

**CYSTINOSIS RESEARCH
NETWORK, INC.**

FINANCIAL STATEMENTS

YEARS ENDED DECEMBER 31, 2020 AND 2019

CYSTINOSIS RESEARCH NETWORK, INC.

YEARS ENDED DECEMBER 31, 2020 AND 2019

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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, 2020 and 2019, 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, 2020 and 2019, 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 26, 2021

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENTS OF FINANCIAL POSITION

December 31,	2020	2019
ASSETS		
Cash	\$ 517,432	\$ 194,726
Prepaid expenses	14,850	6,850
Property and equipment, net	7,751	13,951
Total assets	\$ 540,033	\$ 215,527
LIABILITIES AND NET ASSETS		
Liabilities:		
Accounts payable and accrued expenses	\$ 17,444	\$ 18,527
Deferred revenue	10,882	12,001
Total liabilities	28,326	30,528
Net assets:		
Without donor restrictions	421,099	122,781
With donor restrictions	90,608	62,218
Total net assets	511,707	184,999
Total liabilities and net assets	\$ 540,033	\$ 215,527

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENTS OF ACTIVITIES

Years ended December 31,	2020			2019		
	Without donor restrictions	With donor restrictions	Total	Without donor restrictions	With donor restrictions	Total
Revenue:						
Grants	\$ 250,000		\$ 250,000	\$ 182,500		\$ 182,500
Contributions	73,513		73,513	49,679		49,679
Fundraising events	124,355	\$ 78,533	202,888	173,099		173,099
Interest income	1,096		1,096	3,292		3,292
Net assets released from restrictions	50,143	(50,143)		113,684	\$ (113,684)	
Total revenue	499,107	28,390	527,497	522,254	(113,684)	408,570
Expenses:						
Program services	114,279		114,279	513,105		513,105
Management and general	60,600		60,600	50,136		50,136
Fundraising	25,910		25,910	5,756		5,756
Total expenses	200,789		200,789	568,997		568,997
Change in net assets	298,318	28,390	326,708	(46,743)	(113,684)	(160,427)
Net assets:						
Beginning of year	122,781	62,218	184,999	169,524	175,902	345,426
End of year	\$ 421,099	\$ 90,608	\$ 511,707	\$ 122,781	\$ 62,218	\$ 184,999

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENTS OF FUNCTIONAL EXPENSES

Year ended December 31, 2020	Program Services			Supporting Services				
	Research	Education and Awareness	Family Support	Total program services	Management and general	Fundraising	Total supporting services	Total
Grants	\$ 33,660			\$ 33,660				\$ 33,660
Depreciation		\$ 6,200		6,200				6,200
Insurance and licenses					\$ 2,158		\$ 2,158	2,158
Marketing and promotion		21,075	\$ 150	21,225	11,520	\$ 12,625	24,145	45,370
Meetings and conferences		3,477	34	3,511		10,007	10,007	13,518
Professional fees					43,430		43,430	43,430
Scholarships and sponsorships		4,000	2,000	6,000				6,000
Supplies and other sundry expenses		42,410	1,273	43,683	3,492	3,278	6,770	50,453
Total expenses	\$ 33,660	\$ 77,162	\$ 3,457	\$ 114,279	\$ 60,600	\$ 25,910	\$ 86,510	\$ 200,789

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENTS OF FUNCTIONAL EXPENSES (CONTINUED)

Year ended December 31, 2019	Program Services			Supporting Services				Total
	Research	Education and Awareness	Family Support	Total program services	Management and general	Fundraising	Total supporting services	
Grants	\$ 136,492			\$ 136,492				\$ 136,492
Depreciation		\$ 6,039		6,039				6,039
Insurance and licenses					\$ 1,812		\$ 1,812	1,812
Marketing and promotion		11,142	\$ 3,040	14,182	14,715	\$ 3,313	18,028	32,210
Meetings and conferences		45,673	252,222	297,895				297,895
Professional fees			2,768	2,768	27,567		27,567	30,335
Scholarships and sponsorships		2,000		2,000				2,000
Supplies and other sundry expenses		30,507	23,222	53,729	6,042	2,443	8,485	62,214
Total expenses	\$ 136,492	\$ 95,361	\$ 281,252	\$ 513,105	\$ 50,136	\$ 5,756	\$ 55,892	\$ 568,997

See notes to financial statements.

CYSTINOSIS RESEARCH NETWORK, INC.

STATEMENTS OF CASH FLOWS

Years ended December 31,	2020	2019
Cash flows from operating activities:		
Change in net assets	\$ 326,708	\$ (160,427)
Adjustments to reconcile change in net assets to net cash provided by (used in) operating activities:		
Depreciation	6,200	6,039
(Increase) decrease in operating asset:		
Prepaid expenses	(8,000)	3,685
Increase (decrease) in operating liabilities:		
Accounts payable and accrued expenses	(1,083)	(27,712)
Deferred revenue	(1,119)	12,001
Net cash provided by (used in) operating activities	322,706	(166,414)
Net change in cash	322,706	(166,414)
Cash, beginning of year	194,726	361,140
Cash, end of year	\$ 517,432	\$ 194,726

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, 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 the 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.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

2. Summary of significant accounting policies (continued)

Recent accounting pronouncement:

The Organization adopted the provisions of Accounting Standards Update 2018-08, *Not-for-Profit Entities (Topic 958): Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made*, for the year ended December 31, 2019 for contributions received and for the year ended December 31, 2020 for contributions (grants) made. This guidance provides a more robust framework for determining whether a transaction should be accounted for as a contribution or as an exchange transaction. The guidance also helps determine whether a contribution is conditional and better distinguishes a donor-imposed condition from a donor-imposed restriction. The change in accounting principle was adopted on a modified prospective basis in 2019 for contributions received and in 2020 for contributions (grants) made. The adoption of this standard did not materially impact the financial statements of the Organization.

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.

Management reviews the carrying values of property and equipment for impairment whenever events or circumstances indicate that the carrying value of an asset may not be recoverable from the estimated future cash flows expected to result from its use and eventual disposition. When considered impaired, an impairment loss is recognized to the extent the carrying value exceeds the fair value of the asset. There were no indicators of asset impairment during 2020 and 2019.

Deferred revenue:

Deferred revenue of \$10,882 and \$12,001 as of December 31, 2020 and 2019, respectively, represents conditional contributions received for which the conditions have not yet been met (scholarships that have not yet been awarded). Accordingly, revenue from contributions and grants received are deferred until the conditions are met.

Grants and contributions:

Grants and contributions are recognized when cash, or other assets, an unconditional promise to give, or notification of a beneficial interest is received. Conditional promises to give are not recognized until the conditions on which they depend have been substantially met.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

2. Summary of significant accounting policies (continued)

Contributed goods and services:

Contributed goods and services are reported at fair value in the financial statements at the time of donation. Contributed services are reported when the services create or enhance nonfinancial assets or require specialized skills provided by individuals possessing those skills and are services which would be typically purchased if not provided by donation.

During the year ended December 31, 2020, the Organization received contributed goods of \$7,000 included in contributions revenue on the statements of activities and marketing and promotion expense allocated to fundraising on the statements of functional expense. The Organization did not receive contributed goods in 2019.

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 accordance 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 October 26, 2021, the date the financial statements were available to be issued.

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

3. COVID-19 impact

On March 11, 2020, the World Health Organization (WHO) recognized COVID-19 as a global pandemic, prompting many national, regional, and local governments to implement preventative or protective measures, such as travel and business restrictions, temporary store closures, and wide spread quarantines and stay-at-home orders. As a result, COVID-19 and the related restrictive measures have had a significant adverse impact upon many sectors of the economy.

The Organization was forced to suspend all in-person educational and networking events, forums, and workshops. Such events were either cancelled or reprogrammed to a virtual format including the 2021 family conference. COVID-19 has not had a negative impact on the Organization's financial position.

The Organization believes that the ultimate impact of the COVID-19 pandemic on its operating results, cash flows, and financial condition is likely to be determined by factors which are uncertain, unpredictable, and outside of the Organization's control. The situation surrounding COVID-19 remains fluid, and if disruptions do arise, they could adversely impact the Organization.

4. Liquidity and availability

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

<u>December 31,</u>	<u>2020</u>	<u>2019</u>
Financial asset at year-end:		
Cash	\$ 517,432	\$ 194,726
Less amount not available to be used within one year:		
Net assets with donor restrictions	90,608	62,218
Financial assets available to meet general expenditures within one year	\$ 426,824	\$ 132,508

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

4. Liquidity and availability (continued)

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 a working capital of at least \$90,000, which is the average quarterly spending outside of family conference years (the most recent in-person family conference was held during 2019). To achieve this target, the Organization forecasts its future cash flows and monitors liquidity by reviewing financial statements on a quarterly basis.

5. 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, 2020 and 2019.

6. 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 \$287,000 as of December 31, 2020. The Organization had no cash balance in excess of federally-insured limits as of December 31, 2019. Management believes that the Organization is not exposed to any significant credit risk on cash.

7. Property and equipment

The components of property and equipment were as follows:

<u>December 31,</u>	<u>2020</u>	<u>2019</u>
Websites	\$ 28,600	\$ 28,600
<u>Less accumulated depreciation</u>	<u>(20,849)</u>	<u>(14,649)</u>
<u>Property and equipment, net</u>	<u>\$ 7,751</u>	<u>\$ 13,951</u>

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

8. Conditional grant commitments for research projects

At December 31, 2020, the Organization has agreements with research institutions and 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 2019	Discontinued research in 2019	Funding expensed in 2019	Funding expensed in 2020	Conditional liability payable in future years
University of Rochester Medical Center	\$ 110,000			\$ 73,334		\$ 36,666
KU Leaven Research and Development	77,001	\$ 51,334	\$ 25,667			
KU Leaven Research and Development	88,493	58,995		29,498		
Albert Einstein College of Medicine	100,980	33,660		33,660	\$ 33,660	
Totals	\$ 376,474	\$ 143,989	\$ 25,667	\$ 136,492	\$ 33,660	\$ 36,666

In January and February 2021, the Organization awarded three additional grants totaling \$436,193 payable in future installments based on satisfactory progress reports. The first installments totaling \$138,071 were paid from January to March 2021.

9. Net assets with donor restrictions

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

December 31,	2020	2019
Purpose restrictions:		
Brighter Days program	\$ 14,696	
Family meetings	18,399	\$ 29,945
Future by Design workshops	23,773	23,773
Research grants	25,240	
Respite Care handbook	8,500	8,500
Total net assets with donor restrictions	\$ 90,608	\$ 62,218

CYSTINOSIS RESEARCH NETWORK, INC.

NOTES TO FINANCIAL STATEMENTS (CONTINUED)

9. Net assets with donor restrictions (continued)

During the years ended December 31, 2020 and 2019, net assets were released from donor restrictions by incurring expenses satisfying the following purpose restrictions:

<u>Years ended December 31,</u>	<u>2020</u>	<u>2019</u>
Purpose restrictions:		
2019 Family Conference		\$ 80,000
Brighter Days program	\$ 4,937	
Comic book series		6,068
Family meetings	11,546	361
Future by Design retreat		12,460
Future by Design workshops		7,451
Newsletter		7,344
Research grants	33,660	
Total net assets released from restrictions	\$ 50,143	\$ 113,684

10. Concentrations

For the year ended December 31, 2020, three donors provided approximately 68% of the Organization's funding. For the year ended December 31, 2019, three donors provided approximately 58% of the Organization's funding.

The Organization does not expect one of the donors to continue funding going forward. Grants and contributions from the donor were \$78,500 in 2020 and \$59,000 in 2019. The Organization expects to seek funding from other sources as needed to fund future operations.