

**CYSTINOSIS RESEARCH
NETWORK, INC.**

YEARS ENDED DECEMBER 31, 2012 AND 2011

CYSTINOSIS RESEARCH NETWORK, INC.

YEARS ENDED DECEMBER 31, 2012 AND 2011

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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, 2012 and 2011 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 of material misstatements.

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.

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, 2012 and 2011 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.

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August 28, 2013

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF FINANCIAL POSITION

December 31,	2012	2011
ASSETS		
Cash	\$ 102,654	\$ 212,219
Pledges receivable	20,000	
Prepaid expenses		2,022
Deposits	6,000	
Total assets	\$ 128,654	\$ 214,241
LIABILITIES AND NET ASSETS		
Liabilities:		
Accounts payable and accrued expenses	\$ 14,318	\$ 7,039
Other liability		16,567
Grants payable	21,465	
Total liabilities	35,783	23,606
Net assets:		
Unrestricted	92,871	190,635
Total liabilities and net assets	\$ 128,654	\$ 214,241

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF ACTIVITIES

Years ended December 31,	2012			2011
	Unrestricted	Temporarily restricted	Total	Unrestricted
Public support and revenue:				
Grants	\$ 39,975	\$ 65,000	\$ 104,975	\$ 51,985
Contributions	68,122		68,122	76,335
Fundraising and special events:				
Gross proceeds	215,142		215,142	215,153
Less: Direct benefits to donors	(17,674)		(17,674)	(20,113)
Contributed goods and services	20,000		20,000	40,550
Interest income	419		419	1,677
Other income				4,950
Net assets released from restrictions:				
Satisfaction of purpose and/or time restrictions	65,000	(65,000)		
Total public support and revenue	390,984		390,984	370,537
Expenses:				
Program services	409,933		409,933	472,758
Management and general	50,457		50,457	36,951
Fundraising	28,358		28,358	24,117
Total expenses	488,748		488,748	533,826
Change in net assets	(97,764)		(97,764)	(163,289)
Net assets:				
Beginning of year	190,635		190,635	353,924
End of year	\$ 92,871	\$ -	\$ 92,871	\$ 190,635

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF FUNCTIONAL EXPENSES

Year ended December 31, 2012	Program services				Supporting services				Total
	Research	Education	Family Support	Total program services	Management and general	Fundraising	Direct	Total supporting services	
		and Awareness					benefits to donors		
Grants	\$ 325,078			\$ 325,078					\$ 325,078
Equipment rental						\$ 90		\$ 90	90
Insurance					\$ 3,037			3,037	3,037
Licenses and registration					665			665	665
Marketing and promotion		\$ 26,400		26,400		6,600		6,600	33,000
Meetings and conferences		5,124		5,124					5,124
Outside services					3,755	3,755		7,510	7,510
Postage					1,560			1,560	1,560
Printing and copying	47	28,742	\$ 73	28,862	426	2,273		2,699	31,561
Professional fees					16,300			16,300	16,300
Rental of facilities						3,040	\$ 17,674	20,714	20,714
Scholarships			4,000	4,000					4,000
Sponsorships		1,500		1,500					1,500
Sundry					378	5,773		6,151	6,151
Supplies		1,661	144	1,805	359	4,139		4,498	6,303
Telephone		940		940	3,536			3,536	4,476
Travel and transportation		16,224		16,224	20,441	2,688		23,129	39,353
Total expenses	325,125	80,591	4,217	409,933	50,457	28,358	17,674	96,489	506,422
Less: Expenses included with revenues on the statement of activities							(17,674)	(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	\$ -	\$ 78,815	\$ 488,748

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF FUNCTIONAL EXPENSES (CONTINUED)

Year ended December 31, 2011	Program services				Supporting services				Total
	Research	Education and	Family	Total	Management and general	Fundraising	Direct	Total	
		Awareness	Support	program services			benefits to donors	supporting services	
Grants	\$ 233,651			\$ 233,651					\$ 233,651
Books and publications					\$ 300			\$ 300	300
Equipment rental			\$ 5,086	5,086		\$ 90		90	5,176
Insurance					1,913			1,913	1,913
Licenses and registration					40			40	40
Meetings and conferences		\$ 3,433	149,405	152,838					152,838
Outside services					8,089	8,089		16,178	16,178
Postage		394	6,724	7,118	913	1,861		2,774	9,892
Printing and copying		21,043		21,043					21,043
Professional fees					20,560			20,560	20,560
Rental of facilities						3,610	\$ 20,113	23,723	23,723
Scholarships			3,000	3,000					3,000
Sponsorships	4,000	1,800		5,800					5,800
Sundry		40	1,300	1,340	134	3,532		3,666	5,006
Supplies		22	3,167	3,189	607	328		935	4,124
Telephone		1,099		1,099	4,395			4,395	5,494
Travel and transportation		18,305	20,289	38,594		6,607		6,607	45,201
Total expenses	237,651	46,136	188,971	472,758	36,951	24,117	20,113	81,181	553,939
Less: Expenses included with revenues on the statement of activities							(20,113)	(20,113)	(20,113)
Total expenses included in the expense section of the statement of activities	\$ 237,651	\$ 46,136	\$ 188,971	\$ 472,758	\$ 36,951	\$ 24,117	\$ -	\$ 61,068	\$ 533,826

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENT OF CASH FLOWS

Years ended December 31,	2012	2011
Cash flows from operating activities:		
Change in net assets	\$ (97,764)	\$ (163,289)
Adjustments to reconcile change in net assets to cash used in operating activities:		
Change in operating assets and operating liabilities:		
Pledges receivable	(20,000)	
Prepaid expenses	2,022	11,378
Deposits	(6,000)	
Accounts payable and accrued expenses	7,279	7,039
Other liability	(16,567)	16,567
Grants payable	21,465	(136,804)
Cash used in operating activities	(109,565)	(265,109)
Decrease in cash	(109,565)	(265,109)
Cash, beginning of year	212,219	477,328
Cash, end of year	\$ 102,654	\$ 212,219

See notes to financial statements.

CYSTITINOSIS 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. There were no temporarily restricted or permanently restricted net assets at December 31, 2012 and 2011.

During 2012, the Organization received and expended grant funds for the following purposes: \$25,000 for the publication of a newsletter, \$5,000 for exhibit materials at medical conferences and meetings and \$35,000 for the Education and Awareness program. There were no purpose-restricted donations received during the year ended December 31, 2011.

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 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, 2012, \$20,000 is receivable in 2013.

Other liability:

The Organization received monies from another organization during the year ended December 31, 2011 for a new research grant that the Organization and the other organization co-sponsored. The agreement was formalized and paid out in full by the Organization during the year ended December 31, 2012.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

2. Summary of significant accounting policies (continued)

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 4.

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 \$20,000 in donated travel expenses and \$40,550 in donated facilities during the years ended December 31, 2012 and 2011, respectively.

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.

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.

4. Conditional grant commitments for research projects

At December 31, 2012, 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 2011	Funding paid or accrued in 2011	Funding paid or accrued in 2012	Discontinued research in 2012	Conditional liability payable in future years
Dr. Rosaleen Anderson, PhD*	\$ 130,366	\$ 30,217	\$ 25,116	\$ 53,104		\$ 26,073
Martine Besouw, M.D.	49,700			49,700		
Dr. H.J. Blom**	62,636	18,935		42,184		
Maya Doyle, LCSW	17,200		17,200			
Dr. Ewa Elenberg	21,000	13,125		7,875		
Francisco Emma, M.D.	114,480	93,015		21,465		
Dr. Paul Goodyer	36,000	36,000				
Elena Levtchenko, M.D.	68,090	51,068			\$ 17,022	
Leticia Belmont Martinez, M.D.	31,972	15,986			15,986	
Dr. Neveen Soliman	16,695			15,750		945
Jess Thoene, M.D.	165,732	82,866	82,866			
Jess Thoene, M.D.	202,500		67,500	135,000		
Catherine Tuleu, PhD*	203,500	123,666	40,969		40,927	
Totals	\$ 1,119,871	\$ 464,878	\$ 233,651	\$ 325,078	\$ 73,935	\$ 27,018

* 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)

5. Change in net assets

During the years ended December 31, 2012 and 2011, the Organization incurred a decrease in net assets of \$97,764 and \$163,289, respectively. Through efforts from the Board of Directors, the Organization plans to increase public support and revenue primarily with increased grants, contributions and fundraising events as well as to decrease the amount of grants and other expenses incurred based on the cash flow needs of the Organization.

6. Subsequent events

Management of the Organization has reviewed and evaluated subsequent events from December 31, 2012, the financial statement date, through August 28, 2013, 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.