

**CYSTINOSIS RESEARCH
NETWORK, INC.**

FINANCIAL STATEMENTS

YEARS ENDED DECEMBER 31, 2017 AND 2016

CYSTINOSIS RESEARCH NETWORK, INC.

YEARS ENDED DECEMBER 31, 2017 AND 2016

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Independent Auditors' Report

Board of Directors
Cystinosis Research Network, Inc.

We have audited the accompanying financial statements of Cystinosis Research Network, Inc. (the Organization), which comprise the statements of financial position as of December 31, 2017 and 2016, 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.

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 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, 2017 and 2016, 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.

October 5, 2018

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENTS OF FINANCIAL POSITION

December 31,	2017	2016
ASSETS		
Cash	\$ 198,218	\$ 269,314
Pledges receivable		200,000
Prepaid expenses	2,100	3,000
Property and equipment, net	4,723	8,056
Total assets	\$ 205,041	\$ 480,370
LIABILITIES AND NET ASSETS		
Liabilities:		
Accounts payable and accrued expenses	\$ 28,112	\$ 33,096
Net assets:		
Unrestricted	139,637	189,072
Temporarily restricted	37,292	258,202
Total net assets	176,929	447,274
Total liabilities and net assets	\$ 205,041	\$ 480,370

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENTS OF ACTIVITIES

Years ended December 31,	2017			2016		
	Unrestricted	Temporarily restricted	Total	Unrestricted	Temporarily restricted	Total
Public support and revenue:						
Grants	\$ 250,500		\$ 250,500	\$ 60,000	\$ 200,000	\$ 260,000
Contributions	37,687		37,687	37,921		37,921
Fundraising and special events	106,495		106,495	113,470		113,470
Interest income	811		811	1,024		1,024
Net assets released from restrictions	220,910	\$ (220,910)		22,064	(22,064)	
Total public support and revenue	616,403	(220,910)	395,493	234,479	177,936	412,415
Expenses:						
Program services	620,788		620,788	216,158		216,158
Management and general	33,717		33,717	47,104		47,104
Fundraising	11,333		11,333	18,380		18,380
Total expenses	665,838		665,838	281,642		281,642
Change in net assets	(49,435)	(220,910)	(270,345)	(47,163)	177,936	130,773
Net assets:						
Beginning of year	189,072	258,202	447,274	236,235	80,266	316,501
End of year	\$ 139,637	\$ 37,292	\$ 176,929	\$ 189,072	\$ 258,202	\$ 447,274

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENTS OF FUNCTIONAL EXPENSES

Year ended December 31, 2017	Program services			Supporting services				
	Research	Education and Awareness	Family Support	Total program services	Management and general	Fundraising	Total supporting services	Total
Grants	\$ 214,828			\$ 214,828				\$ 214,828
Depreciation		\$ 3,333		3,333				3,333
Equipment rental		431	\$ 7,129	7,560		\$ 1,744	\$ 1,744	9,304
Insurance					\$ 1,562		1,562	1,562
Licenses and registration					222		222	222
Marketing and promotion		18,185	21,100	39,285		2,041	2,041	41,326
Meetings and conferences		14,172	45,600	59,772		15	15	59,787
Outside services					2,378		2,378	2,378
Postage					750		750	750
Printing and copying		29,259	3,609	32,868	49	1,219	1,268	34,136
Professional fees					23,941		23,941	23,941
Rental facilities						300	300	300
Scholarships		2,000		2,000				2,000
Sponsorships		5,000		5,000				5,000
Sundry		147	2,730	2,877	234	2,703	2,937	5,814
Supplies		2,649	7,421	10,070	420	3,311	3,731	13,801
Telephone		900		900	3,604		3,604	4,504
Travel and transportation		50,961	191,334	242,295	557		557	242,852
Total expenses	\$ 214,828	\$ 127,037	\$ 278,923	\$ 620,788	\$ 33,717	\$ 11,333	\$ 45,050	\$ 665,838

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENTS OF FUNCTIONAL EXPENSES (CONTINUED)

Year ended December 31, 2016	Program services			Supporting services				
	Research	Education and Awareness	Family Support	Total program services	Management and general	Fundraising	Total supporting services	Total
Grants	\$ 72,510			\$ 72,510				\$ 72,510
Books and publications		\$ 300		300				300
Depreciation		2,778		2,778				2,778
Equipment rental		2,306	\$ 313	2,619				2,619
Insurance					\$ 1,562		\$ 1,562	1,562
Licenses and registration					450		450	450
Marketing and promotion	30	20,820	1,305	22,155		\$ 1,050	1,050	23,205
Meetings and conferences		15,772	500	16,272				16,272
Outside services					2,520		2,520	2,520
Postage		96		96	450		450	546
Printing and copying		31,061	337	31,398	27	678	705	32,103
Professional fees					35,760		35,760	35,760
Scholarships		3,000		3,000				3,000
Sponsorships		16,000		16,000				16,000
Sundry		1,040		1,040	217	1,232	1,449	2,489
Supplies		486	712	1,198	229	1,724	1,953	3,151
Telephone		950		950	2,013		2,013	2,963
Travel and transportation	763	44,403	676	45,842	3,876	13,696	17,572	63,414
Total expenses	\$ 73,303	\$ 139,012	\$ 3,843	\$ 216,158	\$ 47,104	\$ 18,380	\$ 65,484	\$ 281,642

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENTS OF CASH FLOWS

Years ended December 31,	2017	2016
Cash flows from operating activities:		
Change in net assets	\$ (270,345)	\$ 130,773
Adjustments to reconcile change in net assets to net cash used in operating activities:		
Depreciation	3,333	2,778
Change in operating assets and operating liabilities:		
Pledges receivable	200,000	(186,000)
Other receivable		136
Prepaid expenses	900	(3,000)
Accounts payable and accrued expenses	(4,984)	18,253
Net cash used in operating activities	(71,096)	(37,060)
Cash flows from investing activity:		
Purchase of property and equipment		(10,000)
Net cash used in investing activity		(10,000)
Net decrease in cash	(71,096)	(47,060)
Cash, beginning of year	269,314	316,374
Cash, end of year	\$ 198,218	\$ 269,314

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.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

2. Summary of significant accounting policies

Basis of accounting:

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

Basis of presentation:

The Organization reports 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.

Unrestricted – Unrestricted net assets are available to finance the general operations of the Organization. The only limits on the use of unrestricted net assets are the broad limits resulting from the nature of the Organization, the environment in which it operates and the purposes specified in its Articles of Incorporation.

Temporarily restricted – Temporarily restricted net assets result (a) from contributions and other inflows of assets, the use of which by the Organization is limited by donor-imposed stipulations that either expire by passage of time or can be fulfilled and removed by action of the Organization pursuant to those stipulations, (b) from other asset enhancements and diminishments subject to the same kinds of stipulations and (c) from reclassifications to (or from) other classes of net assets as a consequence of donor-imposed stipulations, their expiration by passage of time or their fulfillment and removal by actions of the Organization pursuant to those stipulations. See Note 7.

Permanently restricted – Permanently restricted net assets (generally referred to as endowment funds) are assets that have donor-imposed restrictions that stipulate that the contributed resources be maintained permanently, but permit the entity to utilize or expend part or all of the income or other economic benefits derived from the donated assets. The Organization has no permanently restricted net assets as of December 31, 2017 and 2016.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

2. Summary of significant accounting policies (continued)

Pledges receivable:

Pledges receivable include unconditional promises to give. Management provides for uncollectible amounts based on its assessment of the current state of individual accounts and donor history. There are no pledges receivable at December 31, 2017. At December 31, 2016, \$200,000 was receivable and collected in 2017.

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 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 statements of activities as net assets released from restrictions.

Contributed 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 statements of activities because the criteria for recognition has not been met.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

2. Summary of significant accounting policies (continued)

Functional allocation of expenses:

The costs of providing various programs and activities have been summarized on a functional basis in the statements of activities and functional expenses. 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.

Subsequent events:

Management has evaluated subsequent events from December 31, 2017, the financial statement date, through October 5, 2018, the date the financial statements were available to be issued.

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. Management has determined that the Organization was not required to record a liability related to uncertain tax positions as of December 31, 2017 and 2016.

4. Cash

The Organization maintains its cash in bank accounts which, at times, exceeds federally-insured limits. The Organization had no cash balances in excess of federally-insured limits at December 31, 2017. The Organization had cash balances in excess of federally-insured limits of approximately \$19,000 at December 31, 2016. Management believes that the Organization is not exposed to any significant credit risk on cash.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

5. Property and equipment

The components of property and equipment were as follows:

December 31,	2017	2016
Websites	\$ 20,000	\$ 20,000
Less accumulated depreciation	(15,277)	(11,944)
Property and equipment, net	\$ 4,723	\$ 8,056

6. Conditional grant commitments for research projects

At December 31, 2017, the Organization has agreements with administrators of the Organization's research grants and fellowships that are to be funded 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 expensed in years prior to 2016	Funding expensed in 2016	Funding expensed in 2017	Conditional liability payable in future years
John Foxe, PhD	\$ 110,001			\$ 36,667	\$ 73,334
John Foxe, PhD	38,352			19,176	19,176
Elena Levtchenko, MD, PhD	77,001	\$ 25,667	\$ 25,667		25,667
Elena Levtchenko, MD, PhD	14,173		14,173		
Elena Levtchenko, MD, PhD	88,493			58,995	29,498
Steven Walkley, PhD	98,010	32,670	32,670	32,670	
Steven Walkley, PhD	100,980			67,320	33,660
Totals	\$ 527,010	\$ 58,337	\$ 72,510	\$ 214,828	\$ 181,335

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

7. Temporarily restricted net assets

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

<u>December 31,</u>	<u>2017</u>	<u>2016</u>
Purpose restricted:		
Comic book series	\$ 6,068	\$ 14,388
Future by Design meetings	31,224	43,814
Time restricted		200,000
Total	\$ 37,292	\$ 258,202

During the years ended December 31, 2017 and 2016, net assets were released from donor restrictions by incurring expenses satisfying the following purpose or time restrictions:

<u>Years ended December 31,</u>	<u>2017</u>	<u>2016</u>
Purpose restricted:		
“Dream, Achieve, Inspire” art exhibit		\$ 11,452
Comic book series	\$ 8,320	10,612
Future by Design meetings	12,590	
Time restricted	200,000	
Total	\$ 220,910	\$ 22,064

8. Concentrations

For the year ended December 31, 2017, two donors provided approximately 64% of the Organization’s funding.

For the year ended December 31, 2016, two donors provided approximately 59% of the Organization’s funding. The pledges receivable balance for these donors represented 100% of the outstanding balance as of December 31, 2016.