

EveryLife Foundation for Rare Diseases

Financial Statements
and Independent Auditor's Report

December 31, 2024 and 2023

EveryLife Foundation for Rare Diseases

Financial Statements
December 31, 2024 and 2023

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INDEPENDENT AUDITOR'S REPORT

To the Board of Directors of
EveryLife Foundation for Rare Diseases

Opinion

We have audited the accompanying financial statements of EveryLife Foundation for Rare Diseases ("the Foundation"), which comprise the statements of financial position as of December 31, 2024 and 2023; the related statements of activities, functional expenses, and cash flows for the years 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 the Foundation as of December 31, 2024 and 2023, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

Basis for Opinion

We conducted our audits 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 Financial Statements section of our report. We are required to be independent of the Foundation and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audits. 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.

Responsibilities of Management for the Financial Statements (continued)

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 the Foundation's ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

Auditor's Responsibilities for the Audit of the Financial Statements

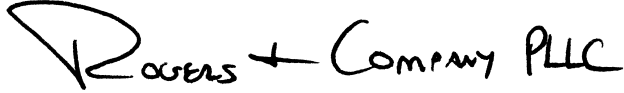
Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance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

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 the Foundation'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 the Foundation's ability to continue as a going concern for a reasonable period of time.

Auditor's Responsibilities for the Audit of the Financial Statements (continued)

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.

Handwritten signature of Rogers + Company PLLC in black ink.

Vienna, Virginia
June 11, 2025

EveryLife Foundation for Rare Diseases

Statements of Financial Position December 31, 2024 and 2023

	2024	2023
Assets		
Cash and cash equivalents	\$ 490,278	\$ 2,783,412
Investments	4,036,902	1,196,875
Accounts receivable	7,660	387
Contributions receivable	509,648	525,050
Prepaid expenses	239,752	149,331
Property and equipment, net	11,877	9,857
Right-of-use assets – operating leases	908,108	1,128,587
Deposits	13,363	13,363
Total assets	<u>\$ 6,217,588</u>	<u>\$ 5,806,862</u>
Liabilities and Net Assets		
Liabilities		
Accounts payable and accrued expenses	\$ 275,465	\$ 123,343
Accrued salaries and related benefits	259,924	211,507
Deferred revenue	542,250	338,000
Deposits payable	9,475	7,675
Lease liabilities – operating leases	922,359	1,127,290
Total liabilities	<u>2,009,473</u>	<u>1,807,815</u>
Net Assets		
Without donor restrictions	2,799,782	2,320,714
With donor restrictions	1,408,333	1,678,333
Total net assets	<u>4,208,115</u>	<u>3,999,047</u>
Total liabilities and net assets	<u>\$ 6,217,588</u>	<u>\$ 5,806,862</u>

See accompanying notes.

EveryLife Foundation for Rare Diseases

Statement of Activities For the Year Ended December 31, 2024

	Without Donor Restrictions	With Donor Restrictions	Total
Operating Revenue and Support			
Contributions and grants:			
Corporations	\$ 3,204,898	\$ 1,200,000	\$ 4,404,898
Board	63,649	-	63,649
Individuals	76,204	-	76,204
Foundations	324,367	-	324,367
Corporate membership	1,917,750	-	1,917,750
Rental income	103,560	-	103,560
Other revenue	11,354	-	11,354
Net assets released from restrictions	1,470,000	(1,470,000)	-
Total operating revenue and support	7,171,782	(270,000)	6,901,782
Expenses			
Program services	4,819,643	-	4,819,643
Supporting services:			
General and administrative	1,494,046	-	1,494,046
Fundraising	519,051	-	519,051
Total supporting services	2,013,097	-	2,013,097
Total expenses	6,832,740	-	6,832,740
Change in Net Assets from Operations	339,042	(270,000)	69,042
Non-Operating Activity			
Investment return, net	140,026	-	140,026
Total non-operating activity	140,026	-	140,026
Change in Net Assets	479,068	(270,000)	209,068
Net Assets, beginning of year	2,320,714	1,678,333	3,999,047
Net Assets, end of year	\$ 2,799,782	\$ 1,408,333	\$ 4,208,115

See accompanying notes.

EveryLife Foundation for Rare Diseases

Statement of Activities For the Year Ended December 31, 2023

	Without Donor Restrictions	With Donor Restrictions	Total
Operating Revenue and Support			
Contributions and grants:			
Corporations	\$ 2,742,100	\$ 1,678,333	\$ 4,420,433
Board	16,565	-	16,565
Individuals	58,828	-	58,828
Foundations	270,402	-	270,402
Corporate membership	1,877,250	-	1,877,250
Rental income	88,895	-	88,895
Other revenue	10,334	-	10,334
Net assets released from restrictions	1,366,665	(1,366,665)	-
Total operating revenue and support	6,431,039	311,668	6,742,707
Expenses			
Program services	4,747,144	-	4,747,144
Supporting services:			
General and administrative	982,482	-	982,482
Fundraising	321,755	-	321,755
Total supporting services	1,304,237	-	1,304,237
Total expenses	6,051,381	-	6,051,381
Change in Net Assets from Operations	379,658	311,668	691,326
Non-Operating Activity			
Investment return, net	66,759	-	66,759
Total non-operating activity	66,759	-	66,759
Change in Net Assets	446,417	311,668	758,085
Net Assets, beginning of year	1,874,297	1,366,665	3,240,962
Net Assets, end of year	\$ 2,320,714	\$ 1,678,333	\$ 3,999,047

See accompanying notes.

EveryLife Foundation for Rare Diseases

Statement of Functional Expenses For the Year Ended December 31, 2024

	Program Services	Supporting Services			Total Expenses
		General and Administrative	Fundraising	Total Supporting Services	
Advertising and promotion	\$ 6,096	\$ -	\$ -	\$ -	\$ 6,096
Bad debt expenses	-	881	-	881	881
Bank charges/processing fees	975	631	231	862	1,837
Conferences and other events	465,610	-	6,690	6,690	472,300
Consulting	740,624	-	10,381	10,381	751,005
Depreciation and amortization	3,190	2,155	755	2,910	6,100
Grants	624,757	-	-	-	624,757
Insurance	4,517	2,919	1,069	3,988	8,505
Lobbying	176,944	-	-	-	176,944
Miscellaneous	36,752	37,799	1,475	39,274	76,026
Occupancy	180,172	58,755	21,414	80,169	260,341
Postage and printing	29,472	1,626	11,955	13,581	43,053
Professional fees	38,937	97,410	9,217	106,627	145,564
Salaries, payroll taxes, and benefits	1,716,982	1,241,708	398,777	1,640,485	3,357,467
Supplies and office	22,901	8,353	3,028	11,381	34,282
Technology and website	260,040	11,798	24,331	36,129	296,169
Telephone and internet	4,021	-	-	-	4,021
Travel, meals, and lodging	507,653	30,011	29,728	59,739	567,392
Total Expenses	\$ 4,819,643	\$ 1,494,046	\$ 519,051	\$ 2,013,097	\$ 6,832,740

See accompanying notes.

EveryLife Foundation for Rare Diseases

Statement of Functional Expenses For the Year Ended December 31, 2023

	Program Services	Supporting Services			Total Expenses
		General and Administrative	Fundraising	Total Supporting Services	
Advertising and promotion	\$ 10,126	\$ -	\$ -	\$ -	\$ 10,126
Bank charges/processing fees	610	213	83	296	906
Conferences and other events	390,809	-	3,146	3,146	393,955
Consulting	799,646	-	-	-	799,646
Depreciation and amortization	6,004	2,097	820	2,917	8,921
Grants	446,372	-	-	-	446,372
Insurance	5,047	1,763	689	2,452	7,499
Lobbying	116,164	-	-	-	116,164
Miscellaneous	30,803	30,113	-	30,113	60,916
Occupancy	192,130	37,379	14,619	51,998	244,128
Postage and printing	34,841	684	171	855	35,696
Professional fees	49,494	56,232	8,325	64,557	114,051
Salaries, payroll taxes, and benefits	1,949,524	805,659	264,335	1,069,994	3,019,518
Supplies and office	27,974	4,154	1,356	5,510	33,484
Technology and website	209,148	8,032	8,870	16,902	226,050
Telephone and internet	3,643	-	-	-	3,643
Travel, meals, and lodging	474,809	36,156	19,341	55,497	530,306
Total Expenses	\$ 4,747,144	\$ 982,482	\$ 321,755	\$ 1,304,237	\$ 6,051,381

See accompanying notes.

EveryLife Foundation for Rare Diseases

Statements of Cash Flows For the Years Ended December 31, 2024 and 2023

	2024	2023
Cash Flows from Operating Activities		
Change in net assets	\$ 209,068	\$ 758,085
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Depreciation and amortization	6,100	8,921
Realized and unrealized gain on investments	(19,179)	(20,175)
Amortization of right-of-use operating lease assets	220,479	443,185
Change in operating assets and liabilities:		
(Increase) decrease in:		
Accounts receivable	(7,273)	6,228
Contributions receivable	15,402	175,468
Prepaid expenses	(90,421)	(1,779)
Increase (decrease) in:		
Accounts payable and accrued expenses	152,122	(250,751)
Accrued salaries and related benefits	48,417	(5,624)
Deferred revenue	204,250	30,550
Deposits payable	1,800	1,175
Lease liabilities – operating leases	(204,931)	(474,047)
Net cash provided by operating activities	535,834	671,236
Cash Flows from Investing Activities		
Purchase of investments	(3,314,848)	(60,734)
Proceeds from sales of investments	-	14,150
Proceeds from redemption of certificates of deposit	494,000	-
Purchase of fixed assets	(8,120)	-
Net cash used in investing activities	(2,828,968)	(46,584)
Net (Decrease) Increase in Cash and Cash Equivalents	(2,293,134)	624,652
Cash and Cash Equivalents, beginning of year	2,783,412	2,158,760
Cash and Cash Equivalents, end of year	\$ 490,278	\$ 2,783,412
Supplemental Cash Flow Information		
Noncash transactions arising from ASC 842 adoption:		
Establishment of right-of-use assets	\$ -	\$ 1,252,069
Establishment of operating lease liabilities	\$ -	\$ 1,252,069

See accompanying notes.

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
December 31, 2024 and 2023

1. Nature of Operations

The EveryLife Foundation for Rare Diseases (“the Foundation”) is a nonprofit, nonpartisan 501(c)(3) organization headquartered in the United States. The Foundation is dedicated to empowering the rare disease patient community and advancing science-driven policies and legislation that improve health outcomes for individuals living with rare diseases. Its primary activities focus on advocacy, policy development, scientific research, community engagement, and public education related to the rare disease ecosystem. Operating in a landscape where more than 30 million Americans are affected by one or more of the 10,000+ known rare diseases—of which 95% have no FDA-approved therapies—the Foundation’s work addresses significant gaps in diagnosis, treatment access, and healthcare equity. Through its advocacy and research-driven approach, the Foundation serves as a catalyst for systemic change and long-term impact within the rare disease community and the broader healthcare policy environment.

Founded with the mission of improving health outcomes for rare disease patients, the Foundation operates nationally and is guided by a vision of a world where patients face no barriers to timely and accurate diagnosis, comprehensive and appropriate treatment, and equitable access to affordable healthcare. The Foundation’s work is powered by the rare disease community, emphasizing a patient-centered, data-driven, and community-informed approach to policy change.

2. Summary of Significant Accounting Policies

Basis of Accounting and Presentation

The Foundation’s financial statements are prepared on the accrual basis of accounting. Net assets are reported based on the presence or absence of donor-imposed restrictions as follows:

- *Net Assets Without Donor Restrictions* – Net assets available for use in general operations and not subject to donor (or certain grantor) restrictions.
- *Net Assets With Donor Restrictions* – Net assets subject to donor (or certain grantor) imposed restrictions. Some donor-imposed restrictions are temporary in nature, such as those that will be met by the passage of time or other events specified by the donor. Other donor-imposed restrictions are perpetual in nature, where the donor stipulates that resources be maintained in perpetuity. Donor-imposed restrictions are released when a restriction expires, that is, when the stipulated time has elapsed, when the stipulated purpose for which the resource was restricted has been fulfilled, or both.

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
December 31, 2024 and 2023

2. Summary of Significant Accounting Policies (continued)

Cash Equivalents

For the purpose of the statements of cash flows, the Foundation considers as cash equivalents all highly liquid investments, including money market funds not held for long-term investment purposes. Excluded from this definition of cash equivalents are amounts held for investments.

Investments

Investments are recorded at fair value. Realized and unrealized gains and losses, net of investment management fees, are reported as components of net investment return in the accompanying statements of activities.

Accounts Receivable

Accounts receivable primarily consist of amounts due within one year related to dues to others and membership dues. Accounts receivable are presented net of an allowance for credit loss, which is an estimate of amounts that may not be collectible. The allowance for credit losses is based upon historical loss experience in combination with current economic conditions and forecast of future economic conditions. Any change in the assumptions used in analyzing a specific account receivable might result in an additional allowance for credit losses being recognized in the period in which the change occurs. However, the Foundation has historically had insignificant write-offs due to bad debts.

Contributions Receivable

Contributions receivable consist primarily of unconditional promises to give from various corporations, foundations, and individuals, to be used in support of the Foundation's programs. All contributions receivable are expected to be collected within one year and are recorded at net realizable value at both December 31, 2024 and 2023. The Foundation periodically reviews an aging of its contributions receivable for collection purposes on a case-by-case basis and writes off uncollectable items. No allowance for doubtful accounts is recorded at December 31, 2024 and 2023, as management believes that all amounts are fully collectible.

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
December 31, 2024 and 2023

2. Summary of Significant Accounting Policies (continued)

Property and Equipment

Property and equipment acquisitions with a cost in excess of \$1,500 and a projected useful life exceeding one year are capitalized and recorded at cost. Depreciation and amortization is computed using the straight-line method over the shorter of the estimated useful lives of the related assets or applicable lease terms. The useful lives range from three to seven years. Leasehold improvements are amortized over the remaining life of the lease. Repairs and maintenance costs are expensed as incurred.

Operating Leases

The Foundation determines if an arrangement is a lease at inception. Operating leases are included in right-of-use (ROU) assets, which represent the Foundation's right to use an underlying asset for the lease terms, and lease liabilities represent the Foundation's obligation to make lease payments arising from the lease. Operating ROU lease assets and liabilities are recognized at the commencement date based on the present value of lease payments over the lease term. As the Foundation's leases do not provide an implicit rate, the Foundation used a risk-free rate based on the information available at the commencement date in determining the present value of lease payments.

The ROU assets also include any lease payments made and exclude lease incentives. The Foundation's lease terms may include options to extend or terminate the lease when it is reasonably certain that the Foundation will exercise that option. Lease expense for lease payments is recognized on a straight-line basis over the lease term.

Revenue Recognition

Revenue Accounted for as Contracts with Customers

Revenue is recognized when the Foundation satisfies a performance obligation by transferring a promised good to, or performing a service for, a customer. The amount of revenue recognized reflects the consideration the Foundation expects to receive in exchange for satisfying distinct performance obligations. If a performance obligation does not meet the criteria to be considered distinct, the Foundation combines it with other performance obligations until a distinct bundle of goods or services exists. Fees or amounts received in advance of satisfying contractual performance obligations are reflected as deferred revenue in the statements of financial position. Revenue is recognized either over time or at the point in time that contractual obligations are met.

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
December 31, 2024 and 2023

2. Summary of Significant Accounting Policies (continued)

Revenue Recognition (continued)

Revenue Accounted for as Contracts with Customers (continued)

Specifically, for the various types of contracts, the Foundation recognizes revenue as follows:

Corporate membership consists of dues received for the Foundation's Community Congress. Community Congress is a membership-based program of the Foundation dedicated to bringing patient organizations, industry leaders, and other rare disease stakeholders together, and also acts as a strategic advisory council and response team, providing advice on existing Foundation programs and responding to urgent policy issues. Membership is calendar year based. Membership dues are comprised of an exchange element based on the benefits received and include a bundle of membership benefits that represent the performance obligations. The Foundation has concluded the performance obligation related to member benefits is satisfied throughout the membership period as member benefits are received and consumed simultaneously during the membership period. Membership dues received that are applicable to the following year are included in deferred revenue in the accompanying statements of financial position. As of December 31, 2024 and 2023, deferred membership dues were \$542,250 and \$338,000, respectively.

Special events are registration fees that are recorded as revenue when the performance obligation is met, which is when the related event has occurred.

Contracts revenues are classified as exchange transactions and record revenue when the performance obligations are met. The revenue is recorded directly to net assets without donor restrictions and the transaction price is based on expenses incurred in compliance with the criteria stipulated in the grant or contract agreements.

Rental income from the subleasing portion of the Foundation's office lease and revenue from all other sources is recognized when earned.

Revenue Accounted for in Accordance with Contribution Accounting

The majority of the Foundation's revenue is received through contributions and grants. Contributions and grants are recognized in the appropriate category of net assets in the period received.

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
December 31, 2024 and 2023

2. Summary of Significant Accounting Policies (continued)

Revenue Recognition (continued)

Revenue Accounted for in Accordance with Contribution Accounting (continued)

The Foundation performs an analysis to determine if the revenue streams follow the contribution rules or if they are considered exchange transactions depending on whether the transaction is reciprocal or nonreciprocal under Financial Accounting Standards Board (FASB) Accounting Standards Update 2018-08, *Not-for-Profit Entities* (Topic 958): *Clarifying the Scope and Accounting Guidance for Contributions Received and Contributions Made*.

For contributions and grants qualifying under the contribution rules, revenue is recognized upon notification of the award and satisfaction of all conditions, if applicable.

Contributions and grants qualifying as contributions that are unconditional that have donor restrictions are recognized as net assets without donor restrictions only to the extent of actual expenses incurred in compliance with the donor-imposed restrictions and satisfaction of time restrictions; such funds in excess of expenses incurred are shown as net assets with donor restrictions in the accompanying financial statements.

Conditional promises to give are not recognized until the conditions on which they depend are substantially met. Grant agreements qualifying as conditional contributions contain a right of return and barrier. Revenue is recognized when the condition or conditions are satisfied.

Functional Allocation of Expenses

The costs of program and supporting services activities have been summarized on a functional basis in the statements of activities. The statements of functional expenses present the natural classification detail of expenses by function. Accordingly, certain costs have been allocated among the programs and supporting services benefited.

Use of Estimates

The preparation of financial statements in conformity with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect the amounts reported in the financial statements and accompanying notes. Actual results could differ from those estimates.

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
December 31, 2024 and 2023

2. Summary of Significant Accounting Policies (continued)

Advertising and Promotion Costs

Advertising and promotion costs are expensed as incurred, and were approximately \$6,096 and \$10,126 during the years ended December 31, 2024 and 2023, respectively.

Measure of Operations

The Foundation includes in its measure of operations all revenues and expenses that are an integral part of its programs and supporting activities, and excludes net investment return.

Subsequent Events

In preparing these financial statements, the Foundation has evaluated events and transactions for potential recognition or disclosure through June 11, 2025, the date the financial statements were available to be issued.

3. Liquidity and Availability

Financial assets available for general expenditures, that is, without donor or other restrictions limiting their use, within one year of the statements of financial position date, comprise the following at December 31:

	<u>2024</u>	<u>2023</u>
Cash and cash equivalents	\$ 490,278	\$ 2,783,412
Investments	4,036,902	1,196,875
Accounts receivable	7,660	387
Contributions receivable	<u>509,648</u>	<u>525,050</u>
Total financial assets	5,044,488	4,505,724
Less: restricted by donors	<u>(1,408,333)</u>	<u>(1,678,333)</u>
Total available for general expenditures	<u><u>\$ 3,636,155</u></u>	<u><u>\$ 2,827,391</u></u>

The Foundation structures its financial assets to be available as its general expenditures, liabilities, and other obligations come due. As part of this liquidity management, the Foundation invests cash and cash equivalents in excess of daily requirements in various short-term investments.

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
December 31, 2024 and 2023

4. Concentrations of Credit Risk

Financial instruments that potentially subject the Foundation to significant concentrations of credit risk consist of cash and cash equivalents, and investments. The Foundation maintains interest-bearing cash deposits and investments with a financial institution that exceeds insurable limits under the Federal Deposit Insurance Corporation (FDIC) and Securities Investor Protection Corporation (SIPC). The uninsured portions of these accounts are backed solely by the asset of the underlying financial institution. Therefore, the failure of an underlying institution could result in financial loss of the Foundation. The Foundation has established guidelines relative to diversification and maturities that maximize safety and liquidity. These guidelines are periodically reviewed and modified to take advantage of trends in yields and interest rate. At December 31, 2024 and 2023, the Foundation's balances exceeded federally insured limits by approximately \$4,027,180 and \$3,480,000, respectively.

5. Investments and Fair Value Measurements

Net investment return consists of the following for the years ended December 31:

	2024	2023
Interest and dividends	\$ 129,792	\$ 52,318
Realized loss	-	(381)
Unrealized gain	19,179	20,556
Less: investment management fees	(8,945)	(5,734)
Total investment return, net	<u>\$ 140,026</u>	<u>\$ 66,759</u>

The Foundation follows FASB Accounting Standards Codification 820, *Fair Value Measurements and Disclosures*, for its financial assets. This standard establishes a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value. Fair value measurement standards require an entity to maximize the use of observable inputs (such as quoted prices in active markets) and minimize the use of unobservable inputs (such as appraisals or other valuation techniques) to determine fair value. The categorization of a financial instrument within the hierarchy is based upon the pricing transparency of the instrument and does not necessarily correspond to the entity's perceived risk of that instrument.

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
December 31, 2024 and 2023

5. Investments and Fair Value Measurements (continued)

The inputs used in measuring fair value are categorized into three levels. Level 1 inputs consist of unadjusted quoted prices in active markets for identical assets and liabilities and have the highest priority. Level 2 is based upon observable inputs other than quoted market prices, and Level 3 is based on unobservable inputs. Transfers between levels in the fair value hierarchy are recognized at the end of the reporting period.

Investments include money market funds and mutual funds. In general, and where applicable, the Foundation uses quoted prices in active markets for identical assets to determine fair value. This pricing methodology applies to Level 1 investments. Certificates of deposit held in the investment portfolio are not subject to the provisions of fair value measurements as they are recorded at cost and are excluded from the fair value hierarchy, but still included in total investments for reconciliation.

The following table presents the Foundation's fair value hierarchy for those investments measured on a recurring basis as of December 31:

	Level 1	Level 2	Level 3	Total fair value
<u>2024:</u>				
Money market funds	\$ 648,517	\$ -	\$ -	\$ 648,517
Mutual funds	1,927,155	-	-	1,927,155
Total investments at fair value	\$ 2,575,672	\$ -	\$ -	\$ 2,575,672
Certificates of deposit				1,461,230
Total investments				\$ 4,036,902
<u>2023:</u>				
Money market funds	\$ 42,674	\$ -	\$ -	\$ 42,674
Mutual funds	1,154,201	-	-	1,154,201
Total investments	\$ 1,196,875	\$ -	\$ -	\$ 1,196,875

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
December 31, 2024 and 2023

6. Property and Equipment

The Foundation held the following property and equipment at December 31:

	<u>2024</u>	<u>2023</u>
Furniture and equipment	\$ 36,338	\$ 28,218
Leasehold improvements	<u>18,046</u>	<u>18,046</u>
Total property and equipment	54,384	46,264
Less: accumulated depreciation and amortization	<u>(42,507)</u>	<u>(36,407)</u>
Property and equipment, net	<u><u>\$ 11,877</u></u>	<u><u>\$ 9,857</u></u>

7. Net Assets

Net Assets With Donor Restrictions

Net assets with donor restrictions consist of the following at December 31:

	<u>2024</u>	<u>2023</u>
Subject to expenditure for specific purpose:		
Rare Disease Week	\$ 605,000	\$ 340,000
Newborn Screening Bootcamp	135,000	210,000
Rare Disease Legislative Advocates	205,000	265,000
Rare Scholarship	-	305,000
Economic Burden Study	23,333	68,333
Diversity Fellowship	110,000	180,000
State Advocacy	15,000	15,000
RareGiving	110,000	210,000
Rare Artist	5,000	50,000
Annual Scientific Workshop	-	35,000
Subject to passage of time	<u>200,000</u>	<u>-</u>
Total net assets with donor restrictions	<u><u>\$ 1,408,333</u></u>	<u><u>\$ 1,678,333</u></u>

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
December 31, 2024 and 2023

7. Net Assets (continued)

Net Assets With Donor Restrictions (continued)

The following net assets with donor restrictions were released from donor restrictions by incurring expenses (or through the passage of time), which satisfied the restricted purposes specified by the donors at December 31:

	2024	2023
Purpose restrictions accomplished:		
Rare Disease Week	\$ 340,000	\$ 345,000
Newborn Screening Bootcamp	205,000	275,000
Rare Disease Legislative Advocates	265,000	230,000
Rare Scholarship	305,000	200,000
Economic Burden Study	45,000	75,000
Rare Voice Awards Gala	-	30,000
Diversity Fellowship	100,000	20,000
State Advocacy	15,000	15,000
RareGiving	110,000	10,000
Rare Artist	50,000	-
Annual Scientific Workshop	35,000	-
Passage of time	-	166,665
Total net assets released from donor restrictions	<u>\$ 1,470,000</u>	<u>\$ 1,366,665</u>

8. Designated Beneficiary Funds

EveryLife Rainy Day Fund

In 2021, an agreement was signed between Emil Kakkis and Jenny Soriano (“the Donors”), and the Marin Community Foundation (“the Community Foundation”) to establish a designated beneficiary fund in the amount of \$500,000, entitled *EveryLife Rainy Day Fund* of the Marin Community Foundation (“the Fund”).

The purpose of the Fund is to provide support to or for the benefit of the Foundation and its activities in pursuit of its mission. The Community Foundation has legal control of the Fund and approves the amount and timing of distributions to the Foundation, while the Donors retain advisory privileges.

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
December 31, 2024 and 2023

8. Designated Beneficiary Funds (continued)

EveryLife Rainy Day Fund (continued)

Distributions from the Fund may be requested in writing to the Community Foundation by the Foundation's Board Chair, Treasurer, or Executive Director, and must be supported by a majority vote of the Board of Directors. Funds may only be requested in connection with significant special projects or emergency situations, and are limited to a maximum of \$250,000 per calendar year.

As of December 31, 2024 and 2023, the Fund held total assets of \$282,273 and \$493,241, respectively. These assets are held and controlled by the Community Foundation and, accordingly, are not reflected in the accompanying statements of financial position. On October 21, 2024, the Foundation received a distribution of \$250,000 from the Fund, which is reported as contribution revenue in the accompanying statement of activities for the year ended December 31, 2024. No distributions were received during the year ended December 31, 2023.

EveryLife Endowment Fund

In 2021, the Donors and the Marin Community Foundation entered into an agreement to establish a designated beneficiary fund in the amount of \$5,000,000, titled the *EveryLife Endowment Fund of the Marin Community Foundation* ("the Endowment Fund"). The purpose of the Endowment Fund is to provide long-term support to, or for the benefit of, the Foundation in alignment with its mission. The Community Foundation retains legal control over the Endowment Fund, including discretion over the timing and amount of distributions. The Donors maintain advisory privileges under the terms of the agreement.

Annual distributions from the Endowment Fund began in July 2022 and are made in accordance with the Community Foundation's spending policy. The distribution amount is generally calculated as 4.5% of the Endowment Fund's principal, based on the Foundation's long-term investment strategy. Growth exceeding the spending rate may be retained within the Fund to support future expansion or offset underperformance in other years.

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
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8. Designated Beneficiary Funds (continued)

EveryLife Endowment Fund (continued)

On August 19, 2024, the Foundation received a distribution of \$188,867, which is recognized as contributions revenue in the accompanying statement of activities for the year ended December 31, 2024. On July 31, 2023, a distribution of \$193,912 was received and similarly recognized as contributions revenue for the year ended December 31, 2023. As of December 31, 2024 and 2023, the Endowment Fund held total assets of \$4,631,563 and \$4,454,898, respectively. These assets are legally owned and controlled by the Community Foundation and are therefore not included in the accompanying statements of financial position.

9. Commitments and Contingencies

Conference Space

The Foundation is committed under agreements for conference space through 2025. The total commitments under the agreements are not determinable as they depend upon attendance and other unknown factors. There are cancellation penalties that would be due if the agreements were cancelled prior to the event date. The amount of the cancellation penalties increases through the date of the event.

Operating Leases

The Foundation leases office space under a 65-month agreement, which originated in November 2018. Base rent is \$13,364 per month, plus a proportionate share of expenses, increasing by a factor of 2.5% per year. During the year ended December 31, 2020, the Foundation amended the existing lease agreement to expand the current office space. The terms for the original space remained unchanged. Under the lease amendment, base rent for the expanded space is \$5,266 per month, increasing by a factor of 2.5% per year and continuing through the termination date of the original lease.

In 2021, the Foundation entered into an additional amendment to expand the current office space. The terms for the original space remained unchanged. Under the new amendment, base rent for the expanded space is \$3,994 per month, increasing by a factor of 2.5% per year and continuing through the termination date of the original lease.

EveryLife Foundation for Rare Diseases

Notes to Financial Statements December 31, 2024 and 2023

9. Commitments and Contingencies (continued)

Operating Leases (continued)

On June 20, 2023, the Foundation signed a third amendment to extend the term of the lease, effective from June 1, 2023 to September 30, 2028. The lease term entails base monthly payments of \$21,546 with an annual rental increase of 2.5%. In addition, the lease incorporates a rental abatement period as a leasing incentive. This comprises of four months of complete lease abatement in lease payments.

The Foundation subleases a portion of its office space under various leases with termination dates through 2025. Total rental income was \$103,560 and \$88,895 for the years ended December 31, 2024 and 2023, respectively. Total future minimum lease receipts under the office sublease total \$31,730 for the year ending December 31, 2025. Rent receivable is not recorded in the accompanying statements of financial position due to immateriality.

In addition, the Foundation previously leased office equipment under an operating lease that was scheduled to expire in 2025. The equipment was returned, and the lease effectively terminated in September 2023. At that time, the Foundation entered into a new office equipment lease, also classified as an operating lease, which extends through December 2028. The Foundation does not have any short-term lease arrangements as of December 31, 2024.

Lease Assets – Classification in the Statements of Financial Position

Total ROU assets are as follows at December 31:

	2024	2023
Operating lease ROU asset – office lease	\$ 888,323	\$ 1,104,373
Operating lease ROU asset – copier lease	19,785	24,214
Total operating ROU assets	<u>\$ 908,108</u>	<u>\$ 1,128,587</u>

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
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9. Commitments and Contingencies (continued)

Operating Leases (continued)

Lease Liabilities – Classification in the Statements of Financial Position

Total lease liabilities are as follows at December 31:

	2024	2023
Operating lease liability – office lease	\$ 902,574	\$ 1,103,076
Operating lease liability – copier lease	19,785	24,214
Total lease liabilities	<u>\$ 922,359</u>	<u>\$ 1,127,290</u>

Total lease costs are as follows for the years ended December 31:

	2024	2023
Operating lease costs – office lease	\$ 256,326	\$ 253,710
Operating lease costs – copier lease	5,400	5,649
Rental income	<u>(103,560)</u>	<u>(88,895)</u>
Total lease costs	<u>\$ 158,166</u>	<u>\$ 170,464</u>

Supplemental qualitative information related to the leases is as follows as of, and for the years ended, December 31:

	2024	2023
Cash paid for amounts included in the measurements of operating lease liabilities	\$ 246,177	\$ 274,957
Operating ROU assets obtained in exchange for lease obligations	-	1,252,069
Weighted-average remaining lease term (in years)	3.9	4.9
Weighted-average discount rate	3.97%	3.97%

EveryLife Foundation for Rare Diseases

Notes to Financial Statements
December 31, 2024 and 2023

9. Commitments and Contingencies (continued)

Operating Leases (continued)

Maturities of the lease liabilities under the Foundation's operating leases are as follows for the years ending December 31:

	Office	Copier	Total
2025	\$ 246,796	\$ 5,400	\$ 252,196
2026	252,966	5,400	258,366
2027	259,290	5,400	264,690
2028	216,422	5,400	221,822
Total minimum lease payments	975,474	21,600	997,074
Less: discount to present value	(72,900)	(1,815)	(74,715)
Operating lease liabilities	<u>\$ 902,574</u>	<u>\$ 19,785</u>	<u>\$ 922,359</u>

10. Functionalized Expenses

The financial statements report certain categories of expenses that are attributed to more than one program or supporting function. Therefore, expenses require allocation on a reasonable basis that is consistently applied. Expenses that are allocated include salaries, payroll taxes, and benefits, rent and maintenance, consultants and professional services, occupancy, depreciation and amortization, insurance, office expenses, travel, meals, and lodging, and other, which are allocated on the basis of estimates of time and effort.

11. Retirement Plan

The Foundation sponsors a defined contribution plan covering all full-time employees after two months of employment. The Foundation provides a 100% match to each eligible employee's contribution, up to 6% of covered compensation. Contributions to the plan during the years ended December 31, 2024 and 2023 were \$140,895 and \$134,883, respectively. These amounts are included in salaries, payroll taxes, and benefits in the statements of functional expenses.

EveryLife Foundation for Rare Diseases

Notes to Financial Statements December 31, 2024 and 2023

12. Related Party Transactions

The Foundation receives support from members of the Board of Directors. The support from the Board members is received in the form of contributions and grants, and is included in the accompanying statements of activities. During the years ended December 31, 2024 and 2023, the Foundation received Board member support in the aggregate amount of \$63,649 and \$16,565, respectively.

13. Income Taxes

The Foundation is recognized as a tax-exempt organization under Section 501(c)(3) of the Internal Revenue Code, and is exempt from income taxes except for taxes on unrelated business activities. No tax expense is recorded in the accompanying financial statements for the years ended December 31, 2024 and 2023, as there was no significant unrelated business income.

Management has evaluated the Foundation's tax positions and concluded that there are no significant uncertain tax positions that qualify for either recognition or disclosure in the accompanying financial statements.