EveryLife Foundation for Rare Diseases

Financial Statements
and Independent Auditor's Report

December 31, 2022 and 2021

EveryLife Foundation for Rare Diseases

Financial Statements
December 31, 2022 and 2021

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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, 2022 and 2021; 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, 2022 and 2021, 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.

Emphasis of Matter

As discussed in Note 2 to the financial statements, the Foundation adopted Accounting Standards Update (ASU) 2016-02, *Leases* (Topic 842), as of January 1, 2022, and ASU 2020-07 *Not-for-Profit Entities* (Topic 958): *Presentation and Disclosures by Not-for-Profit Entities for Contributed Nonfinancial Assets.* Our opinion is not modified with respect to this matter.

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 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.

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

- 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.

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.

Rogers + Company PLLC

Vienna, Virginia
May 9, 2023

EveryLife Foundation for Rare Diseases

Statements of Financial Position
December 31, 2022 and 2021

	2022	2021
Assets		
Cash and cash equivalents	$ 2,158,760	$ 2,185,075
Investments	1,130,116	1,249,338
Accounts receivable	6,615	2,678
Contributions receivable	700,518	911,900
Prepaid expenses	147,552	160,493
Property and equipment, net	18,778	27,753
Right-of-use assets – operating leases	319,703	-
Deposits	13,363	13,363
Total assets	$ 4,495,405	$ 4,550,600
Liabilities and Net Assets		
Liabilities		
Accounts payable and accrued expenses	$ 374,094	$ 656,046
Accrued salaries and related benefits	217,131	161,663
Deferred revenue	307,450	295,400
Deposits payable	6,500	4,300
Deferred rent	-	44,491
Lease liabilities – operating leases	349,268	-
Total liabilities	1,254,443	1,161,900
Net Assets		
Without donor restrictions	1,874,297	1,548,450
With donor restrictions	1,366,665	1,840,250
Total net assets	3,240,962	3,388,700
Total liabilities and net assets	$ 4,495,405	$ 4,550,600

EveryLife Foundation for Rare Diseases

Statement of Activities
For the Year Ended December 31, 2022

	Without Donor Restrictions	With Donor Restrictions	Total
Operating Revenue and Support			
Contributions and grants:			
Corporations	$ 2,357,655	$ 1,366,665	$ 3,724,320
Board	65,400	-	65,400
Individuals	57,538	-	57,538
Foundations	257,580	-	257,580
Corporate membership	1,538,250	-	1,538,250
Rental income	98,000	-	98,000
In-kind donations	1,225	-	1,225
Other revenue	17,000	-	17,000
Net assets released from restrictions	1,840,250	(1,840,250)	-
Total operating revenue and support	6,232,898	(473,585)	5,759,313
Expenses			
Program services	4,359,826	-	4,359,826
Supporting services:			
General and administrative	1,076,552	-	1,076,552
Fundraising	351,632	-	351,632
Total supporting services	1,428,184	-	1,428,184
Total expenses	5,788,010	-	5,788,010
Change in Net Assets from Operations	444,888	(473,585)	(28,697)
Non-Operating Activity			
Investment return, net	(119,041)	-	(119,041)
Total non-operating activity	(119,041)	-	(119,041)
Change in Net Assets	325,847	(473,585)	(147,738)
Net Assets, beginning of year	1,548,450	1,840,250	3,388,700
Net Assets, end of year	$ 1,874,297	$ 1,366,665	$ 3,240,962

EveryLife Foundation for Rare Diseases

Statement of Activities
For the Year Ended December 31, 2021

	Without Donor Restrictions	With Donor Restrictions	Total
Operating Revenue and Support			
Contributions and grants:			
Corporations	$ 2,409,632	$ 1,840,250	$ 4,249,882
Board	17,515	-	17,515
Individuals	62,509	-	62,509
Foundations	147,100	-	147,100
Corporate membership	1,239,750	-	1,239,750
Rental income	33,250	-	33,250
In-kind donations	3,025	-	3,025
Other revenue	13,764	-	13,764
Net assets released from restrictions	1,597,500	(1,597,500)	-
Total operating revenue and support	5,524,045	242,750	5,766,795
Expenses			
Program services	3,796,111	-	3,796,111
Supporting services:			
General and administrative	1,000,953	-	1,000,953
Fundraising	290,979	-	290,979
Total supporting services	1,291,932	-	1,291,932
Total expenses	5,088,043	-	5,088,043
Change in Net Assets from Operations	436,002	242,750	678,752
Non-Operating Activities			
Investment return, net	(9,882)	-	(9,882)
Change in donor's designation of the contribution receivable	(500,000)	-	(500,000)
Gain on extinguishment of debt	214,140	-	214,140
Total non-operating activities	(295,742)	-	(295,742)
Change in Net Assets	140,260	242,750	383,010
Net Assets, beginning of year	1,408,190	1,597,500	3,005,690
Net Assets, end of year	$ 1,548,450	$ 1,840,250	$ 3,388,700

EveryLife Foundation for Rare Diseases

Statement of Functional Expenses
For the Year Ended December 31, 2022

	Program Services	Supporting Services: General and Administrative	Supporting Services: Fundraising	Supporting Services: Total Supporting Services	Total Expenses
Advertising and promotion	$ 19,507	$ -	$ 6,627	$ 6,627	$ 26,134
Bank charges/processing fees	1,218	500	209	709	1,927
Conferences and other events	486,602	-	953	953	487,555
Consulting	759,446	-	-	-	759,446
Depreciation and amortization	5,592	2,399	984	3,383	8,975
Grants	421,405	-	-	-	421,405
In-kind services	-	1,225	-	1,225	1,225
Insurance	4,509	1,935	794	2,729	7,238
Lobbying	140,205	-	-	-	140,205
Miscellaneous	46,593	29,664	-	29,664	76,257
Occupancy	190,728	43,260	17,701	60,961	251,689
Postage and printing	33,449	428	337	765	34,214
Professional fees	6,091	78,016	1,073	79,089	85,180
Salaries, payroll taxes, and benefits	1,728,079	866,016	302,949	1,168,965	2,897,044
Supplies and office	52,374	7,080	2,515	9,595	61,969
Technology and website	165,736	8,512	8,614	17,126	182,862
Telephone and internet	6,418	-	-	-	6,418
Travel, meals, and lodging	291,874	37,517	8,876	46,393	338,267
Total Expenses	$ 4,359,826	$ 1,076,552	$ 351,632	$ 1,428,184	$ 5,788,010

EveryLife Foundation for Rare Diseases

Statement of Functional Expenses
For the Year Ended December 31, 2021

		Supporting Services			
	Program Services	General and Administrative	Fundraising	Total Supporting Services	Total Expenses
Advertising and promotion	$ 20,700	$ -	$ 6,201	$ 6,201	$ 26,901
Bad debt expenses	-	450	-	450	450
Bank charges/processing fees	1,500	757	321	1,078	2,578
Conferences and other events	431,016	-	540	540	431,556
Consulting	853,903	-	-	-	853,903
Depreciation and amortization	4,076	2,123	897	3,020	7,096
Grants	671,510	-	-	-	671,510
In-kind services	-	3,025	-	3,025	3,025
Insurance	3,552	1,850	781	2,631	6,183
Lobbying	197,058	-	-	-	197,058
Miscellaneous	32,494	25,864	610	26,474	58,968
Occupancy	155,993	47,190	19,886	67,076	223,069
Postage and printing	39,747	929	87	1,016	40,763
Professional fees	2,872	74,866	632	75,498	78,370
Salaries, payroll taxes, and benefits	1,140,965	804,944	250,953	1,055,897	2,196,862
Supplies and office	59,342	6,764	2,515	9,279	68,621
Technology and website	171,048	9,316	7,095	16,411	187,459
Telephone and internet	6,710	-	-	-	6,710
Travel, meals, and lodging	3,625	22,875	461	23,336	26,961
Total Expenses	$ 3,796,111	$ 1,000,953	$ 290,979	$ 1,291,932	$ 5,088,043

EveryLife Foundation for Rare Diseases

Statements of Cash Flows
For the Years Ended December 31, 2022 and 2021

	2022	2021
Cash Flows from Operating Activities		
Change in net assets	$ (147,738)	$ 383,010
Adjustments to reconcile change in net assets to net cash (used in) provided by operating activities:		
Depreciation and amortization	8,975	7,096
Realized and unrealized loss on investments	144,660	20,142
Gain on extinguishment of debt	-	(214,140)
Change in operating assets and liabilities:		
Decrease (increase) in:		
Accounts receivable	(3,937)	(2,678)
Contributions receivable	211,382	569,502
Prepaid expenses	12,941	12,062
Right-of-use assets – operating leases	(319,703)	-
(Decrease) increase in:		
Accounts payable and accrued expenses	(281,952)	413,342
Accrued salaries and related benefits	55,468	(53,796)
Deferred revenue	12,050	(247,500)
Deposits payable	2,200	1,200
Deferred rent	(44,491)	827
Lease liabilities – operating leases	349,268	-
Net cash (used in) provided by operating activities	(877)	889,067
Cash Flows from Investing Activities		
Purchase of investments	(53,459)	(1,259,985)
Proceeds from sales of investments	28,021	-
Purchase of fixed assets	-	(9,398)
Net cash used in investing activities	(25,438)	(1,269,383)
Net Decrease in Cash and Cash Equivalents	(26,315)	(380,316)
Cash and Cash Equivalents, beginning of year	2,185,075	2,565,391
Cash and Cash Equivalents, end of year	$ 2,158,760	$ 2,185,075

See accompanying notes.

1. Nature of Operations

The EveryLife Foundation for Rare Diseases ("the Foundation") is a nonprofit organization located in Washington, D.C. The Foundation is dedicated to accelerating biotech innovation for rare disease treatments through science-driven public policy. The Foundation believes it can do more with existing science and bring life-saving treatments to millions of people suffering from rare diseases.

Currently, there are fewer than 400 approved treatments for over 7,000 rare diseases affecting more than 30 million Americans. The science exists for many of these diseases to be treated; however, treatments may never be developed because of roadblocks in the development process, such as lack of investment and a challenging regulatory environment. The Foundation works with patient organizations, industry, academic scientists, the Food and Drug Administration, and the National Institutes of Health to improve the clinical development process through the Cure the Process Campaign, Rare Disease Workshop Series, and legislation.

The Foundation is a 501(c)(3) nonprofit, nonpartisan organization dedicated to advancing the development of treatment and diagnostic opportunities for rare disease patients through science-driven public policy. The Foundation does not speak for patients, but instead provides the training, education, resources, and opportunities to make patient voices heard. By activating the patient advocate, the Foundation believes it can change public policy and save lives.

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.

2. Summary of Significant Accounting Policies (continued)

Basis of Accounting and Presentation (continued)

- *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.

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

The Foundation's accounts receivable are all due in less than one year and are recorded at net realizable value. The Foundation analyzes and writes off accounts receivable when they become uncollectible. When necessary, an allowance for uncollectible accounts receivable is determined based upon management's best estimate of the potential future uncollectibility of accounts outstanding. All receivables were deemed fully collectible, and no allowance for uncollectible accounts was established at December 31, 2022 and 2021.

2. Summary of Significant Accounting Policies (continued)

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, 2022 and 2021. 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, 2022 and 2021, as management believes that all amounts are fully collectible.

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.

2. Summary of Significant Accounting Policies (continued)

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.

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.

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.

2. Summary of Significant Accounting Policies (continued)

<u>Revenue Recognition (continued)</u>

Revenue Accounted for as Contracts with Customers (continued)

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.

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 (ASU) 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.

2. Summary of Significant Accounting Policies (continued)

In-Kind Contributions

The Foundation receives in-kind contributions in the form of contributed professional services, which totaled $1,225 and $3,025 for the years ended December 31, 2022 and 2021, respectively. Services are recognized only when they create or enhance nonfinancial assets, or require specialized skills, are provided by qualified individuals, and would typically be purchased if not donated. In-kind contributions are recognized as revenue and expenses in the accompanying statements of activities at their estimate fair value, as provided by donor, at the date of receipt.

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.

Advertising and Promotion Costs

Advertising and promotion costs are expensed as incurred, and were approximately $26,134 and $26,901 during the years ended December 31, 2022 and 2021, 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, change in donor's designation of the contribution receivable, and gain on extinguishment of debt.

2. Summary of Significant Accounting Policies (continued)

Adopted Accounting Pronouncements

In February 2016, the FASB issued ASU 2016-02, Accounting Standards Codification (ASC) 842, *Leases*. The update requires a lessee to recognize a right-of-use asset and lease liability, initially measured at the present value of the lease payments, in its statements of financial position. The guidance also expands the required quantitative and qualitative lease disclosures. The Foundation adopted ASC 842 during the year ended December 31, 2022, and adjusted the presentation in the financial statements as permitted by ASC 842. A modified retrospective transition approach is required for lessees for finance and operating leases existing at, or entered into after, the beginning of the earliest comparative period presented in the financial statements, with certain practical expedients available.

In September 2020, the FASB issued ASU 2020-07, *Not-for-Profit Entities* (Topic 958): *Presentation and Disclosures by Not-for-Profit Entities for Contributed Nonfinancial Assets*. This guidance is intended to increase transparency of contributed nonfinancial assets for nonprofit entities through enhancements in presentation and disclosure requirements. Nonprofit entities will be required to present contributed nonfinancial assets as a separate line item in the statements of activities, apart from contributions of cash and other financial contributions. Nonprofit entities will also be required to disclose various information related to contributed nonfinancial assets. ASU 2020-07 is effective for fiscal years beginning after June 15, 2021. The Foundation has implemented ASU 2020-07. The implementation had no impact on previously reported net assets.

Reclassifications

Certain amounts in the 2021 financial statements have been reclassified to conform to the 2022 presentation. These reclassifications have no effect on the change in net assets previously reported.

Subsequent Events

In preparing these financial statements, the Foundation has evaluated events and transactions for potential recognition or disclosure through May 9, 2023, the date the financial statements were available to be issued.

3. Liquidity and Availability

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.

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:

	2022	2021
Cash and cash equivalents	$ 2,158,760	$ 2,185,075
Investments	1,130,116	1,249,338
Accounts receivable	6,615	2,678
Contributions receivable	700,518	911,900
Total financial assets	3,996,009	4,348,991
Less: restricted by donors	(1,366,665)	(1,840,250)
Total available for general expenditures	$ 2,629,344	$ 2,508,741

4. Concentration 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, 2022 and 2021, the Foundation’s balances exceeded federally insured limits by approximately $2,786,000 and $2,934,000, respectively.

5. Investments and Fair Value Measurements

The Foundation follows FASB ASC 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.

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.

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
2022:				
Money market funds	$ 52,205	$ -	$ -	$ 52,205
Mutual funds	1,077,911	-	-	1,077,911
Total investments	$ 1,130,116	$ -	$ -	$ 1,130,116
2021:				
Money market funds	$ 47,485	$ -	$ -	$ 47,485
Mutual funds	1,201,853	-	-	1,201,853
Total investments	$ 1,249,338	$ -	$ -	$ 1,249,338

5. Investments and Fair Value Measurements (continued)

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

	2022	2021
Interest and dividends	$ 31,465	$ 13,276
Realized loss	(292)	(11,949)
Unrealized loss	(144,368)	(8,193)
Investment management fees	(5,846)	(3,016)
Total investment return, net	$ (119,041)	$ (9,882)

6. Property and Equipment

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

	2022	2021
Furniture and equipment	$ 28,218	$ 28,218
Leasehold improvements	18,046	18,046
Total property and equipment	46,264	46,264
Less: accumulated depreciation and amortization	(27,486)	(18,511)
Property and equipment, net	$ 18,778	$ 27,753

7. Deferred Revenue

Deferred revenue consists of the following at December 31:

	2022	2021
Membership dues	$ 307,450	$ 292,000
Other	-	3,400
Total deferred revenue	$ 307,450	$ 295,400

8. Loan Payable

The Foundation applied for a loan under the Paycheck Protection Program (PPP) pursuant to Division A, Title 1 of the CARES Act, which was enacted on March 27, 2020. The PPP is a loan designed to provide a direct incentive for small businesses to keep their workers on the payroll through the COVID-19 pandemic, for which the Foundation qualified. After the loan was granted, the Small Business Administration (SBA) will forgive the loans if all employee retention criteria are met, and the funds are used for eligible expenses (which primarily consist of payroll costs, costs used to continue group healthcare benefits, rent, and utilities).

On May 2, 2020, the Foundation received a PPP loan in the amount of $214,140. During the covered period, the Foundation incurred qualifying expenditures and applied for forgiveness of the full amount. On April 15, 2021, the PPP loan was fully forgiven by the SBA and the related amount was recognized as gain on extinguishment of debt in the accompanying statement of activities for the year ended December 31, 2021.

9. Net Assets

Net Assets With Donor Restrictions

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

	2022	2021
Subject to expenditure for specific purpose:		
Rare Disease Week	$ 345,000	$ 410,000
Newborn Screening Bootcamp	275,000	120,000
Rare Disease Legislative Advocates	230,000	251,500
Rare Scholarship	200,000	300,000
Economic Burden Study	75,000	495,000
Rare Voice Awards Gala	30,000	-
Diversity Fellowship	20,000	5,000
State Advocacy	15,000	-
RareGiving	10,000	35,000
Rare Artist	-	55,000
Subject to passage of time	166,665	168,750
Total net assets with donor restrictions	$ 1,366,665	$ 1,840,250

9. 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:

	2022	2021
Purpose restrictions accomplished:		
Rare Disease Week	$ 410,000	$ 225,000
Newborn Screening Bootcamp	120,000	160,000
Rare Disease Legislative Advocates	251,500	170,000
Rare Scholarship	300,000	200,000
Rare on the Road	-	20,000
Economic Burden Study	495,000	55,000
Diversity Fellowship	5,000	40,000
State Advocacy	-	170,000
RareGiving	35,000	15,000
Rare Artist	55,000	40,000
Annual Scientific Workshop	-	2,500
Passage of time	168,750	500,000
Total net assets released from donor restrictions	$ 1,840,250	$ 1,597,500

10. 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.

10. Designated Beneficiary Funds (continued)

EveryLife Rainy Day Fund (continued)

The distributions from the Fund can be made upon a written request made to the Community Foundation from the Foundation's Board Chair, Treasurer, or Executive Director and based on a majority vote of the Board. The funds may be requested only toward important special projects or emergency situations, with a maximum annual request of up to $250,000. As of December 31, 2022 and 2021, total assets of the Fund were $434,603 and $507,396, respectively, which represent the assets of the Community Foundation and, as such, are not included in the accompanying statements of financial position. During the years ended December 31, 2022 and 2021, the Foundation did not request distributions from the Fund.

EveryLife Endowment Fund

In 2021, another agreement was signed between the Donors and the Community Foundation to establish a designated beneficiary fund in the amount of $5,000,000, entitled *EveryLife Endowment Fund* of the Marin Community Foundation ("the Endowment 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 retains advisory privileges.

The distributions from the Endowment Fund will be made every year, starting in July 2022, and in accordance with the spending rule of the Community Foundation. The distribution is based on the long-term investment plan and is expected to constitute 4.5% of the principal each year, with remaining growth above that percentage to support expansion of the Endowment Fund, in years that exceed that growth rate or make up for shortfall in growth in other years. On September 14, 2022, the Foundation received a distribution of $222,495 from the Endowment Fund, which was recognized as contributions revenue in the accompanying statement of activities for the year ended December 31, 2022.

At December 31, 2022 and 2021, total assets of the fund were $4,077,216 and $5,072,881, respectively, which represent assets of the Community Foundation and, as such, are not included in the accompanying statements of financial position.

11. 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

Office Lease

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.

The unamortized portion of the cumulative difference between the actual rent paid and the straight-line rent is reflected as deferred rent in the accompanying statements of financial position. At December 31, 2021, deferred rent liability was $44,491.

On January 1, 2022, the Foundation adopted Topic 842 and recorded a right-of-use asset and a lease liability in the accompanying statements of financial position for the year ended December 31, 2022.

11. Commitments and Contingencies (continued)

<u>Operating Leases (continued)</u>

Office Lease (continued)

The Foundation subleases a portion of its office space under various leases with termination dates through 2023. Total future minimum lease receipts under the office sublease total $29,700 for the year ending December 31, 2023.

Occupancy expense for the years ended December 31, 2022 and 2021 was $251,689 and $223,069, respectively, and is recorded in the accompanying statements of functional expenses.

The Foundation has no short-term leases.

Lease cost was comprised of the following for the year ended December 31, 2022:

Operating lease cost (lease expense)	$	254,099
Rental income		(98,000)
Total lease cost	$	156,099

Supplemental qualitative information related to the office lease is as follows as of, and for the year ended, December 31, 2022:

Cash paid for amounts included in the measurement of lease liabilities – operating cash flows	$	259,606
Right-of-use assets obtained in exchange for lease obligations	$	306,961
Weighted-average remaining lease term (in years)		1.1
Weighted-average discount rate		4.75%

11. Commitments and Contingencies (continued)

Operating Leases (continued)

Office Lease (continued)

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

2023	$	268,281
2024		58,939
Total minimum lease payments		327,220
Less: discount to present value at 4.75%		9,306
Present value of operating lease liabilities	$	336,526

Equipment Lease

The Foundation also leases office equipment under an operating lease, which expires in 2025. Total operating lease costs under this lease were $5,732 for the year ended December 31, 2022. The right-of-use asset obtained in exchange for lease obligation under this lease totaled $12,742 at December 31, 2022. The present value of lease liability under this lease totaled $12,897 at December 31, 2022. The weight-average discount rate used was 1.04%.

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

2023	$	5,732
2024		5,732
2025		1,433
2026		-
Total minimum lease payments		12,897
Less: discount to present value at 1.04%		(155)
Present value of operating lease liabilities	$	12,742

12. 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.

13. 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, 2022 and 2021 were $121,185 and $95,974, respectively. These amounts are included in salaries, payroll taxes, and benefits in the statements of functional expenses.

14. 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, 2022 and 2021, the Foundation received Board member support in the aggregate amount of $65,400 and $17,515, respectively.

15. 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, 2022 and 2021, 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.