

CYSTINOSIS RESEARCH FOUNDATION
FINANCIAL STATEMENTS
YEARS ENDED JUNE 30, 2024 AND 2023



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**CYSTINOSIS RESEARCH FOUNDATION
TABLE OF CONTENTS
YEARS ENDED JUNE 30, 2024 AND 2023**

| | |
|---|----------|
| MANAGEMENT’S DISCUSSION AND ANALYSIS | i |
| INDEPENDENT AUDITORS’ REPORT | 1 |
| FINANCIAL STATEMENTS | |
| STATEMENTS OF FINANCIAL POSITION | 4 |
| STATEMENTS OF ACTIVITIES | 5 |
| STATEMENTS OF FUNCTIONAL EXPENSES | 6 |
| STATEMENTS OF CASH FLOWS | 8 |
| NOTES TO FINANCIAL STATEMENTS | 9 |



MISSION STATEMENT

Cystinosis Research Foundation's (CRF) mission is to support bench, clinical and translational research to find better treatments and a cure for cystinosis. CRF is dedicated to funding research that will improve the quality of life for those with cystinosis and to find a cure for this devastating disease.

ORGANIZATION MISSION

CRF is committed to finding a cure through an aggressively funded research agenda. CRF awards research grants bi-annually to accelerate the research process and to ensure that there is never a gap in funding new cutting-edge research projects. CRF is dedicated to improving the quality of life for cystinosis patients and to finding better treatments, including a cure, for our adults and children living with cystinosis.

EDUCATION

The Cystinosis Research Foundation is dedicated to educating the cystinosis community, the public and the medical community about cystinosis to ensure early diagnosis and immediate and proper treatment.

NATALIE'S WISH

Natalie's wish, '*To have my disease go away forever*', was the driving force and inspiration that led to the establishment of the Cystinosis Research Foundation (CRF) in 2003. We knew at that moment that we needed to make every effort to make Natalie's wish – and the wish of others with cystinosis – a reality.

HISTORY AND RESEARCH

Cystinosis is a rare, metabolic, genetic disease that afflicts approximately 2,500 children and adults worldwide. CRF is increasingly focused on funding clinical and translational research which is crucial to finding new treatments and a cure for cystinosis. CRF is committed to prioritizing and aggressively supporting research that has the potential to significantly improve the quality of life for children and adults with cystinosis.

RESEARCH GIVES US HOPE

We firmly believe that funding and supporting research gives us hope for a brighter future for those living with cystinosis. Hope allows us to live with cystinosis until the day a cure is found.

Since 2003, the Cystinosis Research Foundation (CRF) has raised over \$70 million and has become the leading provider of funds for cystinosis research throughout the world. CRF has strategically and aggressively invested millions of dollars into cystinosis research creating a thriving and collaborative global research community that has changed the course of cystinosis. From the beginning, all CRF operating costs have been privately underwritten, so 100 percent of all donations received by CRF go to support cystinosis research.

We are pleased to announce that during the 12-month period ending June 30, 2024, CRF awarded 15 new grants totaling \$3,403,407 for cystinosis research. The new grants bring us that much closer to better treatments and a cure.

CRF awards grants to the best and brightest researchers in the world. To date, CRF has awarded 245 studies at leading research institutions in 13 countries. CRF-funded researchers have published 110 articles in prestigious, top-rated journals. Those articles, available to everyone in the world, have contributed to the understanding of the pathogenesis and treatment of cystinosis.

RESEARCH PROGRESS

From the start of the foundation, we have understood that funding basic and bench research was important to understanding cystinosis. Over the years, as discoveries were made in the lab, CRF began funding clinical research, and now we are translating the data from the clinical studies to the patients.

Our strategy of providing seed money to talented researchers has been successful. Our first project involved funding researchers who were focused on a new treatment. CRF provided grants that funded every bench and clinical trial that led to the discovery of a delayed-release form of the life-saving medication for cystinosis. That medication, Procysbi® was approved by the FDA on April 30, 2013, and is considered the most significant advancement in the treatment of cystinosis in 30 years.

In 2007, CRF began funding Dr. Stéphanie Cherqui, at UC San Diego who was focused on stem cell and gene therapy research. As a direct result of CRF's early and continuous funding, in December 2018, the FDA approved a clinical trial to assess the efficacy and safety of a stem cell and gene therapy treatment for cystinosis patients. In October 2019, the first cystinosis patient received the stem cell gene therapy treatment. In 2020, two patients received the therapy, in November 2021, the fourth patient received the treatment and in March 2022, the fifth patient received the treatment. The sixth and final patient in Phase I/II of the clinical trial was treated in October 2022. The grants awarded to Dr. Cherqui for her stem cell work have been leveraged by multi-million-dollar grants from other funding agencies. If this treatment works, it could stop the progression of cystinosis or be the cure for cystinosis.

Since cystinosis is a systemic disease and affects every cell, CRF has targeted multiple areas of research to fund including kidney disease, muscle wasting, neurological issues, corneal cystinosis, and stem cell and gene therapy, all with the goal of finding better treatments and a cure for cystinosis.

CYSTINOSIS RESEARCH HELPS OTHERS

Many of the discoveries made by CRF researchers are currently being applied to other more prevalent and well-known disorders and diseases including other corneal diseases, kidney diseases and genetic and systemic diseases similar to cystinosis. Support for cystinosis research has reached far beyond the cystinosis community. A cure for cystinosis will help find cures for other diseases potentially helping millions of people.

CRF FAMILIES AND PARTNERS

The Cystinosis Research Foundation has witnessed tremendous growth over the years as cystinosis families have joined our fundraising efforts. People from all over the world have embraced the cystinosis cause and have enthusiastically raised funds to support cystinosis research through CRF. We have found strength in numbers and our joint effort gives us a renewed sense of community and purpose.

DAY OF HOPE CONFERENCE

Each year the Cystinosis Research Foundation hosts the Day of Hope Family Conference. In 2024, 57 families from around the world gathered to share their stories, hopes and dreams and to build life-long friendships. Leading CRF funded researchers attended the conference and updated the cystinosis community on their research progress including updates on gene and stem cell therapies, novel eye research and neurological research. The conference educates cystinosis families about current and ongoing research and offers them hope that brighter days are ahead for cystinosis patients.

CURE CYSTINOSIS INTERNATIONAL REGISTRY

The Cystinosis Research Foundation is excited to announce that a new, updated registry, the Cure Cystinosis International Registry (CCIR) was launched in April 2021. Today, more than 171 cystinosis families have registered with CCIR. The new registry will track patients' natural history data, collect data about current treatments, identify known and unknown medical complications and collect information about quality-of-life issues. The CCIR will be a central hub of information for the global community. The deidentified patient data from the registry can be shared with cystinosis clinicians, researchers and scientists who are pursuing research focused on better treatments and a cure for cystinosis.

CRF INTERNATIONAL RESEARCH SYMPOSIUM

CRF's International Research Symposium is held every two years and is a highlight for cystinosis researchers. Attendees are CRF funded researchers and scientists from around the world. Approximately 60 cystinosis experts from leading international universities and research institutions are invited to give presentations about their work. Attendees share their research progress and are encouraged to form collaborations in an effort to accelerate the research process. The symposium has created a synergistic research community working in partnership with CRF.



INDEPENDENT AUDITORS' REPORT

Board of Directors
Cystinosis Research Foundation
Irvine, California

Report on the Audit of the Financial Statements

Opinion

We have audited the accompanying financial statements of Cystinosis Research Foundation (a nonprofit organization) (the Foundation), which comprise the statements of financial position as of June 30, 2024 and 2023, and 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 Cystinosis Research Foundation as of June 30, 2024 and 2023, and the change 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 (GAAS). Our responsibilities under those standards are further described in the Auditors' Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of 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.

Change in Accounting Principle

As discussed in Note 1 to the financial statements, in 2024, the Foundation adopted new accounting guidance for allowance for credit losses. The guidance requires the Foundation to estimate and account for expected credit losses for financial assets over the entirety of the asset's life. 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 Cystinosis Research Foundation 's ability to continue as a going concern for one year after the date the financial statements are available to be issued.

Auditors' Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditors' report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with GAAS will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with GAAS, 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 Cystinosis Research 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 Cystinosis Research 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.

Management Discussion and Analysis

Management is responsible for the other information included in the annual report. The other information comprises the letter from the Board President but does not include the basic financial statements and our auditors' report thereon. Our opinion on the basic financial statements does not cover the other information, and we do not express an opinion or any form of assurance thereon.

In connection with our audit of the basic financial statements, our responsibility is to read the other information and consider whether a material inconsistency exists between the other information and the basic financial statements, or the other information otherwise appears to be materially misstated. If, based on work performed, we conclude that an uncorrected material misstatement of the other information exists, we are required to describe it in our report.

CliftonLarsonAllen LLP

CliftonLarsonAllen LLP

Irvine, California
November 15, 2024

**CYSTINOSIS RESEARCH FOUNDATION
STATEMENTS OF FINANCIAL POSITION
JUNE 30, 2024 AND 2023**

| | 2024 | 2023 |
|--|---------------|---------------|
| ASSETS | | |
| CURRENT ASSETS | | |
| Cash and Cash Equivalents | \$ 5,144,486 | \$ 6,005,918 |
| Prepaid Expenses | 48,476 | 18,797 |
| Total Current Assets | 5,192,962 | 6,024,715 |
| PROPERTY AND EQUIPMENT, NET | 17,123 | 35,012 |
| OPERATING RIGHT-OF-USE ASSET | 64,774 | 33,481 |
| OTHER ASSETS - INVESTMENTS | 5,140,525 | 4,212,457 |
| Total Assets | \$ 10,415,384 | \$ 10,305,665 |
| LIABILITIES AND NET ASSETS | | |
| CURRENT LIABILITIES | | |
| Accounts Payable | \$ 28,915 | \$ 6,774 |
| Research Grants Payable - Current Portion | 1,884,781 | 1,507,916 |
| Accrued Expenses | 2,865 | 7,428 |
| Lease Liability - Operating | 64,609 | 36,310 |
| Total Current Liabilities | 1,981,170 | 1,558,428 |
| LONG-TERM LIABILITIES | | |
| Research Grants Payable, Net of Current Portion and Discount | 688,123 | 84,721 |
| Total Liabilities | 2,669,293 | 1,643,149 |
| NET ASSETS | | |
| Without Donor Restrictions | 7,746,091 | 8,662,516 |
| With Donor Restrictions | - | - |
| Total Net Assets | 7,746,091 | 8,662,516 |
| Total Liabilities and Net Assets | \$ 10,415,384 | \$ 10,305,665 |

See accompanying Notes to Financial Statements.

**CYSTINOSIS RESEARCH FOUNDATION
STATEMENTS OF ACTIVITIES
YEARS ENDED JUNE 30, 2024 AND 2023**

| | 2024 | 2023 |
|--|--------------|--------------|
| NET ASSETS WITHOUT DONOR RESTRICTIONS | | |
| Revenues and Other Support: | | |
| Contributions | \$ 2,411,656 | \$ 2,425,339 |
| Fundraising | 328,131 | 468,784 |
| Subtotal | 2,739,787 | 2,894,123 |
| Investment Revenues, Net | 501,000 | 413,954 |
| Total Revenues and Other Support | 3,240,787 | 3,308,077 |
| Expenses: | | |
| Program Services: | | |
| Research and Education | 3,690,815 | 2,322,731 |
| Supporting Services: | | |
| General and Administrative | 233,525 | 238,180 |
| Fundraising | 232,872 | 310,809 |
| Total Supporting Services | 466,397 | 548,989 |
| Total Expenses | 4,157,212 | 2,871,720 |
| INCREASE (DECREASE) IN TOTAL NET ASSETS | (916,425) | 436,357 |
| Net Assets - Beginning of Year | 8,662,516 | 8,226,159 |
| NET ASSETS - END OF YEAR | \$ 7,746,091 | \$ 8,662,516 |

See accompanying Notes to Financial Statements.

**CYSTINOSIS RESEARCH FOUNDATION
STATEMENT OF FUNCTIONAL EXPENSES
YEAR ENDED JUNE 30, 2024**

| | Program Services | | Supporting Services | | Total |
|--|------------------------|----------------------------|---------------------|---------------------|-------|
| | Research and Education | General and Administrative | Fundraising | | |
| Accounting | \$ 12,745 | \$ 65,752 | \$ 10,379 | \$ 88,876 | |
| Advertising/Public Relations | 43,218 | - | 72,269 | 115,487 | |
| Bank Service Charges and Management Fees | - | 1,392 | - | 1,392 | |
| Computer Expense | - | 8,640 | - | 8,640 | |
| Credit Card Fees | - | 7,993 | - | 7,993 | |
| Education | 498,111 | - | - | 498,111 | |
| Depreciation | - | 17,888 | - | 17,888 | |
| Dues and Subscriptions | - | 1,203 | - | 1,203 | |
| Equipment Rental | - | 4,353 | - | 4,353 | |
| Grants | 2,975,940 | - | - | 2,975,940 | |
| Insurance | - | 12,122 | - | 12,122 | |
| Legal Fees | 13,104 | 31,191 | - | 44,295 | |
| Magazine/Starfacts Newsletter | 50,188 | - | 92,563 | 142,751 | |
| Other | - | 5,048 | 15,339 | 20,387 | |
| Outside Services | 64,500 | 1,500 | 18,000 | 84,000 | |
| Payroll Service Fee | - | 1,765 | - | 1,765 | |
| Postage | 3,739 | 1,663 | 78 | 5,480 | |
| Printing | - | 664 | 11,831 | 12,495 | |
| Rental Expense | 8,865 | 11,529 | 11,694 | 32,088 | |
| Salaries | 18,336 | 43,933 | 523 | 62,792 | |
| Taxes - Payroll | 1,403 | 3,555 | 196 | 5,154 | |
| Telephone and Internet | - | 5,397 | - | 5,397 | |
| Website and Software | 666 | 7,937 | - | 8,603 | |
| Total Expenses by Function | \$ 3,690,815 | \$ 233,525 | \$ 232,872 | \$ 4,157,212 | |

See accompanying Notes to Financial Statements.

**CYSTINOSIS RESEARCH FOUNDATION
STATEMENT OF FUNCTIONAL EXPENSES
YEAR ENDED JUNE 30, 2023**

| | Program Services | Supporting Services | | Total |
|--|---------------------------|-------------------------------|-------------------|---------------------|
| | Research and Education | General and Administrative | Fundraising | |
| Accounting | \$ 14,919 | \$ 77,665 | \$ 15,736 | \$ 108,320 |
| Advertising/Public Relations | 39,640 | - | 70,722 | 110,362 |
| Auction Items | - | - | 1,750 | 1,750 |
| Bank Service Charges and Management Fees | - | 2,334 | - | 2,334 |
| Computer Expense | - | 8,811 | - | 8,811 |
| Credit Card Fees | - | 10,026 | - | 10,026 |
| Education | 467,801 | - | - | 467,801 |
| Depreciation | - | 17,888 | - | 17,888 |
| Dues and Subscriptions | - | 1,035 | - | 1,035 |
| Equipment Rental | - | 4,220 | - | 4,220 |
| Grants | 1,629,100 | - | - | 1,629,100 |
| Hotel Fees | - | - | 76,772 | 76,772 |
| Insurance | - | 10,289 | - | 10,289 |
| Legal Fees | 833 | 8,302 | - | 9,135 |
| Magazine/Starfacts Newsletter | 67,139 | - | 68,018 | 135,157 |
| Other | - | 3,018 | 10,160 | 13,178 |
| Outside Services | 66,500 | - | 17,500 | 84,000 |
| Payroll Service Fee | - | 1,114 | - | 1,114 |
| Postage | 4,822 | 992 | 4,426 | 10,240 |
| Printing | 760 | 3,049 | 23,712 | 27,521 |
| Rental Expense | 16,299 | 15,586 | 12,757 | 44,642 |
| Salaries | 13,687 | 42,106 | 8,492 | 64,285 |
| Supplies and Software | - | 2,821 | - | 2,821 |
| Taxes - Payroll | 1,231 | 3,078 | 764 | 5,073 |
| Taxes - Other | - | 1,050 | - | 1,050 |
| Telephone and Internet | - | 4,359 | - | 4,359 |
| Travel | - | 7,293 | - | 7,293 |
| Website and Software | - | 13,144 | - | 13,144 |
| Total Expenses by Function | \$ 2,322,731 | \$ 238,180 | \$ 310,809 | \$ 2,871,720 |

See accompanying Notes to Financial Statements.

**CYSTINOSIS RESEARCH FOUNDATION
STATEMENTS OF CASH FLOWS
YEARS ENDED JUNE 30, 2024 AND 2023**

| | 2024 | 2023 |
|--|--------------|--------------|
| CASH FLOWS FROM OPERATING ACTIVITIES | | |
| Increase (Decrease) in Net Assets | \$ (916,425) | \$ 436,357 |
| Adjustments to Reconcile Increase (Decrease) in Net Assets to Net Cash Provided (Used) by Operating Activities: | | |
| Depreciation and Amortization | 17,889 | 17,888 |
| Realized Gains on Sales of Investments | (164,862) | (109,075) |
| Unrealized Loss (Gain) on Investments | (85,084) | 157,110 |
| Discount on Grants Payable | 30,166 | 30,166 |
| Noncash Lease (Income) Expense | (2,994) | 2,829 |
| Changes in Assets and Liabilities: | | |
| (Increase) Decrease in: | | |
| Receivables | - | 30,933 |
| Prepaid Expenses | (29,679) | 71,089 |
| Increase (Decrease) in: | | |
| Accounts Payable | 22,141 | (16,256) |
| Research Grants Payable | 950,101 | (348,987) |
| Accrued Expenses | (4,563) | (582) |
| Net Cash Provided (Used) by Operating Activities | (183,310) | 271,472 |
| CASH FLOWS FROM INVESTING ACTIVITIES | | |
| Purchases of Investments | (1,548,401) | (1,349,406) |
| Proceeds from Sales of Investments | 870,279 | 925,329 |
| Net Cash Used by Investing Activities | (678,122) | (424,077) |
| NET DECREASE IN CASH AND CASH EQUIVALENTS | (861,432) | (152,605) |
| Cash and Cash Equivalents - Beginning of Year | 6,005,918 | 6,158,523 |
| CASH AND CASH EQUIVALENTS - END OF YEAR | \$ 5,144,486 | \$ 6,005,918 |
| SUPPLEMENTAL DISCLOSURES OF CASH FLOW INFORMATION | | |
| Right-of-Use Asset and lease Liability Recorded Upon Adoption of ASC 842 | \$ - | \$ 39,290 |

See accompanying Notes to Financial Statements.

**CYSTINOSIS RESEARCH FOUNDATION
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2024 AND 2023**

NOTE 1 NATURE OF OPERATIONS AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Nature of Operations

Cystinosis Research Foundation (the Foundation) was founded in 2003 as a California nonprofit public benefit corporation. The mission of the Foundation is twofold and focuses to support bench, clinical, and translational cystinosis research for better treatments and to find a cure for cystinosis. The Foundation is also dedicated to educating the public and the medical community about cystinosis to ensure early diagnosis and proper treatment. The Foundation's support comes entirely from donor contributions.

Basis of Presentation

The accompanying financial statements are presented using the accrual basis of accounting in accordance with accounting principles generally accepted in the United States of America (U.S. GAAP). References to the "ASC" hereafter refer to the *Accounting Standards Codification* established by the Financial Accounting Standards Board (FASB) as the source of authoritative U.S. GAAP.

The accounts of the Foundation are reported in the following net asset categories:

Net Assets Without Donor Restrictions – Net assets of the Foundation that are not subject to donor-imposed restrictions (donors include other types of contributors, including makers of certain grants).

Net Assets With Donor Restrictions – Net assets of the Foundation that are subject to donor-imposed restrictions (donors include other types of contributors, including makers of certain grants).

Cash and Cash Equivalents

For purposes of the statements of cash flows, the Foundation considers all highly liquid investments with a maturity of three months or less when purchased to be cash and cash equivalents.

Investments and Fair Value Measurements

The carrying value of the Foundation's cash and cash equivalents, pledges receivable, prepaid expenses, accounts payable, and accrued expenses approximate their respective fair values due to their short maturities. Grants receivable and grants payable are discounted based upon the average yield of U.S. Treasury securities with a two-year maturity, which approximates fair value.

The Foundation reports investments in equity securities with readily determinable fair values and all investments in debt securities at quoted market values. The gains and losses are included in the statements of activities. A limited partnership invests in hedge funds and private equity funds, and a limited liability company invests primarily in loans secured by residential real estate.

**CYSTINOSIS RESEARCH FOUNDATION
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2024 AND 2023**

**NOTE 1 NATURE OF OPERATIONS AND SUMMARY OF SIGNIFICANT ACCOUNTING
POLICIES (CONTINUED)**

Accounts Receivable and Allowance for Credit Losses

The Foundation uses the allowance method to determine uncollectable receivables. The allowance is based on review of outstanding receivables.

The Foundation has adopted the current expected credit losses (CECL) methodology for estimating credit losses on financial assets, effective July 1, 2023, utilizing the modified retrospective transition method. The adoption of CECL resulted in changes to the Foundation's accounting policies, including the recognition of credit losses based on expected future credit losses rather than incurred credit losses. The Foundation also updated its accounting policies for determining the recoverability of trade receivables, loans, and other financial assets. The adoption of this standard did not have a material impact on the Foundation's financial statements but did change how the allowance for credit losses is determined. At June 30, 2024 and 2023, the allowance is \$-0-.

Property and Equipment

Assets are carried at cost if purchased or at fair market value if contributed. Donations are reported as unrestricted support unless the donor has restricted the donated asset for a specific purpose. The Foundation follows the practice of capitalizing all expenditures for property in excess of \$500. The Foundation's website is an intangible asset subject to amortization. Depreciation and amortization are calculated using the straight-line method over the estimated useful lives of 7 to 15 years for property and equipment and 5 to 7 years for software and the website.

Leases

The Foundation leases its Irvine space under noncancelable lease arrangements. The Foundation determines if an arrangement is a lease at inception. In evaluating contracts to determine if they qualify as a lease, the Foundation considers factors such as if the Foundation has obtained substantially all of the rights to the underlying asset through exclusivity, if the Foundation can direct the use of the asset by making decisions about how and for what purpose the asset will be used and if the lessor has substantive substitution rights. This evaluation may require significant judgment.

Operating leases are included in operating lease right-of-use (ROU) assets and operating lease liabilities on the accompanying statements of financial position. ROU assets represent the Foundation's right to use an underlying asset for the lease term and lease liabilities represent the Foundation's obligation to make lease payments arising from the lease.

CYSTINOSIS RESEARCH FOUNDATION
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2024 AND 2023

NOTE 1 NATURE OF OPERATIONS AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

Leases (Continued)

ROU assets and liabilities are recognized at the lease commencement date based on the present value of lease payments over the lease term. For leases that do not provide an implicit rate, the Foundation has elected to use a risk-free discount rate of a period comparable with that of the lease term for computing the present value of lease liabilities. The operating lease ROU asset also includes any lease payments made and excludes lease incentives. The 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.

The Foundation has elected to recognize payments for short-term leases with a lease term of 12 months or less as expense as incurred and these leases are not included as lease liabilities or right-of-use assets on the accompanying statements of financial position.

The Foundation has elected not to separate nonlease components from lease components and instead accounts for each separate lease component and the nonlease component as a single lease component. The Foundation's lease agreements do not contain any material residual value guarantees or material restrictive covenants. Additionally, the individual lease contracts do not provide information about the discount rate implicit in the lease. Therefore, the Foundation has elected to use the risk-free discount rate determined using a period comparable with that of the lease term for computing the present value of the lease liabilities.

Long-Lived Assets and Asset Impairment

The Foundation accounts for long-lived assets in accordance with FASB ASC 360-10, *Property, Plant, and Equipment*. FASB ASC 360-10 requires impairment losses to be recognized for long-lived assets used in operations when indicators of impairment are present and the undiscounted future cash flows are not sufficient to recover the assets' carrying amounts. For the years ended June 30, 2024 and 2023, there was no impairment of the value of such assets.

Contributions, Grants, and Grant Payments

Contributions and grants are recognized as revenue in accordance with FASB ASC 958-605, *Revenue Recognition*. Contributions and grants are recognized when the donor makes a promise to give that is, in substance, unconditional. Contributions and grants that are restricted by the donor are reported as increase in net assets without donor restrictions if the restrictions expire in the fiscal year in which the contributions are recognized. All other donor-restricted contributions and grants are reported as increase in net assets with donor restrictions depending on the nature of the restrictions. When a restriction expires, net assets with donor restrictions are reclassified to net assets without donor restrictions. Contributions of assets other than cash are recorded at their estimated fair value.

**CYSTINOSIS RESEARCH FOUNDATION
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2024 AND 2023**

NOTE 1 NATURE OF OPERATIONS AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

Contributions, Grants, and Grant Payments (Continued)

Conditional promises to give – that is, those with a measurable performance or other barrier and a right of return – are not recognized until the conditions on which they depend have been met. There are no conditional promises to give at June 30, 2024 and 2023.

All grants receivable are considered to be fully collectible and accordingly, there is no allowance for doubtful grants receivable.

Grants payable represent all unconditional grants that have been authorized prior to year-end, but remain unpaid as of the statement of financial position date. There were no conditional grants at June 30, 2024 and 2023. Subsequent to June 30, 2024, approximately \$550,000 of grants were approved for funding.

Functional Allocation of Expenses

The costs of providing the various program and supporting services have been summarized on a functional basis in the statements of functional expenses. The Foundation achieves some of its programmatic goals with its magazine. As of June 30, 2024 and 2023, joint costs of approximately \$143,000 and \$135,000, respectively, associated with the magazine have been allocated to program services and fundraising based on the percentage of each issue's content intended to serve the respective function. Certain categories of expenses that are attributable to more than one program or supporting function require allocation on a reasonable basis that is consistently applied. Expenses are allocated in the following ways: Salaries, payroll taxes, accounting, and outside services are allocated based on the percentage of the time that each employee or contractor spends working on projects specific to the program or supporting function. Costs, such as postage, printing, website, and software, are allocated based on each program's direct expense. All other remaining costs are allocated based on the estimated benefit to each functional area.

The major programs of the Foundation are as follows:

Research and Education – The Foundation is dedicated to finding better treatments to improve the quality of life for those with cystinosis, and ultimately find a cure for this devastating disease. The Foundation educates the public and the medical/scientific community about cystinosis to ensure early diagnosis and proper treatments. Through its aggressively funded research agenda, the Foundation issues grants for bench and clinical research studies biannually to accelerate research progress and ensure that cystinosis research is ongoing and focused on novel treatments and a cure. The Foundation sponsors an annual Day of Hope Family Conference for cystinosis patients and their families to educate attendees about the research progress being made by the Foundation-funded researchers. The Foundation hosts a biennial International Cystinosis Research Symposium where the Foundation-funded researchers gather from around the world to share their research progress. The mission of the conference is to unite cystinosis researchers and scientists in an effort to encourage collaboration and accelerate the research process.

**CYSTINOSIS RESEARCH FOUNDATION
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2024 AND 2023**

**NOTE 1 NATURE OF OPERATIONS AND SUMMARY OF SIGNIFICANT ACCOUNTING
POLICIES (CONTINUED)**

Income Taxes

The Foundation is a California nonprofit corporation that has qualified for tax-exempt status under Section 501(c)(3) of the Internal Revenue Code and the State Revenue and Tax Code Section 23701(d). Accordingly, no provision for income taxes has been made in the accompanying financial statements.

The Foundation follows the accounting for uncertainty in income taxes recognized in a nonpublic entity's financial statements, including changes to the Foundation's status as a nonprofit entity. It details how entities should recognize, measure, present, and disclose uncertain tax positions that have been or are expected to be taken. As such, financial statements will reflect expected future tax consequences of uncertain tax positions presuming the taxing authorities' full knowledge of the position and all relevant facts. Management believes that there was no impact to the Foundation's financial statements as a result of these provisions.

Potential interest and penalties accrued related to unrecognized tax benefits are recorded within income tax expense. For the years ended June 30, 2024 and 2023, no interest or penalties were recorded in the statements of activities. No interest or penalties were accrued in the statements of net position at June 30, 2024 and 2023, relating to unrecognized benefits. The Foundation's tax years from 2020 to 2023 are open to review for federal tax purposes, and tax years from 2019 to 2023 are open to review for state income tax purposes.

Advertising, Promotion, and Marketing

The Foundation follows the policy of charging the costs of advertising to expenses as incurred. Advertising expense for the years ended June 30, 2024 and 2023, was \$115,487 and \$110,362, respectively.

Use of Estimates and Assumptions

The preparation of the financial statements in accordance with U.S. GAAP requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenues and expenses during the reporting period.

Significant estimates made in the accompanying financial statements include, but are not limited to, the valuation of investments. Actual results could differ from those estimates in the near term.

**CYSTINOSIS RESEARCH FOUNDATION
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2024 AND 2023**

NOTE 1 NATURE OF OPERATIONS AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

Concentration of Credit Risk

The Foundation maintains deposits in excess of federally insured limits. This concentration in credit risk is managed by maintaining all deposits in high-quality financial institutions.

Recent Accounting Pronouncements – Adopted

At the beginning of the fiscal year, the Foundation adopted FASB ASU 2016-13, Financial Instruments – Credit Losses (Topic 326): measurement of Credit Losses on Financial Instruments, as amended, which modifies the measurement of expected credit losses. The Foundation adopted this new guidance utilizing the modified retrospective transition method. The adoption of this standard did not have a material impact on the Foundations financial statements but did change how the allowance for credit losses is determined.

NOTE 2 FAIR VALUE MEASUREMENTS

The Foundation follows the accounting policy that establishes a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value. The hierarchy gives the highest priority to unadjusted quoted prices in active markets for identical assets or liabilities (Level 1 measurements) and the lowest priority to measurements involving significant unobservable inputs (Level 3 measurements). Financial assets valued using Level 1 inputs are based on unadjusted quoted market prices within active markets. Financial assets valued using Level 2 inputs are based on quoted prices for similar assets in active or inactive markets or quoted prices that are observable for the asset or inputs that are derived from observable market data by correlation or other means. Financial assets valued using Level 3 inputs are based on a valuation methodology that is unobservable and significant to the fair value measurement.

Using Level 3 inputs, the limited partnerships and the limited liability company were primarily valued using internal financial statements of the various portfolio funds within the limited partnerships and limited liability company or from redemption values at June 30, 2024 and 2023. Valuation techniques, which are utilized to determine fair value, are applied consistently.

The fair value of assets measured on a recurring basis at June 30, 2024 is as follows:

| | Fair Value Measurements Using | | | |
|-------------------------|-------------------------------|---------------------|-------------|-------------------|
| | Fair Value | Level 1 | Level 2 | Level 3 |
| Investments: | | | | |
| Alternative Investments | \$ 522,460 | \$ - | \$ - | \$ 522,460 |
| Stock | 621,853 | 621,853 | - | - |
| Mutual Funds | 3,996,212 | 3,996,212 | - | - |
| Total | <u>\$ 5,140,525</u> | <u>\$ 4,618,065</u> | <u>\$ -</u> | <u>\$ 522,460</u> |

CYSTINOSIS RESEARCH FOUNDATION
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2024 AND 2023

NOTE 2 FAIR VALUE MEASUREMENTS (CONTINUED)

The fair value of assets measured on a recurring basis at June 30, 2023 is as follows:

| | Fair Value Measurements Using | | | |
|-------------------------|-------------------------------|---------------------|-------------|-------------------|
| | Fair Value | Level 1 | Level 2 | Level 3 |
| Investments: | | | | |
| Alternative Investments | \$ 644,298 | \$ - | \$ - | \$ 644,298 |
| Stock | 470,242 | 470,242 | - | - |
| Mutual Funds | 3,097,917 | 3,097,917 | - | - |
| Total | <u>\$ 4,212,457</u> | <u>\$ 3,568,159</u> | <u>\$ -</u> | <u>\$ 644,298</u> |

The following summarizes the investment returns in the statements of activities for the years ended June 30:

| | 2024 | 2023 |
|---------------------------|-------------------|-------------------|
| Interest and Dividends | \$ 282,656 | \$ 241,777 |
| Realized Gains | 164,862 | 109,075 |
| Unrealized Gains (Losses) | 85,084 | 87,034 |
| Investment Fees | (31,602) | (23,932) |
| Investment Returns - Net | <u>\$ 501,000</u> | <u>\$ 413,954</u> |

NOTE 3 LIQUIDITY AND AVAILABILITY

The Foundation's financial assets available for general expenditure (that is, without donor or other restrictions limiting their use), within one year of the statement of financial position date, are as follows as of June 30:

| | 2024 | 2023 |
|--|---------------------|---------------------|
| Cash and Cash Equivalents | \$ 5,144,486 | \$ 6,005,918 |
| Investments (Stocks and Mutual Funds) | 4,618,065 | 3,568,159 |
| Total Financial Assets Available to Meet General Expenditures Within One Year | <u>\$ 9,762,551</u> | <u>\$ 9,574,077</u> |

The Foundation is substantially supported by contributions and proceeds from fundraising events without donor restrictions. Generally, all proceeds from such support, excluding the noncurrent portion of grant receivable, are available for general expenditure within one year. As part of the Foundation's liquidity management, it has a policy to structure its financial assets to be available as its general expenditures, liabilities, and other obligations become due. In addition, the Foundation invests cash in excess of the daily requirements in short-term investments. Subsequent to June 30, 2024, approximately \$550,000 of grants were approved for funding.

**CYSTINOSIS RESEARCH FOUNDATION
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2024 AND 2023**

NOTE 4 RESEARCH GRANTS PAYABLE

During the years ended June 30, 2024 and 2023, the Foundation expended approximately \$3,050,000 and \$1,650,000, respectively, for research grants. At June 30, 2024 and 2023, the Foundation had commitments of \$2,686,431 and \$1,633,795, respectively, to fund 18 and 18 grants, respectively, in the next two years. The award amounts of these grants range from approximately \$28,000 to \$440,000.

Research grants payable at June 30, 2024 are expected to be paid as follows:

| <u>Year Ending June 30,</u> | <u>Amount</u> |
|----------------------------------|---------------------|
| 2025 | \$ 1,998,308 |
| 2026 | 688,123 |
| Total | 2,686,431 |
| Less: Discount at 2.92% to 4.98% | (113,527) |
| Research Grants Payable, Net | <u>\$ 2,572,904</u> |

NOTE 5 PROPERTY AND EQUIPMENT

Property and equipment consist of the following at June 30:

| | <u>2024</u> | <u>2023</u> |
|---|------------------|------------------|
| Office Equipment | \$ 49,450 | \$ 49,450 |
| Furniture and Fixtures | 46,835 | 46,835 |
| Leasehold Improvements | 8,874 | 8,874 |
| Total Property and Equipment at Cost | 105,159 | 105,159 |
| Less: Accumulated Depreciation | (88,036) | (70,147) |
| Property and Equipment, at Net Book Value | <u>\$ 17,123</u> | <u>\$ 35,012</u> |

Depreciation expense for the years ended June 30, 2024 and 2023 was \$17,888 for both years.

NOTE 6 REVENUES AND SUPPORT

During the years ended June 30, 2024 and 2023, since the coronavirus pandemic, the Foundation's one major fundraising event (Natalie's Wish Celebration) has been held virtually as an online fundraiser. The online event webpage provides the opportunity to educate donors and the public about cystinosis. Funds are raised through corporate sponsorships and donations. Other fundraising activities are hosted by cystinosis families across the United States who enlighten their local communities about cystinosis and the progress of the Foundation's funded cystinosis research. Because of the virtual online fundraising format, the Natalie's Wish fundraiser has no costs for direct benefits to donors.

CYSTINOSIS RESEARCH FOUNDATION
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2024 AND 2023

NOTE 6 REVENUES AND SUPPORT (CONTINUED)

For the years ended June 30, 2024 and 2023, the Foundation received approximately \$700,000 and \$700,000, respectively, in contributions from an anonymous donor to cover operating and fundraising costs.

NOTE 7 CONTRIBUTED SERVICES

For the year ended June 30, 2024, contributions include approximately \$9,000 of in-kind professional services. For the year ended June 30, 2023, contributions include approximately \$14,000 of in-kind professional services. The valuation of in-kind services is based on information provided by the service provider.

A substantial number of unpaid volunteers have made significant contributions to the Foundation's program services. The value of these contributions is not reflected in the financial statements since they do not meet the criteria for recognition as contributed services.

NOTE 8 RELATED PARTY TRANSACTIONS

A board member's spouse provided fundraising and administrative consulting services to the Foundation for the years ended June 30, 2024 and 2023, of approximately \$84,000 and \$84,000, respectively. At June 30, 2024 and 2023, there were no amounts included in accounts payable, which were due to related parties.

The Foundation awards grants to research institutions naming specific researchers. During 2023, the Foundation granted approximately \$327,000, respectively, to the University of California, San Diego (UCSD), on behalf of a researcher who is also a board member. At June 30, 2024 and 2023, approximately \$245,000 and \$83,600, respectively, were included in research grants payable to UCSD.

NOTE 9 LEASES – ASC 842

The Foundation leases Irvine space on a two-year term under long-term, noncancelable lease agreements. The lease expires on June 30, 2026. In the normal course of business, it is expected that the lease will be renewed or replaced by similar lease.

**CYSTINOSIS RESEARCH FOUNDATION
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2024 AND 2023**

NOTE 9 LEASES – ASC 842 (CONTINUED)

The following table provides quantitative information concerning the Foundation's leases as of June 30, 2024.

| | |
|---|-----------|
| Lease Costs: | |
| Operating Lease Costs | \$ 33,795 |
| Short-Term Lease Costs | - |
| Total Lease Costs | \$ 33,795 |
| Other Information: | |
| Operating Cash Flows from Operating Leases | \$ 36,777 |
| Right-of-Use Assets Obtained in Exchange for New Operating Lease Liabilities | \$ - |
| Remaining Lease Term - Operating Leases | 2 years |
| Discount Rate - Operating Lease | 4.27% |

The Foundation classifies the total undiscounted lease payments that are due in the next 12 months as current. The present value for lease liabilities as of June 30, 2024 is \$64,609, which represents undiscounted cash flows of \$67,425 less imputed interest of \$2,816.

NOTE 10 COMMITMENTS

In 2024, the Foundation invested in a limited partnership bond fund, which requires the Organization to commit to funding up to \$250,000 of capital into the fund over a period of no longer than three years. As of June 30, 2024, the Foundation has funded \$31,250 to this private bond fund. The amounts funded are included in investments.

NOTE 11 SUBSEQUENT EVENTS

The Foundation has evaluated subsequent events through November 15, 2024, the date the financial statements were available to be issued.



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