

**CYSTINOSIS RESEARCH FOUNDATION**  
**FINANCIAL STATEMENTS**  
**YEARS ENDED JUNE 30, 2022 AND 2021**



CPAs | CONSULTANTS | WEALTH ADVISORS

[CLAcconnect.com](https://CLAcconnect.com)

**CYSTINOSIS RESEARCH FOUNDATION  
TABLE OF CONTENTS  
YEARS ENDED JUNE 30, 2022 AND 2021**

<b>MANAGEMENT’S DISCUSSION AND ANALYSIS</b>	<b>i</b>
<b>INDEPENDENT AUDITORS’ REPORT</b>	<b>1</b>
<b>FINANCIAL STATEMENTS</b>	
<b>STATEMENTS OF FINANCIAL POSITION</b>	<b>3</b>
<b>STATEMENTS OF ACTIVITIES</b>	<b>4</b>
<b>STATEMENTS OF FUNCTIONAL EXPENSES</b>	<b>5</b>
<b>STATEMENTS OF CASH FLOWS</b>	<b>7</b>
<b>NOTES TO FINANCIAL STATEMENTS</b>	<b>8</b>



## **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 \$63 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, 2022, CRF awarded 13 new grants totaling \$2,827,107 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 funded 220 studies at leading research institutions in 12 countries. CRF-funded researchers have published 102 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 the phase 1/2 of the trial should be treated in 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 2022, 36 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. The 2020 and 2021 conferences were cancelled because of the pandemic.

## **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 156 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 65 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. The symposium was cancelled during the pandemic but will resume in 2023.



## 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, 2022 and 2021, 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, 2022 and 2021, 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 Cystinosis Research Foundation and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audits. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

#### ***Responsibilities of Management for the Financial Statements***

Management is responsible for the preparation and fair presentation of the financial statements in accordance with accounting principles generally accepted in the United States of America, and for the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

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.

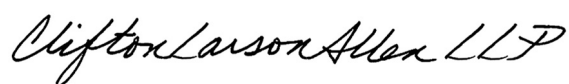
In performing an audit in accordance with GAAS, we:

- 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**

Our audit was conducted for the purpose of forming an opinion on the financial statements as a whole. The Management Discussion and Analysis, which is the responsibility of management, is presented for the purposes of additional analysis and is not a required part of the financial statements. Such information has not been subjected to the auditing procedures applied in the audit of the financial statements, and accordingly, we do not express an opinion or provide any assurance on it.



**CliftonLarsonAllen LLP**

Irvine, California  
November 9, 2022

**CYSTINOSIS RESEARCH FOUNDATION  
STATEMENTS OF FINANCIAL POSITION  
JUNE 30, 2022 AND 2021**

	2022	2021
<b>ASSETS</b>		
<b>CURRENT ASSETS</b>		
Cash and Cash Equivalents	\$ 6,158,523	\$ 5,968,759
Receivables:		
Pledges	-	600,000
Other	30,933	684
Prepaid Expenses	89,886	89,502
Total Current Assets	6,279,342	6,658,945
<b>PROPERTY AND EQUIPMENT, AT NET BOOK VALUE</b>	52,900	70,788
<b>OTHER ASSETS - INVESTMENTS</b>	3,836,415	3,619,845
Total Assets	\$ 10,168,657	\$ 10,349,578
<b>LIABILITIES AND NET ASSETS</b>		
<b>CURRENT LIABILITIES</b>		
Accounts Payable	\$ 23,030	\$ 8,898
Research Grants Payable - Current Portion	1,865,017	1,758,979
Accrued Expenses	8,010	5,469
Deferred Rent	-	3,427
Total Current Liabilities	1,896,057	1,776,773
<b>LONG-TERM LIABILITIES</b>		
Research Grants Payable, Net of Current Portion and Discount	46,441	90,363
Total Liabilities	1,942,498	1,867,136
<b>NET ASSETS</b>		
Without Donor Restrictions	8,226,159	8,482,442
With Donor Restrictions	-	-
Total Net Assets	8,226,159	8,482,442
Total Liabilities and Net Assets	\$ 10,168,657	\$ 10,349,578

See accompanying Notes to Financial Statements.



**CYSTINOSIS RESEARCH FOUNDATION  
STATEMENTS OF ACTIVITIES  
YEARS ENDED JUNE 30, 2022 AND 2021**

	2022	2021
<b>NET ASSETS WITHOUT DONOR RESTRICTIONS</b>		
Revenues and Other Support:		
Contributions	\$ 2,584,510	\$ 2,100,806
Fundraising, Net of Direct Benefits to Donors	336,494	1,557,259
Total Revenues and Other Support	2,921,004	3,658,065
Investment Revenues, Net	(104,574)	745,513
Net Assets Released from Restrictions	-	247,833
Total Revenues, Other Support, and Net Assets Released from Restrictions	2,816,430	4,651,411
Expenses:		
Program Services:		
Research and Education	2,565,114	2,980,113
Total Program Services	2,565,114	2,980,113
Supporting Services:		
General and Administrative	198,246	234,461
Fundraising	309,353	256,286
Total Supporting Services	507,599	490,747
Total Expenses	3,072,713	3,470,860
Increase (Decrease) in Net Assets Without Donor Restrictions	(256,283)	1,180,551
<b>NET ASSETS WITH DONOR RESTRICTIONS</b>		
Net Assets Released from Restrictions	-	(247,833)
Decrease in Net Assets With Donor Restrictions	-	(247,833)
<b>INCREASE (DECREASE) IN TOTAL NET ASSETS</b>	(256,283)	932,718
Net Assets - Beginning of Year	8,482,442	7,549,724
<b>NET ASSETS - END OF YEAR</b>	<b>\$ 8,226,159</b>	<b>\$ 8,482,442</b>

See accompanying Notes to Financial Statements.

**CYSTINOSIS RESEARCH FOUNDATION  
STATEMENT OF FUNCTIONAL EXPENSES  
YEAR ENDED JUNE 30, 2022**

	Program Services		Supporting Services		Total
	Research and Education	General and Administrative	Fundraising		
Accounting	\$ 14,478	\$ 72,320	\$ 14,710		\$ 101,508
Advertising/Public Relations	-	-	110,080		110,080
Auction Items	-	-	61,671		61,671
Credit Card Fees	-	-	10,981		10,981
Depreciation	-	17,888	-		17,888
Dues and Subscriptions	-	1,830	-		1,830
Education	255,245	-	-		255,245
Grants	2,122,358	-	-		2,122,358
Insurance	-	10,324	-		10,324
Legal Fees	5,981	1,604	-		7,585
Magazine/Starfacts Newsletter	57,076	-	69,441		126,517
Promotion/Marketing	-	-	7,970		7,970
Other	-	89	3,545		3,634
Outside Services	66,660	6,135	13,618		86,413
Payroll Service Fee	-	2,239	-		2,239
Photography/Video	2,486	-	-		2,486
Postage	867	1,252	466		2,585
Printing	-	2,031	-		2,031
Rental Expense	12,959	11,554	11,897		36,410
Salaries	12,386	48,562	4,629		65,577
Storage Fees	3,950	-	-		3,950
Supplies	-	2,632	-		2,632
Symposium	9,730	-	-		9,730
Taxes - Payroll	938	3,651	345		4,934
Taxes - Other	-	548	-		548
Telephone and Internet	-	5,825	-		5,825
Website and Software	-	9,762	-		9,762
	<u>\$ 2,565,114</u>	<u>\$ 198,246</u>	<u>\$ 309,353</u>		<u>\$ 3,072,713</u>
Total Expenses					

See accompanying Notes to Financial Statements.

**CYSTINOSIS RESEARCH FOUNDATION  
STATEMENT OF FUNCTIONAL EXPENSES  
YEAR ENDED JUNE 30, 2021**

	Program Services	Supporting Services		Total
	Research and Education	General and Administrative	Fundraising	
Accounting	\$ 3,900	\$ 79,674	\$ 813	\$ 84,387
Advertising/Public Relations	10,315	-	111,438	121,753
Auction Items	-	-	1,080	1,080
Credit Card Fees	-	-	10,217	10,217
Depreciation	-	17,888	-	17,888
Education	25,843	-	-	25,843
Grants	2,791,881	-	-	2,791,881
Insurance	-	11,027	-	11,027
Magazine	68,343	-	69,354	137,697
Other	1,375	4,395	-	5,770
Outside Services	66,825	16,500	8,950	92,275
Patient Registry	1,274	-	-	1,274
Postage	-	1,800	1,716	3,516
Printing	-	835	43,890	44,725
Rental Expense	8,817	24,143	5,582	38,542
Salaries	1,540	58,652	3,015	63,207
Supplies	-	1,079	-	1,079
Taxes - Payroll	-	4,474	231	4,705
Telephone	-	5,628	-	5,628
Website and Software	-	8,366	-	8,366
	<u>\$ 2,980,113</u>	<u>\$ 234,461</u>	<u>\$ 256,286</u>	<u>\$ 3,470,860</u>
Total Expenses	<u>\$ 2,980,113</u>	<u>\$ 234,461</u>	<u>\$ 256,286</u>	<u>\$ 3,470,860</u>

See accompanying Notes to Financial Statements.

**CYSTINOSIS RESEARCH FOUNDATION  
STATEMENTS OF CASH FLOWS  
YEARS ENDED JUNE 30, 2022 AND 2021**

	2022	2021
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>		
Increase (Decrease) in Net Assets	\$ (256,283)	\$ 932,718
Adjustments to Reconcile Increase (Decrease) in Net Assets to Net Cash Provided by Operating Activities:		
Depreciation and Amortization	17,888	17,888
Realized Gains on Sales of Investments	(451,422)	(27,902)
Unrealized Loss (Gain) on Investments	741,669	(620,884)
Discount on Grants Receivable	-	2,167
Discount on Grants Payable	30,166	9,129
Deferred Rent	(3,427)	(3,188)
Changes in Assets and Liabilities:		
(Increase) Decrease in:		
Receivables	569,751	309,582
Prepaid Expenses	(384)	(39,946)
Increase (Decrease) in:		
Accounts Payable	14,132	2,238
Research Grants Payable	31,950	(441,352)
Accrued Expenses	2,541	2,339
Total Adjustments	952,864	(789,929)
Net Cash Provided by Operating Activities	696,581	142,789
<b>CASH FLOWS FROM INVESTING ACTIVITIES</b>		
Purchases of Investments	(2,234,318)	(674,047)
Proceeds from Sales of Investments	1,727,501	515,212
Net Cash Used by Investing Activities	(506,817)	(158,835)
<b>NET INCREASE (DECREASE) IN CASH AND CASH EQUIVALENTS</b>	189,764	(16,046)
Cash and Cash Equivalents - Beginning of Year	5,968,759	5,984,805
<b>CASH AND CASH EQUIVALENTS - END OF YEAR</b>	\$ 6,158,523	\$ 5,968,759
<b>SUPPLEMENTAL DISCLOSURES OF CASH FLOW INFORMATION</b>		
Cash Paid During the Year For:		
Interest	\$ -	\$ -
Income Taxes	\$ -	\$ -

See accompanying Notes to Financial Statements.

**CYSTINOSIS RESEARCH FOUNDATION  
NOTES TO FINANCIAL STATEMENTS  
JUNE 30, 2022 AND 2021**

**NOTE 1 NATURE OF OPERATIONS AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES**

**Nature of Operations**

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

In 2016, CRF established Corneal Cystinolysis, Inc. (CCI) as a Texas corporation. In December 2017, CCI filed with the states of California and Texas to have the corporate name changed to NanoWafer, Inc. (NanoWafer). NanoWafer is 100% owned by CRF. There are 2,000,000 authorized common shares with 1,000,000 shares issued at a par value of \$0.0001. The plan of operations for NanoWafer was to improve treatment for corneal cystinosis. In December 2019, NanoWafer suspended its operations. There were no revenues or expenses from NanoWafer's operations since June 30, 2020. NanoWafer filed its final federal and state tax returns for the six-month period ended June 30, 2021. Corporate dissolution papers were approved by the state of Texas in September 2020.

**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.

**CYSTINOSIS RESEARCH FOUNDATION  
NOTES TO FINANCIAL STATEMENTS  
JUNE 30, 2022 AND 2021**

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

**Pledges**

Pledges are unconditional promises to give toward the Foundation's programs and are recorded as revenue when the pledge is received. At June 30, 2022 and 2021, the Foundation has pledges receivable of \$- and \$600,000, respectively, and all are considered to be fully collectible. Accordingly, there were no allowances for doubtful pledges.

**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.

**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.

**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, 2022 and 2021, there was no impairment of the value of such assets.

**CYSTINOSIS RESEARCH FOUNDATION  
NOTES TO FINANCIAL STATEMENTS  
JUNE 30, 2022 AND 2021**

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

**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.

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, 2022 and 2021.

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, 2022 and 2021. Subsequent to June 30, 2022, approximately \$2,827,000 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. CRF achieves some of its programmatic goals with its magazine. As of June 30, 2022 and 2021, joint costs of approximately \$127,000 and \$138,000, 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.

**CYSTINOSIS RESEARCH FOUNDATION  
NOTES TO FINANCIAL STATEMENTS  
JUNE 30, 2022 AND 2021**

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

**Functional Allocation of Expenses (Continued)**

The major programs of the Foundation are as follows:

*Research and Education* – CRF 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. CRF educates the public and the medical/scientific community about cystinosis to ensure early diagnosis and proper treatments. Through its aggressively funded research agenda, CRF 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. CRF sponsors an annual Day of Hope Family Conference for cystinosis patients and their families to educate attendees about the research progress being made by CRF-funded researchers. CRF hosts a biannual International Cystinosis Research Symposium where CRF-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.

**Income Taxes**

CRF 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 CRF'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. The Foundation filed final tax returns for NanoWafer for the six-month period ended June 30, 2021.



**CYSTINOSIS RESEARCH FOUNDATION  
NOTES TO FINANCIAL STATEMENTS  
JUNE 30, 2022 AND 2021**

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

**Income Taxes (Continued)**

Potential interest and penalties accrued related to unrecognized tax benefits are recorded within income tax expense. For the years ended June 30, 2022 and 2021, 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, 2022 and 2021, relating to unrecognized benefits. CRF and NanoWafer's tax years from 2018 to 2021 are open to review for federal tax purposes, and tax years from 2017 to 2021 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, 2022 and 2021, was approximately \$110,000 and \$122,000, respectively. For the years ended June 30, 2022 and 2021, approximately \$-0- and \$6,900, respectively, of advertising expense was in-kind donations.

**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.

**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.

**CYSTINOSIS RESEARCH FOUNDATION**  
**NOTES TO FINANCIAL STATEMENTS**  
**JUNE 30, 2022 AND 2021**

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

**Risks and Uncertainties**

The Foundation invests in a combination of equity, fixed income, and other investment securities. Investment securities are exposed to various risks, such as interest rate, market, and credit. Due to the level of risk associated with certain investment securities and the level of uncertainty related to changes in the value of investment securities, it is at least reasonably possible that changes in risks in the near term could materially affect investments' account balances and the amounts reported in the statements of financial position and activities.

On January 30, 2020, the World Health Organization (WHO) announced a global health emergency because of an outbreak of a new strain of coronavirus (COVID-19). In March 2020, the WHO classified the COVID-19 outbreak as a pandemic based on the rapid increase of the virus and its global exposure. In addition, several U.S. states, including California where the Foundation is headquartered, have declared a state of emergency.

The Foundation is substantially supported by contributions and proceeds from fundraising events without donor restrictions. As of the date of this report, the Foundation's investment values have experienced significant volatility. At this time, the Foundation cannot anticipate all the ways in which a health pandemic such as COVID-19 could adversely impact it. Although management is continuing to monitor and assess the effects of the COVID-19 pandemic on the Foundation, the ultimate impact of the COVID-19 outbreak or a similar health epidemic is highly uncertain and subject to change.

**Recent Accounting Pronouncements – Not Yet Adopted**

In February 2016, the FASB issued ASU 2016-02, *Leases (Topic 842)*, with subsequent improvements and corrections issued in ASU 2018-01, ASU 2018-10, and ASU 2018-20. ASU 2016-02 amends a number of aspects of lease accounting, including requiring lessees to recognize on their statement of financial position a right-of-use asset and a lease liability for all operating leases with a term of more than 12 months. For leases with a term of 12 months or less, a lessee is permitted to make an accounting policy election by class of asset not to recognize the right-of-use asset and lease liability. ASU 2016-02 is effective for fiscal years beginning after December 15, 2021; however, early adoption is permitted. The Foundation is currently evaluating the impact of the provisions of ASU 2016-02 on the presentation of its financial statements.

**CYSTINOSIS RESEARCH FOUNDATION**  
**NOTES TO FINANCIAL STATEMENTS**  
**JUNE 30, 2022 AND 2021**

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

**Recent Accounting Pronouncements – Not Yet Adopted (Continued)**

In June 2016, the FASB issued ASU 2016-13, *Financial Instruments – Credit Losses (Topic 326)*, with subsequent improvements issued in ASU 2018-19. ASU 2016-13 requires that credit losses on most financial assets measured at amortized cost and certain other instruments, including trade receivables, be measured using an expected credit loss model. The ASU also replaces the current accounting model for purchased credit-impaired loans and debt securities. Further, ASU 2016-13 makes certain targeted amendments to the existing impairment model for available-for-sale debt securities. For nonpublic entities, including nonprofit entities, the amendments are effective for fiscal years beginning after December 15, 2022. The Foundation does not expect the provisions of ASU 2016-13 to have a material impact on the presentation of its financial statements.

**Recent Accounting Pronouncements – Adopted**

In September 2020, the FASB issued ASU 2020-07, *Not-for-Profit Entities for Contributed Nonfinancial Assets (Topic 958)*. ASU 2020-07 requires not-for-profits to present contributed nonfinancial assets as a separate line item in the statement of activities and provide additional disclosures about contributions of nonfinancial assets. The ASU is effective for annual periods beginning after June 15, 2021. All necessary changes required by the new standard, included those related to the Organization's accounting policies, controls, and disclosures, have been identified and implemented as of July 1, 2021, and have been retrospectively applied to prior years presented.

**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, 2022 and 2021. Valuation techniques, which are utilized to determine fair value, are applied consistently.

**CYSTINOSIS RESEARCH FOUNDATION**  
**NOTES TO FINANCIAL STATEMENTS**  
**JUNE 30, 2022 AND 2021**

**NOTE 2 FAIR VALUE MEASUREMENTS (CONTINUED)**

The fair value of assets measured on a recurring basis at June 30, 2022 is as follows:

	Fair Value Measurements Using			
	Fair Value	Level 1	Level 2	Level 3
Investments:				
Alternative Investments	\$ 750,216	\$ -	\$ -	\$ 750,216
Stock	452,533	452,533	-	-
Mutual Funds	2,633,666	2,633,666	-	-
Total	<u>\$ 3,836,415</u>	<u>\$ 3,086,199</u>	<u>\$ -</u>	<u>\$ 750,216</u>

The fair value of assets measured on a recurring basis at June 30, 2021 is as follows:

	Fair Value Measurements Using			
	Fair Value	Level 1	Level 2	Level 3
Investments:				
Alternative Investments	\$ 538,055	\$ -	\$ -	\$ 538,055
Stock	464,934	464,934	-	-
Mutual Funds	2,616,856	2,616,856	-	-
Total	<u>\$ 3,619,845</u>	<u>\$ 3,081,790</u>	<u>\$ -</u>	<u>\$ 538,055</u>

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

	2022	2021
Interest and Dividends	\$ 217,021	\$ 123,546
Realized Gains	451,422	27,902
Unrealized Gains (Losses)	(741,669)	620,886
Investment Fees	(31,348)	(26,821)
Investment Returns - Net	<u>\$ (104,574)</u>	<u>\$ 745,513</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:

	2022	2021
Cash and Cash Equivalents	\$ 6,158,523	\$ 5,968,759
Pledges Receivable	-	600,000
Grant and Other Receivables	-	684
Total Financial Assets Available to Meet General Expenditures Within One Year	<u>\$ 6,158,523</u>	<u>\$ 6,569,443</u>

**CYSTINOSIS RESEARCH FOUNDATION  
NOTES TO FINANCIAL STATEMENTS  
JUNE 30, 2022 AND 2021**

**NOTE 3 LIQUIDITY AND AVAILABILITY (CONTINUED)**

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, 2022, approximately \$2,827,000 of grants were approved for funding.

**NOTE 4 RESEARCH GRANTS PAYABLE**

During the years ended June 30, 2022 and 2021, the Foundation expended approximately \$2,200,000 and \$2,800,000, respectively, for research grants. At June 30, 2022 and 2021, the Foundation had commitments of \$1,947,624 and \$1,849,342, respectively, to fund 15 and 23 grants, respectively, in the next two years. The award amounts of these grants range from approximately \$31,000 to \$765,000.

Research grants payable at June 30, 2022 are expected to be paid as follows:

<u>Year Ending June 30.</u>	<u>Amount</u>
2023	\$ 1,901,183
2024	46,441
Total	<u>1,947,624</u>
Less: Discount at 1.75% to 2.92%	(36,166)
Research Grants Payable - Net	<u><u>\$ 1,911,458</u></u>

**NOTE 5 PROPERTY AND EQUIPMENT**

Property and equipment consist of the following at June 30:

	<u>2022</u>	<u>2021</u>
Office Equipment	\$ 49,450	\$ 49,450
Furniture and Fixtures	46,835	46,835
Leasehold Improvements	<u>8,873</u>	<u>8,873</u>
Total Property and Equipment at Cost	105,158	105,158
Less: Accumulated Depreciation	<u>(52,258)</u>	<u>(34,370)</u>
Property and Equipment, at Net Book Value	<u><u>\$ 52,900</u></u>	<u><u>\$ 70,788</u></u>

Depreciation expense for the years ended June 30, 2022 and 2021 was \$17,888 for both years.

**CYSTINOSIS RESEARCH FOUNDATION**  
**NOTES TO FINANCIAL STATEMENTS**  
**JUNE 30, 2022 AND 2021**

**NOTE 6 REVENUES AND SUPPORT**

During the years ended June 30, 2022 and 2021, the Foundation's one major fundraising event (Natalie's Wish Gala Celebration, in Orange County, California) was cancelled due to the coronavirus pandemic, as described in Note 1, Risks and Uncertainties. However, a virtual event was held for 2022. This fundraiser provides the Foundation with 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 research. Due to the cancellation of the in person Natalie's Wish Gala for 2022 and 2021, there were no costs for direct benefits to donors.

For the years ended June 30, 2022 and 2021, the Foundation received approximately \$401,000 and \$905,000, respectively, in contributions from an anonymous donor to cover operating and fundraising costs.

**NOTE 7 CONTRIBUTED SERVICES**

For the year ended June 30, 2022, contributions include approximately \$13,000 of in-kind professional services. For the year ended June 30, 2021, contributions include approximately \$4,400 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 CRF for the years ended June 30, 2022 and 2021, of approximately \$83,500 and \$78,000, respectively. At June 30, 2022 and 2021, there were no amounts included in accounts payable, which were due to related parties.

CRF awards grants to research institutions naming specific researchers. During 2022 and 2021, CRF granted approximately \$191,000 and \$103,000, respectively, to the University of California, San Diego (UCSD), on behalf of a researcher who is also a board member. At June 30, 2022 and 2021, approximately \$248,600 and \$54,400, respectively, were included in research grants payable to UCSD.

**CYSTINOSIS RESEARCH FOUNDATION**  
**NOTES TO FINANCIAL STATEMENTS**  
**JUNE 30, 2022 AND 2021**

**NOTE 9 NET ASSETS**

Net assets consist of the following at June 30:

	<u>2022</u>	<u>2021</u>
Net Assets Without Donor Restrictions:		
Undesignated	\$ 8,226,159	\$ 8,482,442
Net Assets With Donor Restrictions:		
Subject Only to Time Restriction:		
Grant Receivable for Future Periods	-	-
Total Net Assets	<u>\$ 8,226,159</u>	<u>\$ 8,482,442</u>

**NOTE 10 FACILITY LEASE**

The Foundation leases its office space under a noncancelable operating lease, which expired in April 2022, and was subsequently renewed through May 2023 with the month of May 2022 free of charge. The lease agreement contains provisions for rent holidays and escalating monthly rent payments. Total rental amounts, after consideration of all rent holidays and escalators, are recognized as rent expense on a straight-line basis over the lease term. The difference between the rent paid and the straight-line expense is recorded as deferred rent and is included within accrued expenses in the accompanying statements of financial position.

Minimum future rental payments under the noncancelable operating lease described above as of June 30, 2022 are as follows:

<u>Year Ending June 30.</u>	<u>Amount</u>
2023	\$ 33,704
2024	-
Total	<u>\$ 33,704</u>

Rental expense for the years ended June 30, 2022 and 2021 was \$36,410 and \$37,871, respectively.

**NOTE 11 SUBSEQUENT EVENTS**

The Foundation has evaluated subsequent events through November 9, 2022, the date the financial statements were available to be issued.



CLA (CliftonLarsonAllen LLP) is a network member of CLA Global. See [CLAGlobal.com/disclaimer](http://CLAGlobal.com/disclaimer). Investment advisory services are offered through CliftonLarsonAllen Wealth Advisors, LLC, an SEC-registered investment advisor.