

**CYSTINOSIS RESEARCH  
NETWORK, INC.**

FINANCIAL STATEMENTS

YEARS ENDED DECEMBER 31, 2018 AND 2017

# **CYSTINOSIS RESEARCH NETWORK, INC.**

YEARS ENDED DECEMBER 31, 2018 AND 2017

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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, 2018 and 2017, 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, 2018 and 2017, 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.*

December 17, 2019

# **CYSTINOSIS RESEARCH NETWORK, INC.**

## **STATEMENTS OF FINANCIAL POSITION**

<b>December 31,</b>	<b>2018</b>	<b>2017</b>
<b>ASSETS</b>		
Cash	<b>\$ 361,140</b>	\$ 198,218
Prepaid expenses	<b>10,535</b>	2,100
Property and equipment, net	<b>19,990</b>	4,723
<b>Total assets</b>	<b>\$ 391,665</b>	\$ 205,041
<b>LIABILITIES AND NET ASSETS</b>		
<b>Liabilities:</b>		
Accounts payable and accrued expenses	<b>\$ 46,239</b>	\$ 28,112
<b>Net assets:</b>		
Without donor restrictions	<b>169,524</b>	139,637
With donor restrictions	<b>175,902</b>	37,292
<b>Total net assets</b>	<b>345,426</b>	176,929
<b>Total liabilities and net assets</b>	<b>\$ 391,665</b>	\$ 205,041

*See notes to financial statements.*

**CYSTINOSIS RESEARCH NETWORK, INC.**

STATEMENTS OF ACTIVITIES

Years ended December 31,	2018			2017		
	Without donor restrictions	With donor restrictions	Total	Without donor restrictions	With donor restrictions	Total
Public support and revenue:						
Grants	\$ 165,500	\$ 186,500	\$ 352,000	\$ 250,500		\$ 250,500
Contributions	52,943		52,943	37,687		37,687
Fundraising and special events	131,336		131,336	106,495		106,495
Interest income	1,596		1,596	811		811
Net assets released from restrictions	47,890	(47,890)		220,910	\$ (220,910)	
<b>Total public support and revenue</b>	<b>399,265</b>	<b>138,610</b>	<b>537,875</b>	<b>616,403</b>	<b>(220,910)</b>	<b>395,493</b>
Expenses:						
Program services	303,082		303,082	620,788		620,788
Management and general	57,284		57,284	33,717		33,717
Fundraising	9,012		9,012	11,333		11,333
<b>Total expenses</b>	<b>369,378</b>		<b>369,378</b>	<b>665,838</b>		<b>665,838</b>
Change in net assets	29,887	138,610	168,497	(49,435)	(220,910)	(270,345)
Net assets:						
Beginning of year	139,637	37,292	176,929	189,072	258,202	447,274
End of year	\$ 169,524	\$ 175,902	\$ 345,426	\$ 139,637	\$ 37,292	\$ 176,929

*See notes to financial statements.*

**CYSTINOSIS RESEARCH NETWORK, INC.**

STATEMENTS OF FUNCTIONAL EXPENSES

Years ended December 31,	2018							2017
	Program Services			Supporting Services				Total
	Research	Education and Awareness	Family Support	Total program services	Management and general	Fundraising	Total supporting services	
Grants	\$ 159,830			\$ 159,830			\$ 159,830	\$ 214,828
Depreciation		\$ 3,333		3,333			3,333	3,333
Insurance and licenses					\$ 1,637		\$ 1,637	1,784
Marketing and promotion		25,467	\$ 855	26,322	19,872	\$ 6,692	26,564	41,326
Meetings and conferences		68,623	1,425	70,048	126		70,174	302,939
Professional fees					29,055		29,055	26,319
Scholarships and sponsorships		4,000		4,000			4,000	7,000
Supplies and other sundry expenses		38,592	957	39,549	6,594	2,320	48,463	68,309
<b>Total expenses</b>	<b>\$ 159,830</b>	<b>\$ 140,015</b>	<b>\$ 3,237</b>	<b>\$ 303,082</b>	<b>\$ 57,284</b>	<b>\$ 9,012</b>	<b>\$ 66,296</b>	<b>\$ 369,378</b>

*See notes to financial statements.*

# **CYSTINOSIS RESEARCH NETWORK, INC.**

## **STATEMENTS OF CASH FLOWS**

<b>Years ended December 31,</b>	<b>2018</b>	<b>2017</b>
Cash flows from operating activities:		
Change in net assets	\$ 168,497	\$ (270,345)
Adjustments to reconcile change in net assets to net cash provided by (used in) operating activities:		
Depreciation	3,333	3,333
Changes in operating assets and operating liabilities:		
Pledges receivable		200,000
Prepaid expenses	(8,435)	900
Accounts payable and accrued expenses	18,127	(4,984)
Net cash provided by (used in) operating activities	181,522	(71,096)
Cash flows from investing activity:		
Purchase of property and equipment	(18,600)	
Net cash used in investing activity	(18,600)	
Net change in cash	162,922	(71,096)
Cash, beginning of year	198,218	269,314
Cash, end of year	\$ 361,140	\$ 198,218

*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 based on the existence or absence of donor-imposed restrictions. Accordingly, net assets and changes therein are classified and reported as follows:

**Net assets without donor restrictions** – Net assets available to finance the general operations of the Organization. The only limits on the use of net assets without donor restrictions 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.

**Net assets with donor restrictions** – Net assets subject to donor-imposed restrictions. Some donor-imposed restrictions are temporary in nature, such that they will be met by the passage of time or other events specified by the donor. Other donor-imposed restrictions are perpetual in nature, where the donor stipulates that resources be maintained in perpetuity. The Organization reports contributions restricted by donors as increases in net assets without donor restrictions if the restrictions expire (that is, when a stipulated time restriction ends or purpose restriction is accomplished) in the same reporting period in which the revenue is recognized. All other donor restricted contributions are reported as increases in net assets with donor restrictions. When a restriction expires, net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the statements of activities as net assets released from restrictions.

#### **Property and equipment:**

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 capitalizes all expenditures for property and equipment in excess of \$5,000 with a useful life greater than one year.

# **CYSTINOSIS RESEARCH NETWORK, INC.**

## **NOTES TO FINANCIAL STATEMENTS (CONTINUED)**

### **2. Summary of significant accounting policies (continued)**

#### **Grants and contributions:**

Grants and contributions, including unconditional promises to give, are recognized as revenue in the period the pledge or promise is received and recorded with donor restrictions or without donor restrictions depending on the existence and/or nature of any donor 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.

#### **Functional allocation of expenses:**

The costs of providing various programs and related supporting services have been summarized on a functional basis in the statements of activities. The statements of functional expenses present the natural classification of expenses by function. Accordingly, certain costs have been allocated among the programs and supporting services benefited. Therefore, expenses require allocation on a reasonable basis that is consistently applied. All expenses are reported using the direct allocation method.

#### **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 through December 17, 2019, the date the financial statements were available to be issued.

# **CYSTINOSIS RESEARCH NETWORK, INC.**

## **NOTES TO FINANCIAL STATEMENTS (CONTINUED)**

### **3. Liquidity and availability**

The following represents the Organization's financial assets available to meet general expenditures within one year:

<u>December 31, 2018</u>	
Financial asset at year-end:	
Cash	\$ 361,140
Less amount not available to be used within one year:	
Net assets with donor restrictions	<u>175,902</u>
Financial assets available to meet general expenditures within one year	<u>\$ 185,238</u>

The Organization manages available cash to meet general expenditures following the principles of maintaining financial stability, maintaining adequate liquid assets to fund near-term operating needs, and maintaining sufficient reserves to provide reasonable assurance that obligations will be discharged. The Organization strives to maintain working capital of approximately \$90,000, which is the average quarterly spending outside of family conference years. To achieve these targets, the Organization forecasts its future cash flows and monitors liquidity on a quarterly basis.

### **4. 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, 2018 and 2017.

### **5. Cash**

The Organization maintains its cash in bank accounts which, at times, exceeds federally-insured limits. The Organization had cash balances in excess of federally-insured limits of approximately \$140,000 at December 31, 2018. The Organization had no cash balances in excess of federally-insured limits at December 31, 2017. Management believes that the Organization is not exposed to any significant credit risk on cash.

# CYSTINOSIS RESEARCH NETWORK, INC.

## NOTES TO FINANCIAL STATEMENTS (CONTINUED)

### 6. Property and equipment

The components of property and equipment were as follows:

December 31,	2018	2017
Websites	\$ 20,000	\$ 20,000
Less accumulated depreciation	(18,610)	(15,277)
	1,390	4,723
Website not yet placed into operation	18,600	
Property and equipment, net	\$ 19,990	\$ 4,723

### 7. Conditional grant commitments for research projects

At December 31, 2018, 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 2017	Funding expensed in 2017	Funding expensed in 2018	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	\$ 51,334			\$ 25,667
Elena Levtchenko, MD, PhD	88,493		58,995		29,498
Steven Walkley, PhD	98,010	65,340	32,670		
Steven Walkley, PhD	100,980		67,320	33,660	
Steven Walkley, PhD	100,980			33,660	67,320
Totals	\$ 613,817	\$ 116,674	\$ 214,828	\$ 159,830	\$ 122,485

# **CYSTINOSIS RESEARCH NETWORK, INC.**

## **NOTES TO FINANCIAL STATEMENTS (CONTINUED)**

### **7. Conditional grant commitments for research projects (continued)**

Subsequent to year-end, the Organization awarded an additional grant totaling \$110,001 payable over three installments. The first installment of the grant of \$36,667 was expensed in 2019, leaving an additional conditional liability of \$73,334 as of December 17, 2019.

### **8. Net assets with donor restrictions**

Net assets with donor restrictions are available for the following purpose or time restrictions:

<u>December 31,</u>	<u>2018</u>	<u>2017</u>
Purpose restrictions:		
2019 Family Conference scholarships	\$ 80,000	
Comic book series	6,068	\$ 6,068
Family meetings	30,306	
Future by Design retreat	12,460	
Future by Design workshops	31,224	31,224
Newsletter	7,344	
Respite Care handbook	8,500	
Total	\$ 175,902	\$ 37,292

During the years ended December 31, 2018 and 2017, net assets were released from donor restrictions by incurring expenses satisfying the following purpose or time restrictions:

<u>Years ended December 31,</u>	<u>2018</u>	<u>2017</u>
Purpose restrictions:		
Comic book series		\$ 8,320
Family meetings	\$ 32,694	
Future by Design retreat	2,540	
Future by Design workshops		12,590
Newsletter	12,656	
Time restrictions		200,000
Total	\$ 47,890	\$ 220,910

# **CYSTINOSIS RESEARCH NETWORK, INC.**

## **NOTES TO FINANCIAL STATEMENTS (CONTINUED)**

### **9. Concentrations**

For the year ended December 31, 2018, two donors provided approximately 68% of the Organization's funding.

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