommended by the Society’s Scientific Advisory Board (“SAB”) and the Society’s Therapeutic Accelerator and Research Committee (“TARC”). The Society recognizes an expense for *Scientific Grants and Projects* at the time the Board of Directors votes to approve the SAB and TARC recommendations on awards and all significant conditions have been met. *Grants Payable* are classified as current if they are scheduled to be paid within one year, and non-current when they are expected to be paid in more than one year. Conditional commitments are not recognized in the financial statements until measurable performance or other barriers have substantially been met. As of December 31, 2021, *Long-Term Grants Payable* are due in 2023-2024.

Donated Goods and Services:

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

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

Functional Expenses:

The Organization allocates its expenses on a functional basis among various programs and support services. Expenses that can be identified with a specific program and support service are allocated directly according to their natural expense classification. Other expenses, such as *Salaries and Related Expenses, Website and Computer Related Expenses, Office Expenses, and Occupancy*, that are common to several functions are allocated based on salary dollars. Supporting services are those related to operating and managing the Organization and its programs on a day-to-day basis. Supporting services have been sub-classified as follows:

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

Fund Raising - includes all activities related to maintaining contributor information, writing grant proposals, direct mail solicitation, distribution of materials and other similar projects related to the procurement of funds.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

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(With Summarized Comparative Information for 2020)

(Continued)

NOTE 3 PROPERTY AND EQUIPMENT

As of December 31, 2020, *Property and Equipment* consisted of Furniture and Fixtures with an original cost of \$12,154 and accumulated depreciation of \$7,057, which equals a net book value of \$5,097. Furniture and Fixtures have been depreciated over an estimated useful life of 7 years and during 2021, Furniture and Fixtures were fully depreciated. As of December 31, 2021, *Property and Equipment* is fully depreciated and written-off on the accompanying Statements of Financial Position.

NOTE 4 INVESTMENTS

Investment Components:

As of December 31, 2021, and 2020 *Investments* on the Statements of Financial Position consist of the following:

| <u>Investment Components</u> | <u>2021</u> | <u>2020</u> |
|--|--------------------|--------------------|
| Lewis Family Donor Advised Fund for FSHD | \$2,178,448 | \$1,901,891 |
| Deferred Compensation Investments | <u>67,801</u> | <u>41,878</u> |
| Total Fair Value Investments | 2,246,249 | 1,943,769 |
| Programmatic Equity Investments | <u>150,000</u> | <u>150,000</u> |
| Total Investments | <u>\$2,396,249</u> | <u>\$2,093,769</u> |

As of December 31, 2021 and 2020, investment costs and unrealized gains and losses consisted of the following components:

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

| <u>Investment Type</u> | <u>December 31, 2020</u> | | | | | |
|----------------------------|--------------------------|-------------------------|--------------------------|-----------------------------|-----------------------------|-------------------------|
| | <u>Cost Basis</u> | <u>Unrealized Gains</u> | <u>Unrealized Losses</u> | <u>Fair Value (Level 1)</u> | <u>Fair Value (Level 2)</u> | <u>Total Fair Value</u> |
| Cash and Sweep Accounts | \$ 12,323 | \$ - | \$ - | \$ 12,323 | \$ - | \$ 12,323 |
| Mutual Funds | 1,105,425 | 438,849 | (91) | 1,544,183 | - | 1,544,183 |
| Exchange Traded Funds | 164,576 | 37,180 | - | 201,756 | - | 201,756 |
| Preferred Stocks and Bonds | <u>180,742</u> | <u>6,744</u> | <u>(1,979)</u> | <u>-</u> | <u>185,507</u> | <u>185,507</u> |
| Total | <u>\$1,463,066</u> | <u>\$482,773</u> | <u>\$(2,070)</u> | <u>\$1,758,262</u> | <u>\$185,507</u> | <u>\$1,943,769</u> |

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

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(With Summarized Comparative Information for 2020)

(Continued)

NOTE 4 *(Continued)*

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

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

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

Components of *Investment Return* for the years ended December 31, 2021 and 2020, is as follows:

| <u>Components of Investment Return</u> | <u>2021</u> | <u>2020</u> |
|--|------------------|------------------|
| Interest and Dividends | \$122,027 | \$ 72,211 |
| Unrealized Gains (Losses) | (51,655) | 203,767 |
| Realized Gains (Losses) | <u>299,156</u> | <u>123,901</u> |
| Net Investment Return | <u>\$369,528</u> | <u>\$399,879</u> |

Programmatic Equity Investment:

During 2020, the Organization purchased 13,298 units of in 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 uses all investment proceeds to purchase Class B Common Stock of miRecule RNA Therapeutics (“miRecule”). MiRecule is an early-stage biotechnology company developing RNA-based therapeutics. MiRecule is applying its platform to a variety of diseases, including cancer and muscular dystrophy. The Society’s investment is restricted for research in FSH muscular dystrophy. Total units issued and outstanding in InformiR as of December 31, 2021 and 2020, were 31,030; therefore, the Society’s ownership is 43% of all units issued and outstanding in InformiR. Accordingly, the organization accounts for this programmatic investment using the equity method. It is management’s opinion that the profit and loss of InformiR for the years ended December 31, 2021 and 2020 is immaterial. It is also the opinion of management that no reserve for impairment loss is required for the years ended December 31, 2021 and 2020.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

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(With Summarized Comparative Information for 2020)

(Continued)

NOTE 5 DESIGNATIONS AND RESTRICTIONS OF NET ASSETS

Net Assets With Donor Restrictions:

As of December 31, 2021, and 2020, net assets with donor restrictions were designated for research and education and consisted of the following balances:

| <u>Nature of Restriction</u> | <u>2021</u> | <u>2020</u> |
|--|--------------------|--------------------|
| Lewis Family Donor Advised Fund for FSHD | \$2,178,448 | \$1,901,891 |
| FSHD Therapeutics | 198,080 | 390,181 |
| Research and Education | - | <u>234,176</u> |
| Total | <u>\$2,376,528</u> | <u>\$2,526,248</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>2021</u> | <u>2020</u> |
|--|--------------------|--------------------|
| Lewis Family Donor Advised Fund for FSHD | \$1,000,000 | \$1,000,000 |
| FSHD Therapeutics | 471,703 | 519,785 |
| Clinical Trial Research Network | - | 100,000 |
| Research and Education | 638,293 | 571,102 |
| Payroll Protection Program | <u>285,077</u> | <u>194,500</u> |
| Total | <u>\$2,395,073</u> | <u>\$2,385,387</u> |

NOTE 6 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>2021</u> | <u>2020</u> |
|---|------------------|-----------------|
| Scientific Committees Expenses | \$70,300 | \$59,500 |
| Science time for FSHD Connect and Patient Education | 40,800 | 11,475 |
| Public Awareness | 109,900 | - |
| Investment Advisory Services | <u>4,200</u> | <u>5,100</u> |
| Total | <u>\$225,200</u> | <u>\$76,075</u> |

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(Continued)

NOTE 7 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, 2021 and 2020. The line bears interest at the bank's base rate. As of December 31, 2021, and 2020, the bank's base rate was 3.75%. 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 8 LEASING ARRANGEMENTS

In October 2018, the Society entered a three-year lease for 1,835 square feet of office space through July 2022. The basic rent commencing on August 1, 2019, was \$2,982 and additional amounts are assessed each month for operating costs and utilities. The basic annual rent increases each August 1st through 2021 by \$1.00 per square foot. The Society entered into an agreement to terminate the lease effective March 1, 2022. As of December 31, 2021, the aggregate amount of future lease payments and early termination fee under this agreement was \$9,529, due in FY 2022.

Rent expense for the years ended December 31, 2021 and 2020 was \$38,382 and \$36,547, respectively, which is included in *Occupancy* in the accompanying Statement of Functional Expenses.

NOTE 9 COMMITMENTS AND CONTINGENCIES

Clinical Trial Research Network Memorandum of Understanding

During 2019, the Society entered a memorandum of understanding ("MOU") with the University of Kansas Medical Center ("KUMC") for the development and management of the FSH Clinical Trial Research Network ("CTRN"). Per the MOU, the Society has agreed to pay KUMC \$180,000 in 2021 contingent upon reasonable determination that KUMC has made sufficient progress in developing the CTRN during the prior calendar year. In the opinion of management, KUMC made sufficient progress in developing the CTRN during 2020 and 2021. In addition, the Society commits to awarding KUMC up to an additional \$120,000 per year in 2021-2022 for up to four new CTRN members. CTRN expenses for the years ended December 31, 2021 and 2020 were \$300,000 annually, which are included in *Scientific Grants and Research Projects* in the accompanying Statement of Functional Expenses.

Other Program Service Commitments:

During 2021, the Society entered into various professional service consulting agreements and venue contracts for 2022 conferences and meetings. Obligations during 2022 under these agreements are approximately \$452,000. Approximately \$170,000 of venue commitments are noncancelable. The program service commitments have not been accrued on the accompanying Statement of Financial Position because the various programs primarily occur in 2022.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

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(With Summarized Comparative Information for 2020)

(Continued)

NOTE 10 COVID RELIEF FUNDING

In April 2020, the Society was granted a \$194,500 loan under the Paycheck Protection Program (“PPP”) administered by a Small Business Administration (“SBA”) approved partner. The loan is uncollateralized and is fully guaranteed by the Federal government. The Society initially recorded the loan as a refundable advance and subsequently recognized grant revenue in accordance with guidance for conditional contributions; that is, once the measurable performance or other barrier and right of return of the PPP loan no longer existed. The Society has recognized \$194,500 as grant revenue in the accompanying Statement of Activities for the year ended December 31, 2020. The loan forgiveness application for \$194,500 was approved by the SBA on November 2, 2020.

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

The CARES Act provides an employee retention credit (“CARES Employee Retention credit”), which is a refundable tax credit against certain employment taxes of up to \$5,000 per employee for eligible employers. The tax credit is equal to 50% of qualified wages paid to employees during a quarter, capped at \$10,000 of qualified wages per employee through December 31, 2020. Additional relief provisions were passed by the United States government, which extend and slightly expand the qualified wage caps on these credits through September 30, 2021. Based on these additional provisions, the tax credit in 2021 is equal to 70% of qualified wages paid to employees during a quarter, and the limit on qualified wages per employee has been increased to \$10,000 of qualified wages per quarter. The Society qualifies for the tax credit under the CARES Act. During the year ended December 31, 2021, the Society recorded \$313,636 related to the CARES Employee Retention credit as grant revenue in the accompanying Statement of Activities. As of December 31, 2021, the Society has \$227,839 in *Employee Retention Tax Credits Receivable* recorded in the accompanying Statement of Financial Position. Subsequent to yearend, the Society collected \$60,000 of tax credits related to 2020 CARES Employee Retention credit.

NOTE 11 OTHER LOSS

In April 2020, the Society discovered that it was a victim of an email phishing scam. \$111,934 was transferred to a fraudulent bank account. Following an investigation by the Society’s online bill payment service, the Society was able to recover \$12,000, which resulted in a net loss of \$99,934, which has been recorded as *Other Loss* in the accompanying Statement of Activities. Management took several actions because of this fraud, including the implementation of additional controls over electronic bill payments and wire transfers as well as cybersecurity training and monitoring for the Society’s staff. In addition to its cyber insurance, the Society has also purchased social engineering insurance which insures against email phishing scams.

FSHD SOCIETY

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(With Summarized Comparative Information for 2020)

(Continued)

NOTE 12 RETIREMENT PLANS

During the year ended December 31, 2020, the Society maintained a defined contribution plan qualified under IRC Section 401(k). The defined contribution plan provides that employees who have attained age 21 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 2020, the Society elected to make safe harbor matches of up to 4% of employees' earnings.

Effective December 15, 2020, the Society transitioned to a Professional Employer Organization ("PEO") for its payroll, benefits, and human resource needs. The Society transitioned to the PEO 401(k) Plan effective December 15, 2020. 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 2021 and 2020, the Society elected to make safe harbor matches of up to 4% of employees' earnings.

For the years ended December 31, 2021 and 2020, the total employer contributions to each of the retirement plans outlined above were \$49,240 and \$46,488, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

NOTE 13 457(b) DEFERRED COMPENSATION PLAN

During 2019, the Society's Board of Directors approved a 457(b) deferred compensation plan that allows eligible employees to defer pretax annual compensation up to certain limitations imposed by the IRS. Eligible employees are determined by the Board of Directors. During the years presented, the only eligible employee is the Society's Chief Executive Officer & President. The Society reports assets and liabilities of equal amounts attributable to the amount deferred, as the Society has opted to set aside amounts contributed to the plan; however, these assets are owned by the Society until a vesting event occurs. Eligible employees must remain employed by the Society until December 31, 2024 for employer contributions in the plan to vest. For the years ended December 31, 2021 and 2020, the Board voted to fund this plan in the amount of \$19,500 annually. The assets and liability related to the 457(b) deferred compensation plan are included in *Investments and Long-Term 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 earning and losses since the plan's inception. The related deferred compensation expense for the years ended December 31, 2021 and 2020 were \$25,923 and \$22,878, respectively, and are included in *Salaries and Related Expenses* in the accompanying Statement of Functional Expenses.

FSHD SOCIETY

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(Continued)

NOTE 14 CONCENTRATIONS

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

Cash:

The Organization is subject to concentrations in credit risk relating to cash balances. The Society maintains two bank accounts with one financial institution: (1) a Negotiable Order of Withdrawal account ("NOW account") and (2) an Insured Cash Sweep account("ICS account"). After all debit and credit transactions have posted at the end of each business day, excess balances from the NOW account are automatically moved to the ICS account. ICS account funds are divided into amounts under the standard Federal Deposit Insurance Corporation ("FDIC") maximum and placed with other ICS network members, each an FDIC insured institution. As of December 31, 2020, cash balances in excess of the FDIC limit were \$31,498. As of December 31, 2021, cash balances were not in excess of the FDIC limit. The Organization has not experienced any losses on uninsured cash balances and management considers risk on cash balances to be low.

Investments:

The Organization invests or holds a variety of investment vehicles, including money market funds, mutual fund, EFTs, preferred stocks, and bonds. These investments are exposed to interest rate, market, credit, and other risks depending upon the nature of the investment. Accordingly, it is reasonably possible that these factors will result in changes in the value of the Organization's investments; however, the Organization's investments do not represent significant concentrations of market risk considering the Organization's portfolio is widely diversified among issuers.

Contributions Receivable:

As of December 31, 2021, 76% of *Contributions Receivable* was owed from one donor.
As of December 31, 2020, 59% of *Contributions Receivable* was owed from three donors.

FSHD SOCIETY

NOTES TO FINANCIAL STATEMENTS

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(With Summarized Comparative Information for 2020)

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NOTE 15 AVAILABLE RESOURCES AND LIQUIDITY

As part of the Society's liquidity management, it has a policy to structure its financial assets to be available as its general expenditures, liabilities, and other obligations come due. The Society has various sources of liquidity at its disposal, including cash and cash equivalents, marketable debt and equity securities, and a line of credit. See Note 7 for information about the Society's line of credit.

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, 2021 and 2020:

| | <u>2021</u> | <u>2020</u> |
|---|---------------------|---------------------|
| Financial Assets at Year End: | | |
| Cash and Cash Equivalents | \$ 4,820,728 | \$ 3,280,720 |
| Employee Retention Tax Credit Receivable | 227,839 | - |
| Contributions Receivable | 65,847 | 340,181 |
| Investments | <u>2,396,249</u> | <u>2,093,769</u> |
| Total Financial Assets | <u>7,510,663</u> | <u>5,714,670</u> |
| Less Amounts Not Available to be Used Within One Year: | | |
| Investments in Donor Advised Fund | | |
| With Donor-Imposed Restrictions | \$(2,178,448) | \$(1,901,891) |
| Programmatic Equity Investment | (150,000) | (150,000) |
| Deferred Compensation Liability | (67,801) | (41,878) |
| Contributions Receivable for Restricted Gifts, Net | (65,847) | (340,181) |
| Grants Payable Due Within One Year | (669,087) | (266,550) |
| Reserves for Bi-Annual International Research and Patient Conference | <u>(352,000)</u> | <u>(157,000)</u> |
| Financial Assets Not Available to be Used Within One Year | <u>(3,482,183)</u> | <u>(2,857,500)</u> |
| Financial Assets Available to Meet General Expenditures Within One Year | <u>\$ 4,027,480</u> | <u>\$ 2,857,170</u> |

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(Continued)

NOTE 16 SUBSEQUENT EVENTS

Management is required to consider events subsequent to the financial statement date for potential adjustment to or disclosure in the financial statements. Management has evaluated subsequent events through March 15, 2022, the date which the financial statements were available for issue. Other than the event discussed in Note 10, there were no subsequent events.