

**CYSTINOSIS RESEARCH
NETWORK, INC.**

YEARS ENDED DECEMBER 31, 2013 AND 2012

CYSTINOSIS RESEARCH NETWORK, INC.

YEARS ENDED DECEMBER 31, 2013 AND 2012

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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, 2013 and 2012 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 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, 2013 and 2012 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.

September 16, 2014

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF FINANCIAL POSITION

December 31,	2013	2012
ASSETS		
Cash	\$ 98,264	\$ 102,654
Pledges receivable	92,000	20,000
Prepaid expenses	500	
Property and equipment, net	7,500	
Deposits		6,000
Total assets	\$ 198,264	\$ 128,654
LIABILITIES AND NET ASSETS		
Liabilities:		
Accounts payable and accrued expenses	\$ 15,310	\$ 14,318
Grants payable	85,000	21,465
Total liabilities	100,310	35,783
Net assets (deficit):		
Unrestricted	(5,046)	92,871
Temporarily restricted	103,000	
Total net assets	97,954	92,871
Total liabilities and net assets	\$ 198,264	\$ 128,654

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF ACTIVITIES

Years ended December 31,	2013		2012 (As restated)	
	Unrestricted	Temporarily restricted	Unrestricted	Temporarily restricted
			Total	Total
Public support and revenue:				
Grants	\$ 114,100	\$ 103,000	\$ 217,100	\$ 104,975
Contributions	91,219		91,219	68,122
Fundraising and special events:				
Gross proceeds	197,174		197,174	215,142
Less: Direct benefits to donors				(17,674)
Contributed goods and services				20,000
Interest income	200		200	419
Other income	4,600		4,600	419
Total public support and revenue	407,293	103,000	510,293	390,984
Expenses:				
Program services	458,559		458,559	409,933
Management and general	32,662		32,662	50,457
Fundraising	13,989		13,989	28,358
Total expenses	505,210		505,210	488,748
Change in net assets (deficit)	(97,917)	103,000	5,083	(97,764)
Net assets (deficit):				
Beginning of year	92,871		92,871	190,635
End of year	\$ (5,046)	\$ 103,000	\$ 97,954	\$ 92,871

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF FUNCTIONAL EXPENSES

Year ended December 31, 2013	Program services			Supporting services			Total
	Research	Education and Awareness	Family Support	Management and general	Fundraising	supporting services	
Grants	\$ 224,404			\$ 224,404			\$ 224,404
Books and publications				300		300	300
Equipment rental					\$ 402	402	402
Insurance				849		849	849
Licenses and registration		\$ 4,036	\$ 4,384	154		154	154
Meetings and conferences							8,420
Outside services							7,710
Postage		29,935	2,857	3,855	3,855	7,710	1,659
Printing and copying				1,659		1,659	1,659
Professional fees					21,130	21,130	21,130
Scholarships			3,000			3,000	3,000
Sundry		220	1,100	1,320	234	4,038	4,272
Supplies		243	27,618	27,861	258	1,711	1,969
Telephone		405		405	2,763	2,763	2,763
Travel and transportation		20,386	137,471	157,857	1,460	3,328	4,788
Total expenses before depreciation	224,404	55,225	176,430	456,059	32,662	13,989	46,651
Depreciation		2,500		2,500			2,500
Total expenses included in the expense section of the statement of activities	\$ 224,404	\$ 57,725	\$ 176,430	\$ 458,559	\$ 32,662	\$ 13,989	\$ 46,651
							\$ 505,210

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF FUNCTIONAL EXPENSES (CONTINUED)

Year ended December 31, 2012	Program services			Supporting services			Total
	Research	Education and awareness	Family Support	Total program services	Management and general	Direct benefits to donors	
Grants	\$ 325,078			\$ 325,078			\$ 325,078
Equipment rental					\$ 3,037		\$ 3,037
Insurance					665		665
Licenses and registration		\$ 1,500		\$ 1,500			\$ 1,500
Marketing and promotion		26,400		26,400			26,400
Meetings and conferences		5,124		5,124			5,124
Outside services					3,755		3,755
Postage					1,560		1,560
Printing and copying					426		426
Professional fees	47	28,742	73	28,862	16,300		45,162
Rental of facilities					3,040	\$ 17,674	20,714
Scholarships			4,000	4,000			4,000
Sponsorships					378		378
Sundry		1,661	144	1,805	359		2,164
Supplies		940		940	3,536		4,476
Telephone					20,441		20,441
Travel and transportation		16,224		16,224		2,688	18,912
Total expenses	325,125	80,591	4,217	409,933	50,457	28,358	506,422
Less: Expenses included with revenues on the statement of activities						(17,674)	(17,674)
Total expenses included in the expense section of the statement of activities	\$ 325,125	\$ 80,591	\$ 4,217	\$ 409,933	\$ 50,457	\$ 28,358	\$ 488,748

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF CASH FLOWS

Years ended December 31,	2013	2012
Cash flows from operating activities:		
Change in net assets	\$ 5,083	\$ (97,764)
Adjustments to reconcile change in net assets to cash provided by (used in) operating activities:		
Depreciation	2,500	
Change in operating assets and operating liabilities:		
Pledges receivable	(72,000)	(20,000)
Prepaid expenses	(500)	2,022
Deposits	6,000	(6,000)
Accounts payable and accrued expenses	992	7,279
Other liability		(16,567)
Grants payable	63,535	21,465
Cash provided by (used in) operating activities	5,610	(109,565)
Cash flows from investing activity:		
Purchases of property and equipment	(10,000)	
Cash used in investing activity	(10,000)	
Decrease in cash	(4,390)	(109,565)
Cash, beginning of year	102,654	212,219
Cash, end of year	\$ 98,264	\$ 102,654

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 Entities*. 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, 2013 and 2012.

Cash:

The Organization considers cash, savings and money market accounts to be cash.

The Organization maintains its cash in bank accounts which, at times, may exceed federally-insured limits. The Organization did not have cash balances in excess of federally-insured limits at December 31, 2013 and 2012. 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, 2013, \$92,000 is receivable in 2014. Of the receivable balance at December 31, 2012, \$20,000 was received in 2013.

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.

During the year ended December 31, 2013, the Organization implemented a policy that changes reporting for certain donor-restricted contributions. Contributions that are restricted by the donor are now 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. Previously, all donor-restricted contributions were reported as increases in temporarily or permanently restricted net assets. See Note 8. 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 received no donated goods and services during the year ended December 31, 2013. The Organization received \$20,000 in donated travel expenses during the year ended December 31, 2012.

The Organization also 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.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

2. Summary of significant accounting policies (continued)

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.

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, 2013. Federal and state tax and/or information returns of the Organization are subject to examination by the Internal Revenue Service and state taxing authorities, generally for three years after the returns were filed. Management believes that the Organization is no longer subject to income tax examinations by taxing authorities for years ended prior to December 31, 2010.

4. Concentrations

For the year ended December 31, 2013, two donors provided approximately 49% of the Organization's funding. The receivable balance for these donors represented 96% of the outstanding balance as of December 31, 2013.

For the year ended December 31, 2012, two donors provided approximately 32% of the Organization's funding. The receivable balance for these donors represented 100% of the outstanding balance as of December 31, 2012.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

5. Property and equipment

The components of property and equipment were as follows:

<u>December 31, 2013</u>	
Website	\$ 10,000
Less accumulated depreciation	(2,500)
<u>Total</u>	<u>\$ 7,500</u>

6. Temporarily restricted net assets

As of December 31, 2013, temporarily restricted net assets included the following:

<u>December 31, 2013</u>	
Purpose and time restricted:	
2014 Newsletters	\$ 18,000
2014 Patient meetings	81,000
2014 Website administration	4,000
<u>Total</u>	<u>\$ 103,000</u>

There were no temporarily restricted net assets at December 31, 2012.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

7. Conditional grant commitments for research projects

At December 31, 2013, 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 2012	Funding paid or accrued in 2012	Discontinued research in 2012	Funding paid or accrued in 2013	Conditional liability payable in future years
Dr. Rosaleen Anderson, PhD*	\$ 134,510	\$ 55,333	\$ 53,104		\$ 26,073	
Dr. Rosaleen Anderson, PhD	54,121				36,081	\$ 18,040
Martine Besouw, M.D.	49,700		49,700			
Dr. H.J. Blom**	61,119	18,935	42,184			
Dr. Ewa Elenberg	21,000	13,125	7,875			
Francisco Emma, M.D.	114,480	93,015	21,465			
Elena Levchenko, M.D.	68,090	51,068		\$ 17,022		
Leticia Belmont Martinez, M.D.	31,972	15,986		15,986		
National Institutes of Health	130,000				130,000	
Dr. Neveen Soliman	16,695		15,750		945	
Dr. Neveen Soliman	4,389				4,305	84
Jess Thoene, M.D.	81,000				27,000	54,000
Jess Thoene, M.D.	202,500	67,500	135,000			
Catherine Tuleu, PhD*	205,562	164,635		40,927		
Totals	\$ 1,175,138	\$ 479,597	\$ 325,078	\$ 73,935	\$ 224,404	\$ 72,124

*Amount awarded is shown in U.S. Dollars. Funds to be converted to British Pounds Sterling.

**Amount awarded is shown in U.S. Dollars. Funds to be converted to Euros.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

8. Effects of change in accounting policy

During the year ended December 31, 2013, the Organization implemented a policy that changed reporting for certain donor-restricted contributions (see Note 2). The change in accounting policy decreased temporarily restricted revenue and net assets released from restrictions for the year ended December 31, 2012 by \$65,000.

	Unrestricted	Temporarily Restricted	Total
Grants, year ended December 31, 2012, as previously reported	\$ 39,975	\$ 65,000	\$ 104,975
Adjustment per above	65,000	(65,000)	
Grants, year ended December 31, 2012, as restated	\$ 104,975	\$ -	\$ 104,975
Net assets released from restrictions, year ended December 31, 2012, as previously reported	\$ 65,000	\$ (65,000)	
Adjustment per above	(65,000)	65,000	
Net assets released from restrictions, year ended December 31, 2012, as restated	\$ -	\$ -	

9. Subsequent events

Management of the Organization has reviewed and evaluated subsequent events from December 31, 2013, the financial statement date, through September 16, 2014, 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.