

**CYSTINOSIS RESEARCH FOUNDATION
AND SUBSIDIARY**

**CONSOLIDATED FINANCIAL STATEMENTS FOR
DECEMBER 31, 2016 AND FINANCIAL STATEMENTS
FOR DECEMBER 31, 2015**

**WITH INDEPENDENT AUDITORS'
REPORT THEREON**

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY

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ORGANIZATIONAL DATA



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.

RESEARCH

CRF is dedicated to finding better treatments to improve the quality of life for those with cystinosis and to ultimately find a cure for this devastating disease.

CRF has an aggressive research agenda. CRF issues grants for bench and clinical research studies bi-annually in an effort to accelerate the research process and ensure that cystinosis research is on-going and focused on novel treatments and a cure.

HISTORY AND RESEARCH

Cystinosis is a rare, metabolic and genetic disease that afflicts approximately 2,000 children and adults worldwide. CRF's focus is increasingly on the clinical and translational research crucial to making strides towards a cure for cystinosis. CRF is committed to prioritizing and aggressively supporting research which has the potential to significantly improve the quality of life for patients with cystinosis.

CRF announces two global calls for research proposals each year. After careful evaluation of every application by the CRF Scientific Review Board, research grants are awarded. In 2006, CRF established the first Cystinosis Research Fellowship Program designed to support scientists and new researchers who have an interest in cystinosis.

RESEARCH GIVES US HOPE

We firmly believe that research gives us HOPE – and hope allows us to live with cystinosis until the day a cure is found.

Since 2003, the Cystinosis Research Foundation (CRF) has become the largest fund provider of cystinosis research in the world – raising more than \$39 million. CRF has changed the course of cystinosis by investing donors' gifts strategically and aggressively to create a thriving research

cystinosis by investing donors' gifts strategically and aggressively to create a thriving research community. From the beginning, all CRF operating costs are privately underwritten so that 100 percent of the funds donated goes to support cystinosis research.

We are pleased to announce that in 2016 CRF issued ten new grants totaling more than \$1.56 million for cystinosis research. An additional seven grant agreements were awarded after year-end totaling \$1.39 million with the funding for these grants available in cash reserves. The new grants bring us that much closer to better treatments and a cure.

CRF has issued grants to the best and brightest researchers in the world. To date, we have funded 151 multi-year research studies at leading research institutions in 12 countries. CRF-funded researchers have published more than 67 articles in prestigious, top-rated journals. Those articles, available to everyone in the world, have added to the understanding of the pathogenesis of cystinosis.

From the beginning, 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. One of our earliest milestones, and the one of which we are most proud, is that CRF funded every bench and clinical trial that led to the discovery of a delayed-release form of the life-saving medication cystinosis patients must take. The delayed-release medication, approved by the FDA in 2013, is considered the most significant advancement in the treatment of cystinosis in 30 years. Our latest research milestone is the creation of the first donor stem cell transplantation trial at UCLA, which brings us tantalizingly close to a cure.

Moving forward, we have targeted several areas of research 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.

NANOTECHNOLOGY AND CORNEAL CYSTINOSIS

We are dedicated to finding better treatments for corneal cystinosis. Corneal cystinosis is the build-up of cystine crystals in the eyes that causes photophobia (extreme sensitivity to light) severe eye pain, and sometimes, blindness. There is an existing treatment but it is rigorous and requires hourly dosing of medicated eye drops. For many, compliance is difficult.

Ghanashyam Acharya, PhD, and Jennifer Simpson, MD, have collaborated on a novel treatment for corneal cystinosis. Dr. Acharya has invented a nanowafer that we believe will revolutionize the treatment of corneal cystinosis. The nanowafer can be loaded with cysteamine medication to treat corneal cystinosis. The nanowafer is placed in the eye, and as it dissolves, the medication slowly releases in the eye offering relief for hours.

In 2016, CRF formed Corneal Cystinosis, Inc., (CCI) for the purpose of research and development of a novel treatment for corneal cystinosis. The treatment proposes to use a nanowafer loaded with cysteamine medication to treat corneal cystinosis. CRF owns the license for the cysteamine nanowafer which ensures that we remain focused and committed to bringing the new treatment to the patients. The scientist who developed the nanowafer is Dr. Ghanshyam Acharya at Baylor College of Medicine. CRF and Dr. Acharya are committed to this project and hope to file a new drug application in 2018.

STEM CELL AND GENE THERAPY

We believe that stem cells will be the cure for cystinosis. CRF works closely with Stéphanie Cherqui, PhD, whose focus is stem cells and gene therapy. Dr. Cherqui has worked together with the FDA for several years and is awaiting FDA approval to commence the first autologous stem cell and gene therapy clinical trial. We are optimistic that the FDA will approve this study in 2017. Once it is approved, we can help recruit patients soon thereafter. Dr. Cherqui's work is our hope; not only has the treatment reversed cystinosis in mice, last year she successfully cured corneal cystinosis in the mouse model.

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 as other cystinosis families have joined our efforts. Their friends and families have embraced the cystinosis cause and enthusiastically raise 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 2016, 56 families from around the world gathered along with CRF funded researchers to share stories, hopes and dreams and build life-long friendships. Leading cystinosis researchers shared their progress on gene and stem cell therapies, novel eye research and neurological challenges related to cystinosis. The conference allows families to learn more about the ongoing cystinosis research and the hope it brings to our community.

CURE CYSTINOSIS INTERNATIONAL REGISTRY

The Cure Cystinosis International Registry (CCIR) was launched in 2010 and now has approximately 576 cystinosis patients registered from 44 countries. The Cystinosis Research Foundation in partnership and collaboration with the Cystinosis Foundation and twelve other cystinosis family foundations from around the world, established this comprehensive, global patient registry for cystinosis. The CCIR questionnaire was developed by medical and scientific experts specifically for the cystinosis community. To improve accessibility, the CCIR has been translated into Spanish, Portuguese, Dutch and French. It is our mission to register every person with cystinosis, thus connecting them to the research community in an effort to find a cure for cystinosis. The CCIR is a central hub of information and is an essential tool for the global cystinosis research community. We are certain that the information provided by the patients will accelerate the research process and unite us in our quest to find a cure for cystinosis.

CRF INTERNATIONAL RESEARCH SYMPOSIUM

CRF's International Research Symposium is held every two years and is only open to invited researchers and scientists. Approximately 65 cystinosis experts from leading international universities and research institutions gather to share their research data and to discuss cutting edge research ideas in an effort to accelerate research. The symposium is known for the openness of the attendees, and for their willingness to work together and form collaborations. The symposium has created a synergistic research community working in partnership with CRF.



Link, Murrel & Company, LLP

A PARTNERSHIP INCLUDING PROFESSIONAL CORPORATIONS

INDEPENDENT AUDITORS' REPORT

The Board of Directors
Cystinosis Research Foundation and Subsidiary
Irvine, California

We have audited the accompanying consolidated financial statements of Cystinosis Research Foundation and Subsidiary (a nonprofit organization) (the "Foundation") which comprise the consolidated statement of financial position as of December 31, 2016, and the related consolidated statements of activities, functional expenses, and cash flows for the year then ended, and the related notes to the consolidated financial statements. We have also audited the accompanying financial statements of Cystinosis Research Foundation, which comprise the statement of financial position as of December 31, 2015, 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 audits. We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audits 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 auditors consider internal control relevant to the entity's preparation and fair presentation of the 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.

The Board of Directors
Cystinosis Research Foundation and Subsidiary

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 2016 consolidated financial statements referred to above present fairly, in all material respects, the consolidated financial position of Cystinosis Research Foundation and Subsidiary as of December 31, 2016, and the changes in their net assets and their cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America. Also, in our opinion, the 2015 financial statements present fairly, in all material respects, the financial position of Cystinosis Research Foundation as of December 31, 2015, 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.

Link, Murrel & Company, LLP

Link, Murrel & Co., LLP

Irvine, California
June 14, 2017

FINANCIAL STATEMENTS

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
STATEMENTS OF FINANCIAL POSITION
DECEMBER 31, 2016 AND 2015

	2016	2015
	Consolidated	
Assets:		
Current Assets:		
Cash and cash equivalents	\$ 4,672,285	\$ 3,565,590
Receivables:		
Pledges	16,039	112,500
Other	47,707	-
Investments	1,466,645	977,965
Prepaid expenses	122,507	123,678
Total current assets	6,325,183	4,779,733
Property and Intangible Asset:		
Software	12,038	12,038
Website	44,800	44,800
	56,838	56,838
Accumulated depreciation and amortization	(56,838)	(56,838)
Net property and intangible asset	-	-
Total Assets	\$ 6,325,183	\$ 4,779,733
Liabilities:		
Current Liabilities:		
Accounts payable	\$ 59,962	\$ 73,224
Grants payable - current portion	1,368,483	1,701,647
Accrued expenses	3,799	2,323
Total current liabilities	1,432,244	1,777,194
Long-Term Liability - Grants Payable, net of Current Portion	370,519	418,566
Total liabilities	1,802,763	2,195,760
Net Assets - Unrestricted	4,522,420	2,583,973
Total Liabilities and Net Assets	\$ 6,325,183	\$ 4,779,733

See accompanying notes.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
STATEMENTS OF ACTIVITIES
FOR THE YEARS ENDED DECEMBER 31, 2016 AND 2015

	2016	2015
	Consolidated	
Unrestricted:		
Revenues and Support:		
Contributions	\$ 2,216,916	\$ 1,476,451
Fundraising, net of direct benefits to donors	2,602,043	1,736,676
Interest	8,462	6,738
Investment returns - net gain (loss)	148,574	(11,036)
Total revenues and support	4,975,995	3,208,829
Expenses:		
Program services:		
Research and education	2,013,714	2,221,488
Nanowafer research and development	270,623	-
Total program services:	2,284,337	2,221,488
Supporting services:		
General and administrative	152,412	111,359
Fundraising	600,799	465,515
Total supporting services	753,211	576,874
Total expenses	3,037,548	2,798,362
Increase in Unrestricted Net Assets	1,938,447	410,467
Unrestricted Net Assets, Beginning of Year	2,583,973	2,173,506
Unrestricted Net Assets, End of Year	\$ 4,522,420	\$ 2,583,973

See accompanying notes.

**CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
CONSOLIDATED STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2016
(WITH SUMMARIZED TOTALS FOR 2015)**

	<u>Supporting Services</u>			<u>Totals 2016</u>	<u>Totals 2015</u>
	<u>Program Services</u>	<u>General and Administrative</u>	<u>Fundraising</u>		
Accounting	\$ 2,948	\$ 30,444	\$ 16,748	\$ 50,140	\$ 38,525
Advertising/Public relations	28,258	-	106,799	135,057	80,996
Auction items	-	-	10,073	10,073	13,186
Credit card fees	-	-	27,416	27,416	21,992
Education	189,047	-	-	189,047	118,456
Grants	1,581,860	-	-	1,581,860	1,890,841
Insurance	-	8,036	-	8,036	8,318
Magazine	60,218	-	49,513	109,731	119,090
Nanowafer project	5,988	-	-	5,988	60,002
Other	178	862	63,255	64,295	46,176
Outside services	29,250	46,377	87,305	162,932	148,896
Patient registry	12,135	-	-	12,135	12,059
Photography	-	-	44,797	44,797	36,249
Postage	-	3,612	10,212	13,824	17,421
Printing	9,605	3,696	58,048	71,349	37,375
Salaries	-	-	57,875	57,875	55,700
Supplies	-	1,222	34,035	35,257	38,913
Symposium	93,196	-	-	93,196	8,606
Taxes - payroll	-	-	4,854	4,854	4,446
Telephone	-	1,717	-	1,717	1,798
Tournament site	-	-	11,363	11,363	5,313
Travel	1,031	8,505	14,750	24,286	6,177
Website and software	-	21,001	3,756	24,757	25,806
Expenses before depreciation and amortization	2,013,714	125,472	600,799	2,739,985	2,796,341
Depreciation and amortization	-	-	-	-	2,021
Total expenses before Corneal Cystinolysis, Inc.	2,013,714	125,472	600,799	2,739,985	2,798,362
Corneal Cystinolysis, Inc.:					
Nanowafer research and development	270,623	-	-	270,623	-
Professional fees	-	22,845	-	22,845	-
Other	-	4,095	-	4,095	-
	<u>270,623</u>	<u>26,940</u>	<u>-</u>	<u>297,563</u>	<u>-</u>
Total Expenses	<u>\$ 2,284,337</u>	<u>\$ 152,412</u>	<u>\$ 600,799</u>	<u>\$ 3,037,548</u>	<u>\$ 2,798,362</u>

See accompanying notes.

**CYSTINOSIS RESEARCH FOUNDATION
STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2015**

	Program Services	Supporting Services		Totals
		General and Administrative	Fundraising	
Accounting	\$ 2,351	\$ 24,576	\$ 11,598	\$ 38,525
Advertising/Public relations	5,906	-	75,090	80,996
Auction items	-	-	13,186	13,186
Credit card fees	-	-	21,992	21,992
Education	118,456	-	-	118,456
Grants	1,890,841	-	-	1,890,841
Insurance	-	8,318	-	8,318
Magazine	77,087	-	42,003	119,090
Nanowafer project	60,002	-	-	60,002
Other	6,116	670	39,390	46,176
Outside services	29,624	38,092	81,180	148,896
Patient registry	12,059	-	-	12,059
Photography	-	-	36,249	36,249
Postage	-	5,755	11,666	17,421
Printing	9,842	764	26,769	37,375
Salaries	-	-	55,700	55,700
Supplies	-	3,886	35,027	38,913
Symposium	8,606	-	-	8,606
Taxes - payroll	-	-	4,446	4,446
Telephone	-	1,798	-	1,798
Tournament site	-	-	5,313	5,313
Travel	598	5,579	-	6,177
Website and software	-	19,900	5,906	25,806
Expenses before depreciation and amortization	2,221,488	109,338	465,515	2,796,341
Depreciation and amortization	-	2,021	-	2,021
Total Expenses	<u>\$ 2,221,488</u>	<u>\$ 111,359</u>	<u>\$ 465,515</u>	<u>\$ 2,798,362</u>

See accompanying notes.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
STATEMENTS OF CASH FLOWS
FOR THE YEARS ENDED DECEMBER 31, 2016 AND 2015

	2016	2015
	Consolidated	
Cash Flows from Operating Activities:		
Increase in net assets	\$ 1,938,447	\$ 410,467
Adjustments to reconcile increase in net assets to net cash provided by operating activities:		
Depreciation and amortization	-	2,021
Unrealized loss (gain) on investments	(119,304)	73,874
Changes in assets and liabilities:		
(Increases) decreases in:		
Receivables	48,754	(71,620)
Prepaid expenses	1,171	28,584
Increases (decreases) in:		
Accounts payable	(13,262)	(5,369)
Accrued expenses	1,476	77
Grants payable	(381,211)	(107,181)
Total adjustments	(462,376)	(79,614)
Net cash provided by operating activities	1,476,071	330,853
Cash Flows from Investing Activities:		
Purchases of investments	(636,398)	(712,823)
Proceeds from sales of investments	267,022	714,157
Net cash provided by (used in) investing activities	(369,376)	1,334
Net Increase in Cash and Cash Equivalents	1,106,695	332,187
Cash and Cash Equivalents, Beginning of Year	3,565,590	3,233,403
Cash and Cash Equivalents, End of Year	\$ 4,672,285	\$ 3,565,590
Supplemental Disclosure of Cash Flow Information:		
Cash paid during the year for:		
Interest	\$ -	\$ -
Income taxes	\$ -	\$ -

See accompanying notes.

**CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2016 (CONSOLIDATED) AND 2015**

1. ORGANIZATION AND NATURE OF SERVICES

The Cystinosis Research Foundation (“CRF”) was founded in 2003 as a California nonprofit public benefit corporation. The mission of CRF is two-fold and focused: 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 Cystinosis, Inc. (“CCI”) as a Texas corporation. The business plan of CCI is to improve treatment for corneal cystinosis. This subsidiary is 100% owned by CRF.

2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Principles of Consolidation

The consolidated financial statements for 2016 include the accounts of CRF and CCI. Collectively, these entities are referred to as the “Foundation”. All intercompany balances and transactions have been eliminated in the consolidation. The total assets of CCI were approximately \$2,400 at December 31, 2016. No revenue was reported for the year ended December 31, 2016. The net loss of CCI was approximately \$297,600 for the year ended December 31, 2016.

Basis of Accounting

The financial statements of the Foundation have been prepared on the accrual basis of accounting in accordance with accounting principles generally accepted in the United States of America.

Financial Statement Presentation

The Foundation reports information regarding its financial position and activities according to three classes of net assets: unrestricted net assets, temporarily restricted net assets and permanently restricted net assets.

Unrestricted Net Assets – Net assets that are not subject to donor-imposed restrictions. Unrestricted net assets generally result from unrestricted contributions and interest and dividends, less expenses incurred in providing services and fundraising and other administrative expenses.

Temporarily Restricted Net Assets – Net assets that are subject to donor-imposed restrictions that require the passage of time or the occurrence of a specific event to become available for unrestricted use. At December 31, 2016 and 2015, there were no temporarily restricted net assets.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2016 (CONSOLIDATED) AND 2015

2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

Financial Statement Presentation (Continued)

Permanently Restricted Net Assets – Net assets that are subject to donor-imposed restrictions that may be maintained permanently while permitting the Foundation to use or expense part or all of the income derived from the donated assets. At December 31, 2016 and 2015, there were no permanently restricted net assets.

Use of Estimates and Assumptions

The preparation of the financial statements in conformity with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect the 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.

Cash and Cash Equivalents

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

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.

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 Activities and the Statements of Financial Position.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2016 (CONSOLIDATED) AND 2015

2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

Pledges Receivable

Pledges receivable are unconditional promises to give towards the Foundation's programs and fundraising events and are recorded as revenue when the pledge is received. At December 31, 2016 and 2015, the Foundation considered all remaining pledges of \$16,039 and \$112,500, respectively, 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, other receivables, prepaid expenses, accounts payable, and accrued expenses approximate their respective fair values due to their short maturities. Grants payable are discounted based upon the average yield of United States 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. The Hedge Funds were valued based upon the internal financial statements of the various Portfolio Funds within the Hedge Fund or from redemption values at December 31, 2016 and 2015. Such financial statements generally value securities and other financial instruments on a mark-to-market basis of accounting. The limited partnerships invest in hedge funds and private equity funds.

Property and Intangible Asset

Assets are carried at cost, if purchased, or fair market value at date of contribution, if contributed. Donations are reported as unrestricted support unless the donor has restricted the donated asset to 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 five to seven years for software and the website.

Contributions and Grant Payments

Contributions received are recorded as unrestricted, temporarily restricted or permanently restricted net assets depending on the existence or nature of any donor restrictions.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2016 (CONSOLIDATED) AND 2015

2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

Contributions and Grant Payments (Continued)

Contributions made, including grant payments, can be either unconditional or conditional. Unconditional grants are recognized as an expense in the period in which they are approved. Grants, which are conditional upon a future and uncertain event, are expensed when these conditions are substantially met or expected to be met in a subsequent year. A conditional promise to give is considered unconditional if the possibility that the condition will not be met is remote.

Grants payable represents 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 December 31, 2016 and 2015.

Functional Allocation of Expenses

The costs of providing the various programs and other activities have been summarized on a functional basis in the Statements of Activities and in the Statements of Functional Expenses. CRF achieves some of its programmatic goals with its magazine. The joint costs associated with the magazine have been allocated to program services and to fundraising. Certain other costs have also been allocated among the programs and supporting services benefited.

The major programs of the Foundation are as follows:

Research – CRF is dedicated to finding better treatments to improve the quality of life for those with cystinosis and to ultimately find a cure for this devastating disease. Through their aggressively funded research agenda, CRF issues grants for bench and clinical research studies bi-annually in order to accelerate research progress and ensure that cystinosis research is on-going and focused on novel treatments and a cure.

Education – CRF is dedicated to educating the public and the medical community about cystinosis to ensure early diagnosis and proper treatment.

Corneal cystinosis nanowafer research and development – CCI owns the license to the cysteamine nanowafer technology which research has shown will improve treatment for corneal cystinosis.

CYSTINOSIS RESEARCH FOUNDATION AND SUBSIDIARY
NOTES TO FINANCIAL STATEMENTS
DECEMBER 31, 2016 (CONSOLIDATED) AND 2015

2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

Income Taxes

CRF is a California nonprofit corporation which 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 of income taxes has been made in the accompanying financial statements.

CCI 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 the financial statements and consist of taxes currently due or refundable plus deferred taxes. CCI 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 on deferred tax assets and liabilities of a change in tax rates 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.

CCI follows the accounting for uncertainty in income taxes recognized in a nonpublic entity's financial statements. 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 CCI's financial statements as a result of these provisions.

Potential interest and penalties accrued related to unrecognized tax benefits are recorded within income tax expense. For the year ended December 31, 2016, no interest or penalties were recorded in the Consolidated Statement of Activities. No interest or penalties were accrued in the Consolidated Statement of Position at December 31, 2016 relating to unrecognized benefits.

Advertising

The Foundation follows the policy of charging the costs of advertising to expenses as incurred. Advertising expense for the years ended December 31, 2016 and 2015 were approximately \$135,000 and \$81,000, respectively. For the years ended December 31, 2016 and 2015 approximately \$33,000 and \$22,000 of advertising expense were in-kind donations.

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2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

Subsequent Events

The Foundation has evaluated subsequent events through June 14, 2017, the date the consolidated financial statements were available to be issued.

3. 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 valuation methodology that is unobservable and significant to the fair value measurement.

The hedge funds and limited partnerships, using level 3 inputs, were primarily valued using internal financial statements of the various portfolio funds within the hedge funds and limited partnerships or from redemption values at December 31, 2016 and 2015. Valuation techniques utilized to determine fair value are applied consistently.

The fair value of assets measured on a recurring basis at December 31, 2016 and 2015 are as follows:

Fair Value Measurements Using:

<u>December 31, 2016</u>	<u>Fair Value</u>	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>
Investments:				
Limited partnerships	\$ 774,078	\$ -	\$ -	\$ 774,078
Stocks	307,158	306,158	-	1,000
Mutual funds	382,719	382,719	-	-
Hedge funds	<u>2,690</u>	<u>-</u>	<u>-</u>	<u>2,690</u>
Totals	<u>\$ 1,466,645</u>	<u>\$ 688,877</u>	<u>\$ -</u>	<u>\$ 777,768</u>

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3. FAIR VALUE MEASUREMENTS (Continued)

Fair Value Measurements Using:

<u>December 31, 2015</u>	<u>Fair Value</u>	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>
Investments:				
Limited partnerships	\$ 464,056	\$ -	\$ -	\$ 464,056
Stocks	261,864	260,864	-	1,000
Mutual funds	247,355	247,355	-	-
Hedge funds	<u>4,690</u>	<u>-</u>	<u>-</u>	<u>4,690</u>
Totals	<u>\$ 977,965</u>	<u>\$ 508,219</u>	<u>\$ -</u>	<u>\$ 469,746</u>

The following table sets forth a summary of changes in hedge funds and limited partnerships, which are Level 3 assets, for the years ended December 31, 2016 and 2015:

<u>Hedge Funds</u>	<u>2016</u>	<u>2015</u>
Beginning balances	\$ 4,690	\$ 323,012
Purchases	-	1,584
Sales	(1,727)	(321,643)
Net gains (losses) - realized/unrealized	<u>(273)</u>	<u>1,737</u>
Ending balances	<u>\$ 2,690</u>	<u>\$ 4,690</u>

<u>Limited Partnerships</u>	<u>2016</u>	<u>2015</u>
Beginning balances	\$ 464,056	\$ -
Purchases	250,000	500,000
Sales	(13,535)	(11,482)
Net gains (losses) - realized/unrealized	<u>73,557</u>	<u>(24,462)</u>
Ending balances	<u>\$ 774,078</u>	<u>\$ 464,056</u>

The following summarizes the investment returns in the Statements of Activities for the years ended December 31:

	<u>2016</u>	<u>2015</u>
Interest and dividends	\$ 26,853	\$ 16,020
Realized gains	11,746	55,943
Unrealized losses	119,304	(73,874)
Investment fees	<u>(9,329)</u>	<u>(9,125)</u>
Investment returns – net gain (loss)	<u>\$ 148,574</u>	<u>\$ (11,036)</u>

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4. GRANTS PAYABLE

During the years ended December 31, 2016 and 2015, the Foundation committed to fund research grants of approximately \$1,582,000 and \$1,891,000, respectively. At December 31, 2016, the Foundation had commitments of \$1,753,000 to fund nineteen grants in the next three years. The award amounts of these grants range from approximately \$26,000 to \$300,000.

Research grants payable as of December 31, 2016 are expected to be paid as follows:

Year Ending December 31,

2017	\$ 1,368,483
2018	309,748
2019	<u>75,000</u>
	1,753,231
Less discount at 0.67% to 1.2%	<u>14,229</u>
Research grants payable - net	<u>\$ 1,739,002</u>

In 2016 CRF issued ten new grants totaling more than \$1.56 million for cystinosis research. An additional seven grant agreements were awarded after year-end totaling \$1.39 million with the funding for these grants available in cash reserves. The new grants bring CRF closer to better treatments and a cure.

5. COMMON STOCK

The par value of each of CCI's authorized common shares is \$0.0001. There are 2,000,000 shares authorized and 1,000,000 shares are issued.

6. REVENUES AND SUPPORT

The Foundation receives the majority of its revenues from fundraising events, hosting two major events each year in Orange County, California, the Natalie's Wish Gala Celebration and the Fore a Cure Golf Tournament. Each of these fundraisers provides the Foundation with the opportunity to educate donors and the public about cystinosis. Funds were raised through corporate sponsorships, donations and auctions. Other fundraising activities are hosted by cystinosis families across the U.S. who enlighten their local communities about cystinosis and the progress of the Foundation funded research. Fundraising revenue was decreased for the costs of direct benefits to donors of \$230,418 and \$290,170 for the years ended December 31, 2016 and 2015, respectively.

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6. REVENUES AND SUPPORT (Continued)

For the years ended December 31, 2016 and 2015, the Foundation received approximately \$905,000 and \$626,000, respectively, from anonymous donors to cover operating and fundraising costs.

7. CONTRIBUTED SERVICES

For the year ended December 31, 2016, contributions include approximately \$33,400 of in-kind advertising and printing and \$13,200 of in-kind professional services. For the year ended December 31, 2015, contributions include approximately \$22,000 of in-kind advertising and printing and \$6,100 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 these statements since they do not meet the criteria for recognition as contributed services.

8. RELATED PARTY TRANSACTIONS

CRF utilizes advertising and printing services from a Board member's company, which also pays postage that CRF reimburses. For the years ended December 31, 2016 and 2015 the services totaled approximately \$30,000 and \$115,000, respectively. Another Board member's spouse provides fundraising and administrative consulting services to CRF for the years ended December 31, 2016 and 2015 of approximately \$54,000 for each year. At December 31, 2016 and 2015, approximately \$43,000 and \$600 were included in accounts payable due to related parties, respectively.

CRF awards grants to research institutions naming specific researchers. For the year ended December 31, 2015, CRF granted approximately \$365,000 to the University of California, San Diego (UCSD) on behalf of a researcher who is also a Board member. At December 31, 2016 and 2015, approximately \$184,000 and \$357,000 were included in grants payable to UCSD, respectively.

CRF provides loans to CCI. At December 31, 2016, CCI owed CRF \$250,000. The loan bears interest at 0.65% and the principal and interest are due in March 2018.

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9. INCOME TAXES

CCI's net operating losses ("NOL") carryforward of approximately \$296,000 will begin to expire in 2036 for federal and state purposes and could be limited for use under IRC Section 382. CCI has recorded a valuation allowance against the entire net deferred tax asset balance because there exists a doubt that it will be able to realize the benefits due to its lack of a history of earnings and due to possible limitations under IRC Section 382.

CCI files its income tax compliance with the IRS and in the states of California and Texas with varying statutes of limitations. CCI's policy is to recognize interest expense and penalties related to income tax matters as a component of our provision for income taxes. There were no accrued interest and penalties associated with uncertain tax positions as of December 31, 2016.

The net deferred tax asset consists of the following components at December 31, 2016:

Deferred tax assets:		
Net operating loss carry forwards:		
Federal	\$ 99,300	
State	<u>26,300</u>	\$ 125,600
Valuation allowance		<u>(125,600)</u>
Net deferred tax asset		<u>\$ -</u>

The deferred income tax provision is summarized as follows:

Federal income tax benefit	\$ 99,300
State income tax benefit	<u>26,300</u>
Total income tax benefit	125,600
Valuation allowance	<u>(125,600)</u>
Income tax benefit - net	<u>\$ -</u>

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