EveryLife Foundation for Rare Diseases

Financial Statements
and Independent Auditors' Report

December 31, 2021 and 2020

EveryLife Foundation for Rare Diseases

Financial Statements
December 31, 2021 and 2020

Contents

ROGERS & COMPANY

Rogers & Company PLLC
Certified Public Accountants

8300 Boone Boulevard
Suite 600
Vienna, Virginia 22182

703.893.0300 voice
703.893.4070 facsimile
www.rogerspllc.com

INDEPENDENT AUDITORS' 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 statement of financial position as of December 31, 2021; 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 the Foundation 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 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 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.

ROGERS & COMPANY

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.

Other Matter

The financial statements of the Foundation as of December 31, 2020 were audited by other auditors whose report, dated May 19, 2021, expressed an unmodified opinion on those statements.

Rogers + Company PLLC

Vienna, Virginia
May 20, 2022

EveryLife Foundation for Rare Diseases

Statements of Financial Position
December 31, 2021 and 2020

	2021	2020
Assets		
Cash and cash equivalents	$ 2,185,075	$ 2,565,391
Investments	1,249,338	9,495
Accounts receivable	2,678	-
Contributions receivable	911,900	1,481,402
Prepaid expenses	160,493	172,555
Property and equipment, net	27,753	25,451
Deposits	13,363	13,363
Total assets	$ 4,550,600	$ 4,267,657
Liabilities and Net Assets		
Liabilities		
Accounts payable and accrued expenses	$ 656,046	$ 242,704
Loan payable – Paycheck Protection Program	-	214,140
Accrued salaries and related benefits	161,663	215,459
Deferred revenue	295,400	542,900
Deposits payable	4,300	3,100
Deferred rent	44,491	43,664
Total liabilities	1,161,900	1,261,967
Net Assets		
Without donor restrictions	1,548,450	1,408,190
With donor restrictions	1,840,250	1,597,500
Total net assets	3,388,700	3,005,690
Total liabilities and net assets	$ 4,550,600	$ 4,267,657

See accompanying notes.

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
Non-Operating Activities			
Investment loss, 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 Activities
For the Year Ended December 31, 2020

	Without Donor Restrictions	With Donor Restrictions	Total
Operating Revenue and Support			
Contributions and grants:			
Corporations	$ 2,003,043	$ 1,097,500	$ 3,100,543
Board	57,200	-	57,200
Individuals	47,536	-	47,536
Foundations	246,500	-	246,500
Corporate membership	892,500	-	892,500
Contracts	499	-	499
Rental income	58,850	-	58,850
Income from ISP	5,012	-	5,012
Special event	44,126	-	44,126
Net assets released from restrictions	1,561,800	(1,561,800)	-
Total operating revenue and support	4,917,066	(464,300)	4,452,766
Expenses			
Program services	2,974,532	-	2,974,532
Supporting services:			
General and administrative	722,585	-	722,585
Fundraising	335,465	-	335,465
Total supporting services	1,058,050	-	1,058,050
Total expenses	4,032,582	-	4,032,582
Non-Operating Activity			
Investment loss, net	(14,920)	-	(14,920)
Total non-operating activity	(14,920)	-	(14,920)
Change in Net Assets	869,564	(464,300)	405,264
Net Assets, beginning of year	538,626	2,061,800	2,600,426
Net Assets, end of year	$ 1,408,190	$ 1,597,500	$ 3,005,690

EveryLife Foundation for Rare Diseases

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

	Program Services	Supporting Services: General and Administrative	Supporting Services: Fundraising	Supporting Services: 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

See accompanying notes.

EveryLife Foundation for Rare Diseases

Statement of Functional Expenses
For the Year Ended December 31, 2020

	Program Services	Supporting Services: General and Administrative	Supporting Services: Fundraising	Supporting Services: Total Supporting Services	Total Expenses
Advertising and promotion	$ 32,113	$ -	$ -	$ -	$ 32,113
Bad debt expenses	-	17,775	-	17,775	17,775
Bank charges/processing fees	3,900	1,240	760	2,000	5,900
Conferences and other events	501,877	-	50	50	501,927
Consulting	480,597	-	15,226	15,226	495,823
Depreciation and amortization	4,081	1,868	1,146	3,014	7,095
Grants	524,594	-	-	-	524,594
Insurance	2,440	1,117	685	1,802	4,242
Lobbying	69,949	-	-	-	69,949
Miscellaneous	32,710	21,862	3,976	25,838	58,548
Occupancy	157,276	40,690	24,654	65,344	222,620
Postage and printing	35,192	1,312	225	1,537	36,729
Professional fees	43,355	45,808	13,489	59,297	102,652
Salaries, payroll taxes, and benefits	942,635	575,646	264,674	840,320	1,782,955
Supplies and office	17,113	2,679	1,226	3,905	21,018
Technology and website	91,917	8,713	8,033	16,746	108,663
Telephone and internet	8,936	906	556	1,462	10,398
Travel, meals, and lodging	25,847	2,969	765	3,734	29,581
Total Expenses	$ 2,974,532	$ 722,585	$ 335,465	$ 1,058,050	$ 4,032,582

EveryLife Foundation for Rare Diseases

Statements of Cash Flows
For the Years Ended December 31, 2021 and 2020

	2021	2020
Cash Flows from Operating Activities		
Change in net assets	$ 383,010	$ 405,264
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Depreciation and amortization	7,096	7,095
Realized and unrealized loss on investments	20,142	15,267
Gain on extinguishment of debt	(214,140)	-
Change in operating assets and liabilities:		
Decrease (increase) in:		
Accounts receivable	(2,678)	-
Contributions receivable	569,502	587,752
Prepaid expenses	12,062	(75,366)
Deposits	-	13,364
(Decrease) increase in:		
Accounts payable and accrued expenses	413,342	(178,428)
Accrued salaries and related benefits	(53,796)	115,700
Deferred revenue	(247,500)	212,975
Deposits payable	1,200	(2,000)
Deferred rent	827	11,515
Net cash provided by operating activities	889,067	1,113,138
Cash Flows from Investing Activities		
Purchase of investments	(1,259,985)	-
Purchases of fixed assets	(9,398)	-
Net cash used in investing activities	(1,269,383)	-
Cash Flows from Financing Activity		
Proceeds from loan payable	-	214,140
Net cash provided by investing activity	-	214,140
Net (Decrease) Increase in Cash and Cash Equivalents	(380,316)	1,327,278
Cash and Cash Equivalents, beginning of year	2,565,391	1,238,113
Cash and Cash Equivalents, end of year	$ 2,185,075	$ 2,565,391

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 patience, 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 investment loss 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, 2021 and 2020.

2. Summary of Significant Accounting Policies (continued)

Contributions Receivable

Contributions receivable consist primarily of unconditional promises to give from various corporates, 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, 2021 and 2020. 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, 2021 and 2020, 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 lease. Repairs and maintenance costs are expensed as incurred.

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.

2. Summary of Significant Accounting Policies (continued)

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

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 as well as 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.

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.

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 contributions rules or if considered an exchange transaction 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.

In-Kind Contributions

The Foundation receives in-kind contributions in the form of contributed professional services, which totaled $3,025 and $0 for the years ended December 31, 2021 and 2020, 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.

2. Summary of Significant Accounting Policies (continued)

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 $26,901 and $32,113 during the years ended December 31, 2021 and 2020, 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 loss, change in donor's designation of the contribution receivable, and gain on extinguishment of debt.

Recently Issued Accounting Pronouncements

In February 2016, the FASB issued ASU 2016-02, *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 guidance is effective beginning in 2022. Management continues to evaluate the potential impact of this update on the Foundation's financial statements.

2. Summary of Significant Accounting Policies (continued)

Recently Issued Accounting Pronouncements (continued)

In September 2020, the FASB issued ASU 2020-07, *Presentation and Disclosures by Not-for-Profit Entities for Contributed Nonfinancial Assets.* The amendment is intended to increase transparency of contributed nonfinancial assets for not-for-profit entities through enhancements in presentation and disclosure requirements. Under the new ASU, not-for-profit entities will be required to present contributed nonfinancial assets in the statements of activities as a line item that is separate from contributions of cash or other financial assets. ASU 2020-07 also requires additional qualitative and quantitative disclosures about contributed nonfinancial assets received, disaggregated by category. The guidance is effective beginning in 2022.

Reclassifications

Certain amounts in the 2020 financial statements have been reclassified to conform to the 2021 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 20, 2022, 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.

3. Liquidity and Availability (continued)

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:

	2021	2020
Cash and cash equivalents	$ 2,185,075	$ 2,565,391
Investments	1,249,338	9,495
Contributions receivable	911,900	1,481,402
Total financial assets	4,346,313	4,056,288
Less: restricted by donors	(1,840,250)	(1,597,500)
Total available for general expenditures	$ 2,506,063	$ 2,458,788

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 cash deposit and transaction accounts, along with investments, with various financial institutions and these values, from time to time, exceed insurable limits under the Federal Deposit Insurance Corporation (FDIC) and Securities Investor Protection Corporation (SIPC). The Foundation has not experienced any credit losses on its cash and cash equivalents, and investments to date as it relates to FDIC and SIPC insurance limits. Management periodically assesses the financial condition of these financial institutions and believes that the risk of any credit loss is minimal.

5. Investments and Fair Value Measurements

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.

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.

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
2021:				
Money market funds	$ 47,485	$ -	$ -	$ 47,485
Mutual funds	1,201,853	-	-	1,201,853
Total investments	$ 1,249,338	$ -	$ -	$ 1,249,338
2020:				
Common stocks	$ 9,495	$ -	$ -	$ 9,495
Total investments	$ 9,495	$ -	$ -	$ 9,495

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

	2021	2020
Interest and dividends	$ 13,276	$ 347
Realized loss	(11,949)	-
Unrealized loss	(8,193)	(15,267)
Investment management fees	(3,016)	-
Total investment loss, net	$ (9,882)	$ (14,920)

6. Property and Equipment

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

	2021	2020
Furniture and equipment	$ 28,218	$ 18,820
Leasehold improvements	18,046	18,046
Total property and equipment	46,264	36,866
Less: accumulated depreciation and amortization	(18,511)	(11,415)
Property and equipment, net	$ 27,753	$ 25,451

7. Deferred Revenue

Deferred revenue consists of the following at December 31:

	2021	2020
Membership dues	$ 292,000	$ 539,500
Other	3,400	3,400
Total deferred revenue	$ 295,400	$ 542,900

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).

8. Loan Payable (continued)

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:

	2021	2020
Subject to expenditure for specific purpose:		
Rare on the Road	$ -	$ 20,000
Newborn Screening	120,000	160,000
Diversity Fellowship	5,000	40,000
Rare Artist	55,000	40,000
RareGiving	35,000	15,000
Rare Disease Week	410,000	225,000
Rare Scholarship	300,000	200,000
Rare Disease Legislative Advocates	251,500	170,000
Annual Scientific Workshop	-	2,500
State Advocacy	-	170,000
Economic Burden Study	495,000	55,000
Subject to passage of time	168,750	500,000
Total net assets with donor restrictions	$ 1,840,250	$ 1,597,500

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:

	2021	2020
Purpose restrictions accomplished:		
Rare on the Road	$ 20,000	$ 5,000
Rare Affair	-	75,000
Rare Artist	40,000	10,000
Newborn Screening Bootcamp	160,000	130,000
RareGiving	15,000	5,000
Rare Disease Week	225,000	393,000
Rare Voice Awards Gala	-	55,000
Rare Disease Legislative Advocates	170,000	180,000
Annual Scientific Workshop	2,500	32,500
Fellow	-	5,000
Economic Burden Study	55,000	100,000
Diversity Fellowship	40,000	-
State Advocacy	170,000	-
Rare Scholarship	200,000	-
Passage of time	500,000	571,300
Total net assets released from donor restrictions	$ 1,597,500	$ 1,561,800

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”).

10. Designated Beneficiary Funds (continued)

EveryLife Rainy Day Fund (continued)

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 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, 2021, total assets of the Fund were $507,396, which represent the assets of the Community Foundation and, as such, are not included in the accompanying statements of financial position. During the year ended December 31, 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.

As of December 31, 2021, total assets of the fund were $5,072,881, 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 the year of 2022. 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 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.

The Foundation subleases a portion of its office space under various leases with termination dates through 2022.

Occupancy expense for the years ended December 31, 2021 and 2020 was $223,069 and $222,620, respectively, and are recorded as occupancy in the accompanying statements of functional expenses. As of December 31, 2021 and 2020, the deferred rent was $44,491 and $43,664, respectively. Rental income for the years ended December 31, 2021 and 2020 was $33,250 and $58,850, respectively.

11. Commitments and Contingencies (continued)

Operating Lease (continued)

The Foundation also leases office equipment under an operating lease, which expires in 2025. The lease calls for fixed monthly payments during the term of the lease.

The following is a schedule of the future minimum lease payments and sublease receipts:

	Lease Payments	Rental Income	Net
2022	$ 225,398	$ (40,800)	$ 184,598
2023	251,823	-	251,823
2024	68,531	-	68,531
2025	1,433	-	1,433
Future minimum payments	$ 547,185	$ (40,800)	$ 506,385

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 employee benefits, rent and maintenance, consultants and professional services, occupancy, depreciation and amortization, insurance, office expenses, travel, 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, 2021 and 2020 were $95,974 and $79,547, 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, 2021 and 2020, the Foundation received Board member support in the aggregate amount of $17,515 and $57,200, respectively.

15. Income Taxes

The Foundation is recognized as a tax-exempt organization under Internal Revenue Code (IRC) Section 501(c)(3), 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, 2021 and 2020, as there was no significant unrelated business income. Contributions to the Foundation are deductible as provided in IRC Section 170(b)(1)(A)(vi).

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.