

CYSTINOSIS RESEARCH FOUNDATION
FINANCIAL STATEMENTS
YEARS ENDED JUNE 30, 2021 AND 2020



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**CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
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YEARS ENDED JUNE 30, 2021 AND 2020**

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NATALIE’S WISH

Natalie’s wish, ‘*To have my disease go away forever*’ – those seven words provided the inspiration to establish 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.

MISSION STATEMENT

CRF’s 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 ultimately find a cure for this devastating disease.

RESEARCH

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.

HISTORY AND RESEARCH

Cystinosis is a rare, metabolic, genetic disease that afflicts approximately 2,000 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.

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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 almost \$62 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, and has created a thriving and collaborative research community and as result, has changed the course of cystinosis. From the start of the foundation all CRF operating costs have been privately underwritten so that 100 percent of the funds donated to CRF are used to support cystinosis research.

We are pleased to announce that during the 12-month period ending June 30, 2021, CRF awarded 11 new and extension grants, and one equipment grant totaling \$1,133,667 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 207 studies at leading research institutions in 12 countries. CRF-funded researchers have published 91 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. Stephanie 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 test the efficacy and safety of a stem cell and gene therapy treatment for cystinosis patients. In October 2019, the first cystinosis patient was transplanted and in 2020, two more patients were transplanted with the stem cell therapy. CRF's grants to Dr. Cherqui 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.

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Since cystinosis is a systemic disease and every tissue is affected, CRF has targeted multiple areas of research to fund including 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 2019, 66 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 but we resume the conference in 2022.

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. 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.

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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.



INDEPENDENT AUDITORS' REPORT

Board of Directors
Cystinosis Research Foundation
Irvine, California

We have audited the accompanying financial statements of Cystinosis Research Foundation (a nonprofit organization) (the Foundation), which comprise the statement of financial position as of June 30, 2021, and the related statements of activities, functional expenses, and cash flows for the year then ended, and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes 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.

Auditors' Responsibility

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditors' judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the consolidated financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

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, 2021, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

Other Matters

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 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.

Report on Comparative Information

The consolidated financial statements as of June 30, 2020, were audited by White Nelson Diehl Evans LLP, whose partners and professional staff joined CliftonLarsonAllen LLP as of November 1, 2020, and has subsequently ceased operations. White Nelson Diehl Evans LLP's report dated October 15, 2020, expressed an unmodified opinion on those statements. The comparative information presented herein as of and for the year ended June 30, 2020, is consistent, in all material respects, with the audited consolidated financial statements from which it has been derived.



CliftonLarsonAllen LLP

Irvine, California
October 29, 2021

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
STATEMENTS OF FINANCIAL POSITION
JUNE 30, 2021 AND 2020

	2021	2020
ASSETS		
CURRENT ASSETS		
Cash and Cash Equivalents	\$ 5,968,759	\$ 5,984,805
Receivables:		
Pledges	600,000	664,600
Grant	-	247,833
Other	684	-
Prepaid Expenses	89,502	49,556
Total Current Assets	6,658,945	6,946,794
PROPERTY AND EQUIPMENT, AT NET BOOK VALUE	70,788	88,677
OTHER ASSETS - INVESTMENTS	3,619,845	2,812,223
Total Assets	\$ 10,349,578	\$ 9,847,694
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts Payable	\$ 8,898	\$ 6,660
Research Grants Payable - Current Portion	1,758,979	1,901,679
Accrued Expenses	5,469	3,130
Deferred Rent	3,427	6,615
Total Current Liabilities	1,776,773	1,918,084
LONG-TERM LIABILITIES		
Research Grants Payable, Net of Current Portion and Discount	90,363	379,886
Total Liabilities	1,867,136	2,297,970
NET ASSETS		
Without Donor Restrictions	8,482,442	7,301,891
With Donor Restrictions	-	247,833
Total Net Assets	8,482,442	7,549,724
Total Liabilities and Net Assets	\$ 10,349,578	\$ 9,847,694

See accompanying Notes to Financial Statements.

**CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
STATEMENTS OF ACTIVITIES
YEARS ENDED JUNE 30, 2021 AND 2020**

	2021	2020
Net Assets Without Donor Restrictions:		
REVENUES AND OTHER SUPPORT		
Contributions	\$ 2,100,806	\$ 2,803,160
Fundraising, Net of Direct Benefits to Donors	1,557,259	1,261,660
Total Revenues and Other Support	3,658,065	4,064,820
Investment Revenues, Net	745,513	30,312
Net Assets Released from Restrictions	247,833	247,833
Total Revenues, Other Support, and Net Assets Released from Restrictions	4,651,411	4,342,965
Expenses Before Discontinued Operations:		
Program Services:		
Research and Education	2,980,113	2,625,508
Total Program Services	2,980,113	2,625,508
Supporting Services:		
General and Administrative	234,461	262,082
Fundraising	256,286	312,851
Total Supporting Services	490,747	574,933
Total Expenses Before Discontinued Operations	3,470,860	3,200,441
Increase in Net Assets Without Donor Restrictions from Continuing Operations	1,180,551	1,142,524
LOSS FROM DISCONTINUED OPERATIONS	-	(162,249)
Increase in Net Assets Without Donor Restrictions	1,180,551	980,275
Net Assets With Donor Restrictions:		
Net Assets Released from Restrictions	(247,833)	(247,833)
Decrease in Net Assets With Donor Restrictions	(247,833)	(247,833)
INCREASE IN TOTAL NET ASSETS	932,718	732,442
Net Assets - Beginning of Year	7,549,724	6,817,282
NET ASSETS - END OF YEAR	\$ 8,482,442	\$ 7,549,724

See accompanying Notes to Financial Statements.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
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 AND SUBSIDIARY
STATEMENT OF FUNCTIONAL EXPENSES
YEAR ENDED JUNE 30, 2020

	Program Services		Supporting Services		Total
	Research and Education	General and Administrative	Fundraising		
Accounting	\$ 13,664	\$ 82,037	\$ 745	\$ 96,446	
Advertising/Public Relations	4,040	-	97,119	101,159	
Auction Items	-	-	4,405	4,405	
Credit Card Fees	-	-	13,050	13,050	
Depreciation	3,368	10,588	2,526	16,482	
Education	34,531	-	-	34,531	
Grants	2,251,125	-	-	2,251,125	
Insurance	-	8,240	-	8,240	
Magazine	63,804	-	49,198	113,002	
Other	2,453	2,454	-	4,907	
Outside Services	98,438	28,936	30,411	157,785	
Patient Registry	6,750	-	-	6,750	
Photography	-	-	1,250	1,250	
Postage	-	3,654	5,290	8,944	
Printing	20,415	2,353	30,170	52,938	
Promotion/Marketing	-	26,933	62,842	89,775	
Rental Expense	7,574	24,616	5,681	37,871	
Salaries	12,214	41,293	9,442	62,949	
Supplies	-	3,536	-	3,536	
Symposium	106,243	-	-	106,243	
Taxes - Payroll	889	2,975	722	4,586	
Telephone	-	4,518	-	4,518	
Tournament Site	-	-	-	-	
Travel	-	6,915	-	6,915	
Website and Software	-	13,034	-	13,034	
Total Expenses Before Discontinued Operations	<u>2,625,508</u>	<u>262,082</u>	<u>312,851</u>	<u>3,200,441</u>	
Discontinued Operations - NanoWafer, Inc.:					
Salaries and Payroll Taxes	-	85,697	-	85,697	
Insurance	-	29,735	-	29,735	
Professional Fees	-	13,623	-	13,623	
Other	-	33,194	-	33,194	
Loss from Discontinued Operations	<u>-</u>	<u>162,249</u>	<u>-</u>	<u>162,249</u>	
Total Expenses and Loss from Discontinued Operations	<u>\$ 2,625,508</u>	<u>\$ 424,331</u>	<u>\$ 312,851</u>	<u>\$ 3,362,690</u>	

See accompanying Notes to Financial Statements.

**CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
STATEMENTS OF CASH FLOWS
YEARS ENDED JUNE 30, 2021 AND 2020**

	2021	2020
CASH FLOWS FROM OPERATING ACTIVITIES		
Increase in Net Assets	\$ 932,718	\$ 732,442
Adjustments to Reconcile Increase in Net Assets to Net Cash Provided (Used) by Operating Activities:		
Depreciation and Amortization	17,888	16,482
Realized Gains on Sales of Investments	(27,902)	(154,660)
Unrealized Loss (Gain) on Investments	(620,884)	196,788
Discount on Grants Receivable	2,167	6,030
Discount on Grants Payable	9,129	30,957
Deferred Rent	(3,188)	2,110
Changes in Assets and Liabilities:		
(Increase) Decrease in:		
Receivables	309,582	(368,660)
Prepaid Expenses	(39,946)	83,246
Increase (Decrease) in:		
Accounts Payable	2,238	(109,578)
Research Grants Payable	(441,352)	(501,815)
Accrued Expenses	2,339	2,085
Total Adjustments	(789,929)	(797,015)
Net Cash Provided (Used) by Operating Activities	142,789	(64,573)
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchases of Property and Equipment	-	(71,495)
Purchases of Investments	(674,047)	(2,743,013)
Proceeds from Sales of Investments	515,212	1,270,806
Net Cash Used by Investing Activities	(158,835)	(1,543,702)
NET DECREASE IN CASH AND CASH EQUIVALENTS	(16,046)	(1,608,275)
Cash and Cash Equivalents - Beginning of Year	5,984,805	7,593,080
CASH AND CASH EQUIVALENTS - END OF YEAR	\$ 5,968,759	\$ 5,984,805
SUPPLEMENTAL DISCLOSURE OF CASH FLOW INFORMATION		
Cash Paid During the Year For:		
Interest	\$ -	\$ 28
Income Taxes	\$ -	\$ 1,600

See accompanying Notes to Financial Statements.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2021 AND 2020

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.

Principles of Consolidation

The consolidated June 30, 2020 financial statements include the accounts of CRF and NanoWafer (collectively, the Foundation). All intercompany balances and transactions have been eliminated in the consolidation.

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).

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2021 AND 2020

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

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.

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, 2021 and 2020, the Foundation has pledges receivable of \$600,000 and \$664,600, 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 approximates 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 consolidated 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, 2021 and 2020, there was no impairment of the value of such assets.

**CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2021 AND 2020**

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.

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 consolidated statement of financial position date. There were no conditional grants at June 30, 2021 and 2020. Subsequent to June 30, 2021 approximately \$612,000 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, 2021 and 2020, joint costs of approximately \$138,000 and \$113,000, 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 AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2021 AND 2020

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.

Research and Development – NanoWafer no longer owns the license to the cysteamine nanowafer technology. NanoWafer suspended operations in December 2019.

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 (IRC) and the State Revenue and Tax Code Section 23701(d). Accordingly, no provision for income taxes has been made in the accompanying consolidated financial statements.

NanoWafer is treated as a C corporation for purposes of filing its federal and state income tax returns. Income taxes are provided for the tax effects of transactions reported in NanoWafer's financial statements and consist of taxes currently due or refundable plus deferred taxes. NanoWafer accounts for income taxes under the asset and liability method.

Deferred tax assets and liabilities are recognized for future tax consequences attributable to differences between the financial statement carrying amounts of existing assets and liabilities and their perspective tax bases. Deferred tax assets and liabilities are measured using enacted tax rates expected to apply to taxable income in the years in which the temporary differences are expected to be recovered or settled.

The effect of a change in tax rates on deferred tax assets and liabilities is recognized in income in the period that includes the enactment date. Valuation allowances are recorded, when necessary, to reduce deferred tax assets to the amount expected to be realized. NanoWafer has discontinued operations and filed for corporate dissolution.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2021 AND 2020

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

Income Taxes (Continued)

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 consolidated financial statements as a result of these provisions. The Foundation expects to file final tax returns for NanoWafer for the six month period ended June 30, 2021.

Potential interest and penalties accrued related to unrecognized tax benefits are recorded within income tax expense. For the years ended June 30, 2021 and 2020, 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, 2021 and 2020, relating to unrecognized benefits. CRF and NanoWafer's tax years from 2017 to 2020 are open to review for federal tax purposes, and tax years from 2016 to 2020 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, 2021 and 2020, was approximately \$122,000 and \$191,000, respectively. For the years ended June 30, 2021 and 2020, approximately \$6,900 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 AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2021 AND 2020

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 consolidated 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 – Adopted

In May 2014, the FASB issued ASU 2014-09, *Revenue from Contracts with Customers (Topic 606)*. ASU 2014-09 establishes new revenue recognition guidance (ASC 606), which replaces the current revenue recognition guidance. ASC 606 is a comprehensive revenue recognition standard for virtually all industries, including those that previously followed industry-specific guidance, such as the real estate, construction, and software industries. The core principle of ASC 606 is to recognize revenue to depict the transfer of goods or services to customers in an amount that reflects the consideration for which the entity expects to be entitled in exchange for those goods or services. No cumulative-effect adjustment in net assets was recorded as the adoption of ASU 2014-09 did not significantly impact the Foundation's reported historical revenue.

In August 2018, the FASB issued ASU 2018-13, *Fair Value Measurements (Topic 820)*. The amendments in this update modify the disclosure requirements on fair value measurements in Topic 820. The amendments on changes in unrealized gains and losses, the range and weighted average of significant unobservable inputs used to develop Level 3 fair value measurements, and the narrative description of measurement uncertainty should be applied prospectively for only the most recent interim or annual period presented in the initial fiscal year of adoption. The adoption of ASU 2018-13 did not have a significant impact on the Foundation's financial statements.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2021 AND 2020

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

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 balance sheet 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 consolidated financial statements.

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 consolidated financial statements.

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.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2021 AND 2020

NOTE 2 FAIR VALUE MEASUREMENTS (CONTINUED)

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, 2021 and 2020. 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, 2021 is as follows:

	Fair Value	Fair Value Measurements Using		
		Level 1	Level 2	Level 3
Investments:				
Limited Partnerships	\$ 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 fair value of assets measured on a recurring basis at June 30, 2020 is as follows:

	Fair Value	Fair Value Measurements Using		
		Level 1	Level 2	Level 3
Investments:				
Limited Partnerships	\$ 438,041	\$ -	\$ -	\$ 438,041
Stock	312,879	312,879	-	-
Mutual Funds	2,061,303	2,061,303	-	-
Total	<u>\$ 2,812,223</u>	<u>\$ 2,374,182</u>	<u>\$ -</u>	<u>\$ 438,041</u>

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

	2021	2020
Interest and Dividends	\$ 123,546	\$ 88,944
Realized Gains	27,902	154,660
Unrealized Gains (Losses)	620,886	(196,788)
Investment Fees	(26,821)	(16,504)
Investment Returns - Net	<u>\$ 745,513</u>	<u>\$ 30,312</u>

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2021 AND 2020

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 consolidated statement of financial position date, are as follows as of June 30:

	<u>2021</u>	<u>2020</u>
Cash and Cash Equivalents	\$ 5,968,759	\$ 5,984,805
Pledges Receivable	600,000	664,600
Grant and Other Receivables	<u>684</u>	<u>247,833</u>
Total Financial Assets Available to Meet General Expenditures Within One Year	<u>\$ 6,569,443</u>	<u>\$ 6,897,238</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, 2021, approximately \$612,000 of grants were approved for funding.

NOTE 4 GRANT RECEIVABLE

In 2019, the Foundation received a written grant totaling \$650,000 that provides for payment over a three-year period ending December 15, 2020. The grant receivable is recorded at its estimated net realizable value, including discounts (1.75%) reflecting the estimated impact of the passage of time on amounts to be received over more than one year. The final grant receivable of \$247,833, net of discount of \$2,167 was collected during the year ended June 30, 2021.

NOTE 5 RESEARCH GRANTS PAYABLE

During the years ended June 30, 2021 and 2020, the Foundation expended approximately \$2,800,000 and \$2,300,000, respectively, for research grants. At June 30, 2021 and 2020, the Foundation had commitments of \$1,849,342 and \$2,281,565, respectively, to fund 23 and 21 grants, respectively, in the next two years. The award amounts of these grants range from approximately \$63,000 to \$765,000.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2021 AND 2020

NOTE 5 RESEARCH GRANTS PAYABLE (CONTINUED)

Research grants payable at June 30, 2021 are expected to be paid as follows:

<u>Year Ending June 30,</u>	<u>Amount</u>
2022	\$ 1,758,979
2023	96,664
Total	<u>1,855,643</u>
Less: Discount at 0.16% to 1.75%	<u>(6,301)</u>
Research Grants Payable - Net	<u><u>\$ 1,849,342</u></u>

NOTE 6 PROPERTY AND EQUIPMENT

Property and equipment consist of the following at June 30:

	<u>2021</u>	<u>2020</u>
Office Equipment	\$ 49,450	\$ 49,450
Furniture and Fixtures	46,835	46,835
Leasehold Improvements	<u>8,873</u>	<u>8,874</u>
Total Property and Equipment at Cost	105,158	105,159
Less: Accumulated Depreciation	<u>(34,370)</u>	<u>(16,482)</u>
Property and Equipment, at Net Book Value	<u><u>\$ 70,788</u></u>	<u><u>\$ 88,677</u></u>

Depreciation expense for the years ended June 30, 2021 and 2020 was \$17,888 and \$16,482, respectively.

NOTE 7 DISCONTINUED OPERATIONS

In December 2019, NanoWafer suspended its operations. There were no revenues from NanoWafer's operations for the years ended June 30, 2021 and 2020. There were no expenses for NanoWafer during the year ended June 30, 2021. The expenses from NanoWafer's operations for the year ended June 30, 2020 are reported in the statement of functional expenses and the loss from discontinued operations is included in the statement of activities for the year ended June 30, 2020. NanoWafer will file 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.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2021 AND 2020

NOTE 8 REVENUES AND SUPPORT

During the years ended June 30, 2021 and 2020, 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 2021. 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 2021 and 2020 there were no costs for direct benefits to donors.

For the years ended June 30, 2021 and 2020, the Foundation received approximately \$905,000 and \$600,000, respectively, in contributions from an anonymous donor to cover operating and fundraising costs.

NOTE 9 CONTRIBUTED SERVICES

For the year ended June 30, 2021, contributions include approximately \$4,400 of in-kind professional services. For the year ended June 30, 2020, contributions include approximately \$6,900 of in-kind advertising and \$8,610 of in-kind professional services.

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 consolidated financial statements since they do not meet the criteria for recognition as contributed services.

NOTE 10 RELATED PARTY TRANSACTIONS

A board member's spouse provided fundraising and administrative consulting services to CRF for the years ended June 30, 2021 and 2020, of approximately \$78,000 and \$108,000, respectively. At June 30, 2021 and 2020, there were no amounts included in accounts payable, which were due to related parties.

CRF awards grants to research institutions naming specific researchers. During 2021 and 2020, CRF granted approximately \$103,000 and \$465,500, respectively, to the University of California, San Diego (UCSD), on behalf of a researcher who is also a board member. At June 30, 2021 and 2020, approximately \$54,400 and \$235,823, respectively, were included in research grants payable to UCSD.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2021 AND 2020

NOTE 11 INCOME TAXES

NanoWafer's net operating loss (NOL) carryforwards are approximately \$1,894,000 at June 30, 2021 and 2020. NanoWafer will be filing final federal and state returns for the six month period ended June 30, 2021 and all NOL carryforwards will expire. NanoWafer has recorded a valuation allowance against the entire net deferred tax asset balance because it will be unable to realize benefits due to its lack of a history of earnings and possible limitations under IRC Section 382.

NanoWafer files its income tax compliance with the Internal Revenue Service and in the states of California and Texas with varying statutes of limitations. NanoWafer's policy is to recognize interest expense and penalties related to income tax matters as a component of the provision for income taxes. There were no accrued interest and penalties associated with uncertain tax positions as of June 30, 2021 and 2020.

The net deferred tax asset consists of the following components at June 30:

Deferred Tax Asset:	
NOL Carryforwards:	
Federal	\$ 398,800
State	167,900
Total	<u>566,700</u>
Valuation Allowance	<u>(566,700)</u>
Net Deferred Tax Asset	<u><u>\$ -</u></u>

The deferred income tax provision is summarized as follows for the years ended June 30:

Federal Income Tax Benefit	\$ 34,100
State Income Tax Benefit	14,300
Total Income Tax Benefit	<u>48,400</u>
Change in Valuation Allowance	<u>(48,400)</u>
Income Tax Benefit - Net	<u><u>\$ -</u></u>

NanoWafer believes its income tax filing positions and deductions will be sustained during an audit and does not anticipate any adjustments that will result in a material change to its financial position. Therefore, no reserves for uncertain income tax positions have been recorded.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
JUNE 30, 2021 AND 2020

NOTE 12 NET ASSETS

Net assets consist of the following at June 30:

	2021	2020
Net Assets Without Donor Restrictions:		
Undesignated	\$ 8,482,442	\$ 7,301,891
Net Assets With Donor Restrictions:		
Subject Only to Time Restriction:		
Grant Receivable for Future Periods	-	247,833
Total Net Assets	\$ 8,482,442	\$ 7,549,724

NOTE 13 FACILITY LEASE

The Foundation leases its office space under a noncancelable operating lease expiring in April 2022. 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 consolidated statements of financial position.

Minimum future rental payments under the noncancelable operating lease described above as of June 30, 2021 are as follows:

Year Ending June 30,	Amount
2022	\$ 37,330
2023	31,878
Total	\$ 69,208

Rental expense for the years ended June 30, 2021 and 2020 was approximately \$37,871 and \$37,871, respectively.

NOTE 14 RECLASSIFICATION

Certain amounts in prior periods have been reclassified to match the current period financial statement presentation. These reclassifications have no effect on previously reported net assets or changes in net assets.

NOTE 15 SUBSEQUENT EVENTS

The Foundation has evaluated subsequent events through October 29, 2021, the date the consolidated financial statements were available to be issued.

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