

**CYSTINOSIS RESEARCH
NETWORK, INC.**

YEARS ENDED DECEMBER 31, 2015 AND 2014

CYSTINOSIS RESEARCH NETWORK, INC.

YEARS ENDED DECEMBER 31, 2015 AND 2014

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Independent Auditor's Report

Board of Directors
Cystinosis Research Network, Inc.
Lake Forest, Illinois

We have audited the accompanying financial statements of Cystinosis Research Network, Inc. (the Organization), which comprise the statement of financial position as of December 31, 2015 and 2014 and the related statements of activities, functional expenses and cash flows for the years 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.

Auditor's 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 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 auditor's 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 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 Network, Inc. as of December 31, 2015 and 2014 and the changes 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.

Ostrow Reisin Berk & Abrams, Ltd.

August 9, 2016

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF FINANCIAL POSITION

December 31,	2015	2014
ASSETS		
Cash	\$ 316,374	\$ 424,831
Pledges receivable	14,000	
Other receivable	136	
Prepaid expenses		1,405
Property and equipment, net	834	4,167
Total assets	\$ 331,344	\$ 430,403
LIABILITIES AND NET ASSETS		
Liabilities:		
Accounts payable and accrued expenses	\$ 14,843	\$ 11,144
Grants payable		27,000
Total liabilities	14,843	38,144
Net assets:		
Unrestricted	236,235	329,259
Temporarily restricted	80,266	63,000
Total net assets	316,501	392,259
Total liabilities and net assets	\$ 331,344	\$ 430,403

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF ACTIVITIES

Years ended December 31,	2015			2014		
	Unrestricted	Temporarily restricted	Total	Unrestricted	Temporarily restricted	Total
Public support and revenue:						
Grants	\$ 248,000	\$ 100,000	\$ 348,000	\$ 41,000		\$ 41,000
Contributions	29,829		29,829	55,887		55,887
Fundraising and special events:						
Gross proceeds	237,918		237,918	555,476		555,476
Interest income	1,572		1,572	472		472
Net assets released from restrictions	82,734	(82,734)		40,000	\$ (40,000)	
Total public support and revenue	600,053	17,266	617,319	692,835	(40,000)	652,835
Expenses:						
Program services	642,519		642,519	164,812		164,812
Management and general	32,414		32,414	36,601		36,601
Fundraising	18,144		18,144	157,117		157,117
Total expenses	693,077		693,077	358,530		358,530
Change in net assets	(93,024)	17,266	(75,758)	334,305	(40,000)	294,305
Net assets (deficit):						
Beginning of year	329,259	63,000	392,259	(5,046)	103,000	97,954
End of year	\$ 236,235	\$ 80,266	\$ 316,501	\$ 329,259	\$ 63,000	\$ 392,259

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF FUNCTIONAL EXPENSES

Year ended December 31, 2015	Program services			Supporting services				
	Research	Education and Awareness	Family Support	Total program services	Management and general	Fundraising	Total supporting services	Total
Grants	\$ 83,337			\$ 83,337				\$ 83,337
Books and publications					\$ 300		\$ 300	300
Equipment rental		\$ 1,439	\$ 813	2,252		\$ 646	646	2,898
Insurance					1,628		1,628	1,628
Licenses and registration					329		329	329
Marketing and promotion		6,853	12,302	19,155	75	1,305	1,380	20,535
Meetings and conferences		10,462	196,846	207,308				207,308
Outside services					4,110		4,110	4,110
Postage					844		844	844
Printing and copying		38,735	4,253	42,988		716	716	43,704
Professional fees					21,000		21,000	21,000
Rental of facilities		1,082		1,082				1,082
Scholarships		2,585		2,585				2,585
Sundry			2,546	2,546	150	4,382	4,532	7,078
Supplies		2,987	23,412	26,399	303	5,795	6,098	32,497
Telephone		800		800	3,675		3,675	4,475
Travel and transportation		30,566	220,168	250,734		5,300	5,300	256,034
Total expenses before depreciation	83,337	95,509	460,340	639,186	32,414	18,144	50,558	689,744
Depreciation		3,333		3,333				3,333
Total expenses included in the expense section of the statement of activities	\$ 83,337	\$ 98,842	\$ 460,340	\$ 642,519	\$ 32,414	\$ 18,144	\$ 50,558	\$ 693,077

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF FUNCTIONAL EXPENSES (CONTINUED)

Year ended December 31, 2014	Program services			Supporting services				
	Research	Education and Awareness	Family Support	Total program services	Management and general	Fundraising	Total supporting services	Total
Grants	\$ 75,040			\$ 75,040				\$ 75,040
Equipment rental		\$ 6,260		6,260		\$ 300	\$ 300	6,560
Insurance					\$ 1,628		1,628	1,628
Licenses and registration					329		329	329
Marketing and promotion		2,086		2,086				2,086
Meetings and conferences		8,529		8,529				8,529
Outside services					9,135		9,135	9,135
Postage					1,167		1,167	1,167
Printing and copying		27,184		27,184	6	1,323	1,329	28,513
Professional fees					21,343		21,343	21,343
Rental of facilities						122,031	122,031	122,031
Scholarships		2,000		2,000				2,000
Sponsorships		1,500		1,500				1,500
Sundry		17		17	363	18,566	18,929	18,946
Supplies		176	\$ 1,041	1,217	290	6,236	6,526	7,743
Telephone		700		700	2,093		2,093	2,793
Travel and transportation		35,808	1,138	36,946	247	8,661	8,908	45,854
Total expenses before depreciation	75,040	84,260	2,179	161,479	36,601	157,117	193,718	355,197
Depreciation		3,333		3,333				3,333
Total expenses included in the expense section of the statement of activities	\$ 75,040	\$ 87,593	\$ 2,179	\$ 164,812	\$ 36,601	\$ 157,117	\$ 193,718	\$ 358,530

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF CASH FLOWS

Years ended December 31,	2015	2014
Cash flows from operating activities:		
Change in net assets	\$ (75,758)	\$ 294,305
Adjustments to reconcile change in net assets to cash provided by (used in) operating activities:		
Depreciation	3,333	3,333
Change in operating assets and operating liabilities:		
Pledges receivable	(14,000)	92,000
Other receivable	(136)	
Prepaid expenses	1,405	(905)
Accounts payable and accrued expenses	3,699	(4,166)
Grants payable	(27,000)	(58,000)
Cash provided by (used in) operating activities	(108,457)	326,567
Increase (decrease) in cash	(108,457)	326,567
Cash, beginning of year	424,831	98,264
Cash, end of year	\$ 316,374	\$ 424,831

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS

1. Organization and purpose

Cystinosis Research Network, Inc. (the Organization) is a not-for-profit organization that is dedicated to supporting and advocating research, providing family assistance and educating the public and medical communities about cystinosis. The Organization funds research and programs primarily through donations from the public, grassroots fundraising events and grants.

The following summarizes the Organization's programs:

Research:

The Organization establishes and funds fellowships and research grants focusing on clinical and research training in cystinosis.

Education and Awareness:

The Organization raises awareness and reinforces strong relationships through representation at national medical conferences, affiliation with other organizations such as the National Organization for Rare Disorders (NORD), publication of periodic newsletters and awards of educational scholarships to individuals with cystinosis and their siblings.

Family Support:

The Organization provides information and opportunities to network for individuals with cystinosis and their families through participation in a biennial conference on cystinosis that brings together clinicians, researchers and medical professionals from around the world.

It also supports newly diagnosed and existing families by providing access to world experts via advisory boards, moderation of an email support group and information packets.

2. Summary of significant accounting policies

Basis of accounting:

The financial statements of the Organization have been prepared on the accrual basis of accounting in accordance with generally accepted accounting principles.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

2. Summary of significant accounting policies (continued)

Basis of presentation:

The financial statement presentation follows the recommendations of the Financial Accounting Standards Board (FASB) Accounting Standards Codification (the Codification) for *Financial Statements of Not-for-Profit Organizations*. Under the Codification, the Organization is required to report information regarding its financial position and activities in three classes of net assets: unrestricted net assets, temporarily restricted net assets and permanently restricted net assets. See Note 6. There were no permanently restricted net assets at December 31, 2015 and 2014.

Cash:

The Organization maintains its cash in bank accounts which, at times, may exceed federally-insured limits. The Organization had cash balances in excess of federally-insured limits of approximately \$76,000 and \$201,000 at December 31, 2015 and 2014, respectively. The Organization has not experienced any losses in such accounts. Management believes that the Organization is not exposed to any significant credit risk on cash.

Pledges receivable:

Pledges receivable include unconditional promises to give. At December 31, 2015, \$14,000 is due in 2016.

Property and equipment and related depreciation:

Property and equipment is stated at cost or if donated, at the approximate fair value at the date of donation. Depreciation expense is provided on a straight-line basis over the estimated useful life of the assets. The Organization follows the practice of capitalizing all expenditures for property and equipment in excess of \$5,000 with a useful life greater than one year.

Grants payable:

Grants payable represent unpaid amounts due to administrators of the Organization's research awards in the following year. Such administrators may include other not-for-profit organizations, researchers, doctors, universities, research laboratories and other institutions funding and/or conducting medical research into the detection, treatment and/or cure of cystinosis. See Note 7.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

2. Summary of significant accounting policies (continued)

Grants and contributions:

Contributions, including unconditional promises to give, are recognized as revenue in the period the pledge or promise is received and recorded as unrestricted, temporarily restricted or permanently restricted depending on the existence and nature of any donor-imposed restrictions.

Contributions that are restricted by the donor are reported as increases in unrestricted net assets if the restrictions expire (that is, when a stipulated time restriction ends or purpose of restriction is accomplished) in the same reporting period in which the revenue is recognized. All other donor-restricted contributions are reported as increases in temporarily or permanently restricted net assets, depending on the nature of the restriction. When a restriction expires, temporarily restricted net assets are reclassified to unrestricted net assets and reported in the statement of activities as net assets released from restrictions.

Contributed goods and services:

The Organization follows the recommendations of the Codification for *Accounting for Contributions Received and Contributions Made*, which requires the Organization to recognize as revenue the fair value of contributed (donated) goods and services.

The Organization receives donated services from unpaid volunteers who assist in its fundraising events and programs in the furtherance of its purposes. In addition, many individuals volunteer their time and perform a variety of tasks that assist the Organization. None of these amounts have been recognized in the statement of activities because the criteria for recognition has not been met.

Functional allocation of expenses:

The costs of providing various programs and activities have been summarized on a functional basis in the statement of activities. Accordingly, certain costs have been allocated among the programs and supporting services benefited.

Use of estimates:

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 amounts reported in the financial statements and accompanying notes. Accordingly, actual results could differ from those estimates.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

3. Tax status

The Organization is a tax-exempt organization as described in Section 501(c)(3) of the Internal Revenue Code (the Code) and is exempt from federal income taxes on related income pursuant to Section 501(a) of the Code. In addition, the Internal Revenue Service has determined that the Organization is not a private foundation within the meaning of Section 509(a) of the Code. The Organization has adopted the requirements for accounting for uncertain tax positions and management has determined that the Organization was not required to record a liability related to uncertain tax positions as of December 31, 2015 and 2014.

4. Concentrations

For the year ended December 31, 2015, two donors provided approximately 57% of the Organization's funding. The receivable balance for these donors represented 100% of the outstanding balance as of December 31, 2015.

5. Property and equipment

The components of property and equipment were as follows:

<u>December 31,</u>	<u>2015</u>	<u>2014</u>
Website	\$ 10,000	\$ 10,000
Less accumulated depreciation	(9,166)	(5,833)
Total	\$ 834	\$ 4,167

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

6. Temporarily restricted net assets

Temporarily restricted net assets are available for the following purpose or time restrictions:

<u>December 31,</u>	<u>2015</u>	<u>2014</u>
Purpose and time restricted:		
“Dream, Achieve, Inspire” art exhibit	\$ 11,452	
Comic book series	25,000	
Patient meetings	43,814	\$ 63,000
Total	\$ 80,266	\$ 63,000

During the years ended December 31, 2015 and 2014, net assets were released from donor restrictions by incurring expenses satisfying the following purpose or time restrictions:

<u>Years ended December 31,</u>	<u>2015</u>	<u>2014</u>
Purpose and time restricted:		
“Dream, Achieve, Inspire” art exhibit	\$ 63,548	
Patient meetings	19,186	\$ 18,000
2014 newsletters		18,000
2014 website administration		4,000
Total	\$ 82,734	\$ 40,000

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

7. Conditional grant commitments for research projects

At December 31, 2015, the Organization had agreements with administrators of the Organization's research grants and fellowships in future years. The Organization's Scientific Review Board reviews research grants and fellowships through progress reports, which are provided by the grant administrators. The Organization reserves the right to terminate future funding for an award if its progress report reflects unsatisfactory progress. As such, the Organization is only committed to funding grants based on the most current progress reports. Future conditional research grant and fellowship commitments are as follows:

Award recipient	Award total	Funding paid or accrued in years prior to 2014	Funding paid or accrued in 2014	Funding paid or accrued in 2015	Conditional liability payable in future years
Dr. Rosaleen Anderson, PhD	\$ 54,121	\$ 36,081	\$ 18,040		
Gordon Research	3,000		3,000		
Jess Thoene, M.D.	81,000	27,000	54,000		
KU Leuven Research	77,001			\$ 25,667	\$ 51,334
Dr. Steven Walkley, PhD	98,010			32,670	65,340
Katharina Hohenfellner	25,000			25,000	
Totals	\$ 338,132	\$ 63,081	\$ 75,040	\$ 83,337	\$ 116,674

8. Subsequent events

Management of the Organization has reviewed and evaluated subsequent events from December 31, 2015, the financial statement date, through August 9, 2016, the date the financial statements were available to be issued. No events have occurred in this period that would be required to be recognized and/or disclosed in these financial statements as required by generally accepted accounting principles.