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Form 990  Department of the Treasury Internal Revenue Service	Return of Organization Exempt From Income Tax Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except black lung benefit trust or private foundation)	OMB No 1545-0047 2011 Open to Public Inspection
	The organization may have to use a copy of this return to satisfy state reporting requirements	

A For the 2011 calendar year, or tax year beginning 01-01-2011 and ending 12-31-2011		D Employer identification number	
B Check if applicable ☐ Address change ☐ Name change ☐ Initial return ☐ Terminated ☐ Amended return ☐ Application pending		04-3323789 E Telephone number (866) 276-3669 G Gross receipts \$ 329,987	
C Name of organization CYSTINOSIS RESEARCH NETWORK INC Doing Business As Number and street (or P O box if mail is not delivered to street address) Room/suite 302 WHYTEGATE COURT City or town, state or country, and ZIP + 4 LAKE FOREST, IL 60045			
F Name and address of principal officer CHRISTY GREELEY 302 WHYTEGATE COURT LAKE FOREST, IL 60045		H(a) Is this a group return for affiliates? ☐ Yes ☒ No H(b) Are all affiliates included? ☐ Yes ☐ No If "No," attach a list (see instructions) H(c) Group exemption number ▶	
I Tax-exempt status ☒ 501(c)(3) ☐ 501(c) () ◀ (insert no) ☐ 4947(a)(1) or ☐ 527			
J Website: ▶ WWW.CYSTINOSIS.ORG			
K Form of organization ☒ Corporation ☐ Trust ☐ Association ☐ Other ▶		L Year of formation 1996	M State of legal domicile MA

Part I		Summary		
Activities & Governance	1 Briefly describe the organization's mission or most significant activities THE CYSTINOSIS RESEARCH NETWORK IS AN ALL VOLUNTEER, NON-PROFIT ORGANIZATION DEDICATED TO SUPPORTING AND ADVOCATING RESEARCH, PROVIDING FAMILY ASSISTANCE AND EDUCATING THE PUBLIC AND MEDICAL COMMUNITIES ABOUT CYSTINOSIS			
	2 Check this box ☒ if the organization discontinued its operations or disposed of more than 25% of its net assets			
	3 Number of voting members of the governing body (Part VI, line 1a)	3	23	
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	23	
	5 Total number of individuals employed in calendar year 2011 (Part V, line 2a)	5	0	
	6 Total number of volunteers (estimate if necessary)	6	75	
7a Total unrelated business revenue from Part VIII, column (C), line 12		7a	0	
b Net unrelated business taxable income from Form 990-T, line 34		7b	0	
Revenue			Prior Year	Current Year
	8	Contributions and grants (Part VIII, line 1h)	294,213	323,360
	9	Program service revenue (Part VIII, line 2g)	0	0
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	1,931	1,677
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	0	4,950
	12	Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	296,144	329,987
Expenses	13	Grants and similar amounts paid (Part IX, column (A), lines 1–3)	268,529	233,651
	14	Benefits paid to or for members (Part IX, column (A), line 4)	0	0
	15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)	0	0
	16a	Professional fundraising fees (Part IX, column (A), line 11e)	0	0
	b	Total fundraising expenses (Part IX, column (D), line 25) <u>24,117</u>		
	17	Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)	142,778	259,625
	18	Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25)	411,307	493,276
	19	Revenue less expenses Subtract line 18 from line 12	-115,163	-163,289
Net Assets or Fund Balances			Beginning of Current Year	End of Year
	20	Total assets (Part X, line 16)	490,728	214,241
	21	Total liabilities (Part X, line 26)	136,804	23,606
	22	Net assets or fund balances Subtract line 21 from line 20	353,924	190,635

Part II		Signature Block	
Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.			
Sign Here	***** Signature of officer		2012-11-13 Date
	JEFF LARIMORE, PRESIDENT Type or print name and title		
Paid Preparer's Use Only	Preparer's signature	JAMES G. QUAID	Date
	Check if self-employed	☒	Preparer's taxpayer identification number (see instructions) P00641738
	Firm's name (or yours if self-employed), address, and ZIP + 4	OSTROW REISIN BERK & ABRAMS LTD 455 N. CITYFRONT PLAZA DRIVE SUITE 1 CHICAGO, IL 606115313	
		EIN	36-2938874
		Phone no.	(312) 670-7444
May the IRS discuss this return with the preparer shown above? (see instructions) ☒ Yes ☐ No			

Part III

Statement of Program Service Accomplishments

Check if Schedule O contains a response to any question in this Part III

1

Briefly describe the organization's mission

THE CYSTINOSIS RESEARCH NETWORK IS AN ALL VOLUNTEER, NON-PROFIT ORGANIZATION DEDICATED TO SUPPORTING AND ADVOCATING RESEARCH, PROVIDING FAMILY ASSISTANCE AND EDUCATING THE PUBLIC AND MEDICAL COMMUNITIES ABOUT CYSTINOSIS

2

Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?

Yes

No

If "Yes," describe these new services on Schedule O

3

Did the organization cease conducting, or make significant changes in how it conducts, any program services?

Yes

No

If "Yes," describe these changes on Schedule O

4

Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses Section 501(c)(3) and 501(c)(4) organizations and section 4947(a)(1) trusts are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported

4a

(Code) (Expenses \$ 237,651 including grants of \$ 233,651) (Revenue \$)

THE ORGANIZATION ESTABLISHES AND FUNDS FELLOWSHIPS AND RESEARCH GRANTS FOCUSING ON CLINICAL AND RESEARCH TRAINING IN CYSTINOSIS

4b

(Code) (Expenses \$ 46,136 including grants of \$) (Revenue \$)

THE ORGANIZATION RAISES AWARENESS AND REINFORCES STRONG RELATIONSHIPS THROUGH REPRESENTATION AT NATIONAL MEDICAL CONFERENCES, AFFILIATION WITH OTHER ORGANIZATIONS, PUBLICATION OF PERIODIC NEWSLETTERS AND AWARDS OR EDUCATIONAL SCHOLARSHIPS TO INDIVIDUALS WITH CYSTINOSIS AND THEIR SIBLINGS

4c

(Code) (Expenses \$ 148,421 including grants of \$) (Revenue \$)

THE ORGANIZATION PROVIDES INFORMATION AND OPPORTUNITIES TO NETWORK FOR INDIVIDUALS WITH CYSTINOSIS AND THEIR FAMILIES THROUGH PARTICIPATION IN A BIENNIAL CONFERENCE ON CYSTINOSIS 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

4d

Other program services (Describe in Schedule O)

(Expenses \$ including grants of \$) (Revenue \$)

4e

Total program service expenses

\$ 432,208

Part IV

Checklist of Required Schedules

		Yes	No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A.</i> 	1	Yes
2	Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> (see instructions)? 	2	Yes
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I.</i>	3	No
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II.</i>	4	No
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? <i>If "Yes," complete Schedule C, Part III.</i>	5	No
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I.</i> 	6	No
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas or historic structures? <i>If "Yes," complete Schedule D, Part II.</i> 	7	No
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III.</i> 	8	No
9	Did the organization report an amount in Part X, line 21, serve as a custodian for amounts not listed in Part X, or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV.</i> 	9	No
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? <i>If "Yes," complete Schedule D, Part V.</i> 	10	No
11	If the organization's answer to any of the following questions is 'Yes,' then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable		
a	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI.</i> 	11a	No
b	Did the organization report an amount for investments—other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII.</i> 	11b	No
c	Did the organization report an amount for investments—program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII.</i> 	11c	No
d	Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX.</i> 	11d	No
e	Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X.</i> 	11e	No
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X.</i> 	11f	No
12a	Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI, XII, and XIII.</i> 	12a	Yes
b	Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered 'No' to line 12a, then completing Schedule D, Parts XI, XII, and XIII is optional.</i> 	12b	No
13	Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E.</i>	13	No
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a	No
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Part I.</i> 	14b	Yes
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization or entity located outside the U S ? <i>If "Yes," complete Schedule F, Part II and IV.</i> 	15	No
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or assistance to individuals located outside the U S ? <i>If "Yes," complete Schedule F, Part III and IV.</i> 	16	Yes
17	Did the organization report a total of more than \$15,000, of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I.</i>	17	No
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II.</i>	18	No
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III.</i>	19	No
20a	Did the organization operate one or more hospitals? <i>If "Yes," complete Schedule H.</i>	20a	No
b	If "Yes" to line 20a, did the organization attach its audited financial statement to this return? Note. All Form 990 filers that operated one or more hospitals must attach audited financial statements	20b	

Part IV

Checklist of Required Schedules (continued)

21	Did the organization report more than \$5,000 of grants and other assistance to governments and organizations in the United States on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21		No
22	Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22	Yes	
23	Did the organization answer "Yes" to Part VII, Section A, questions 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	23		No
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer questions 24b–24d and complete Schedule K. If "No," go to line 25</i>	24a		No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
25a	Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a		No
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>	25b		No
26	Was a loan to or by a current or former officer, director, trustee, key employee, highly compensated employee, or disqualified person outstanding as of the end of the organization's tax year? <i>If "Yes," complete Schedule L, Part II</i>	26		No
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor, or a grant selection committee member, or to a person related to such an individual? <i>If "Yes," complete Schedule L, Part III</i>	27		No
28	Was the organization a party to a business transaction with one of the following parties? (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)			
a	A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28a		No
b	A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28b		No
c	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or owner? <i>If "Yes," complete Schedule L, Part IV</i>	28c		No
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	29		No
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>	30		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31		No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>	32		No
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>	33		No
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Parts II, III, IV, and V, line 1</i>	34		No
35a	Is any related organization a controlled entity of the filing organization within the meaning of section 512(b)(13)?	35a		No
b	Did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35b		No
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	36		No
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>	37		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11 and 19? Note. All Form 990 filers are required to complete Schedule O	38	Yes	

Part V Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response to any question in this Part V

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable. .		
	1a4		
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable.		
	1b0		
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements filed for the calendar year ending with or within the year covered by this return.		
	2a0		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions).	2b	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a	No
b	If "Yes," has it filed a Form 990-T for this year? If "No," provide an explanation in Schedule O.	3b	
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account or securities account)?	4a	No
b	If "Yes," enter the name of the foreign country: _____ See instructions for filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a	No
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b	No
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c	
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible?	6a	No
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b	
7	Organizations that may receive deductible contributions under section 170(c).		
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7a	No
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c	No
d	If "Yes," indicate the number of Forms 8282 filed during the year.	7d	
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e	No
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f	No
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g	
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7h	
8	Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?	8	
9	Sponsoring organizations maintaining donor advised funds.		
a	Did the organization make any taxable distributions under section 4966?	9a	
b	Did the organization make a distribution to a donor, donor advisor, or related person?	9b	
10	Section 501(c)(7) organizations. Enter		
a	Initiation fees and capital contributions included on Part VIII, line 12.	10a	
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities.	10b	
11	Section 501(c)(12) organizations. Enter		
a	Gross income from members or shareholders.	11a	
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them).	11b	
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a	
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year.	12b	
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
a	Is the organization licensed to issue qualified health plans in more than one state? Note. All 501(c)(29) organizations must list in Schedule O each state in which they are licensed to issue qualified health plans, the amount of reserves required by each state, and the amount of reserves the organization allocated to each state.	13a	
b	Enter the aggregate amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans.	13b	
c	Enter the aggregate amount of reserves on hand.	13c	
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a	No
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O.	14b	

Part VI

Governance, Management, and Disclosure

For each "Yes" response to lines 2 through 7b below, and for a "No" response to lines 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O. See instructions.
Check if Schedule O contains a response to any question in this Part VI

Section A. Governing Body and Management

		Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year		
1b	Enter the number of voting members included in line 1a, above, who are independent		
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?		No
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?		No
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		No
5	Did the organization become aware during the year of a significant diversion of the organization's assets?		No
6	Did the organization have members or stockholders?		No
7a	Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?		No
7b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?		No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following		
8a	The governing body?	Yes	
8b	Each committee with authority to act on behalf of the governing body?	Yes	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O		No

Section B. Policies

(This Section B requests information about policies not required by the Internal Revenue Code.)

		Yes	No
10a	Did the organization have local chapters, branches, or affiliates?		No
10b	If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?		
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	Yes	
11b	Describe in Schedule O the process, if any, used by the organization to review the Form 990		
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13		No
12b	Were officers, directors or trustees, and key employees required to disclose annually interests that could give rise to conflicts?		
12c	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done		
13	Did the organization have a written whistleblower policy?		No
14	Did the organization have a written document retention and destruction policy?		No
15	Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?		
15a	The organization's CEO, Executive Director, or top management official		No
15b	Other officers or key employees of the organization		No
	If "Yes," to line 15a or 15b, describe the process in Schedule O (see instructions)		
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?		No
16b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?		

Section C. Disclosure

17	List the States with which a copy of this Form 990 is required to be filed	IL , MA
18	Section 6104 requires an organization to make its Form 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply. ☒ Own website ☐ Another's website ☒ Upon request	
19	Describe in Schedule O whether (and if so, how), the organization made its governing documents, conflict of interest policy, and financial statements available to the public. See Additional Data Table.	
20	State the name, physical address, and telephone number of the person who possesses the books and records of the organization.	LISA KOVAR 7784 5000E ROAD MANTENO,IL 60950 (815) 468-0172

Part VII

Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors

Check if Schedule O contains a response to any question in this Part VII

Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

1a Complete this table for all persons required to be listed Report compensation for the calendar year ending with or within the organization's tax year

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation, and **current** key employees Enter -0- in columns (D), (E), and (F) if no compensation was paid
- List all of the organization's **current** key employees, if any See instructions for definition of "key employee "
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations
- List all of the organization's **former** officers, key employees, or highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations

List persons in the following order individual trustees or directors, institutional trustees, officers, key employees, highest compensated employees, and former such persons

Check this box if neither the organization nor any related organizations compensated any current or former officer, director, or trustee

(A) Name and Title	(B) Average hours per week (describe hours for related organizations in Schedule O)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(1) CHRISTY GREELEY PRESIDENT & EXECUTIVE DIRECTOR	40 00	X		X				0	0	0
(2) PAM WOODWARD VICE PRESIDENT, FAMILY SUPPORT	5 00	X		X				0	0	0
(3) ELVA SMITH VICE PRESIDENT, RESEARCH	5 00	X		X				0	0	0
(4) PAULA SHAL VICE PRESIDENT, EDUCATION & AWARENESS	5 00	X		X				0	0	0
(5) JEN WYMAN VICE PRESIDENT, DEVELOPMENT	5 00	X		X				0	0	0
(6) JEFF LARIMORE TREASURER	5 00	X		X				0	0	0
(7) KAREN GLEDHILL SECRETARY	5 00	X		X				0	0	0
(8) COLLEEN HAMMOND DIRECTOR	5 00	X						0	0	0
(9) JESSICA JONDLE DIRECTOR	5 00	X						0	0	0
(10) RICH JORDAN DIRECTOR	5 00	X						0	0	0
(11) DAN JULIAN DIRECTOR	5 00	X						0	0	0
(12) JILL MORRILL DIRECTOR	5 00	X						0	0	0
(13) MARYBETH KRUMMENACKER DIRECTOR	5 00	X						0	0	0
(14) JOSE MORALES DIRECTOR	5 00	X						0	0	0
(15) BRITTNEY LEBEAU DIRECTOR	5 00	X						0	0	0
(16) JENNI SEXSTONE DIRECTOR	5 00	X						0	0	0
(17) JOHN MACCARONE DIRECTOR	5 00	X						0	0	0

Part VII

Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees (continued)

(A) Name and Title	(B) Average hours per week (describe hours for related organizations in Schedule O)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(18) JOHN SHEPPERD DIRECTOR	5 00	X						0	0	0
(19) KATHY M MANDREL DIRECTOR	5 00	X						0	0	0
(20) LORNA SMITH DIRECTOR	5 00	X						0	0	0
(21) MACK MAXWELL DIRECTOR	5 00	X						0	0	0
(22) FRANKIE MCGINNIS DIRECTOR	5 00	X						0	0	0
(23) TAHNIE WOODWARD DIRECTOR	5 00	X						0	0	0
1b Sub-Total										
c Total from continuation sheets to Part VII, Section A										
d Total (add lines 1b and 1c)								0	0	0

2

Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization▶0

		Yes	No
3	Did the organization list any former officer, director or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		No
4	For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? <i>If "Yes," complete Schedule J for such individual</i>		No
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		No

Section B. Independent Contractors

1

Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization Report compensation for the calendar year ending with or within the organization's tax year

(A) Name and business address	(B) Description of services	(C) Compensation

2

Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization ▶0

Part VIII

Statement of Revenue

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514
Contributions, gifts, grants and other similar amounts	1a	Federated campaigns . . .	1a				
	b	Membership dues	1b				
	c	Fundraising events	1c				
	d	Related organizations	1d				
	e	Government grants (contributions)	1e				
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	323,360			
	g	Noncash contributions included in lines 1a-1f \$ _____					
	h	Total. Add lines 1a-1f		323,360			
Program Service Revenue	2a		Business Code				
	b						
	c						
	d						
	e						
	f	All other program service revenue					
	g	Total. Add lines 2a-2f					
	Other Revenue	3	Investment income (including dividends, interest and other similar amounts)		1,677		
4		Income from investment of tax-exempt bond proceeds . .					
5		Royalties					
6a		Gross rents	(i) Real	(ii) Personal			
b		Less rental expenses					
c		Rental income or (loss)					
d		Net rental income or (loss)					
7a		Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other			
b		Less cost or other basis and sales expenses					
c		Gain or (loss)					
d		Net gain or (loss)					
8a		Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c) See Part IV, line 18	a				
b		Less direct expenses	b				
c		Net income or (loss) from fundraising events . .					
9a		Gross income from gaming activities See Part IV, line 19	a				
b		Less direct expenses	b				
c		Net income or (loss) from gaming activities . .					
10a		Gross sales of inventory, less returns and allowances	a				
b		Less cost of goods sold	b				
c		Net income or (loss) from sales of inventory . .					
Miscellaneous Revenue		Business Code					
11a	MISCELLANEOUS	900099	4,950			4,950	
b							
c							
d	All other revenue						
e	Total. Add lines 11a-11d		4,950				
12	Total revenue. See Instructions		329,987	0	0	6,627	

Part IX

Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns

All other organizations must complete column (A) but are not required to complete columns (B), (C), and (D)

Check if Schedule O contains a response to any question in this Part IX

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.		(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to governments and organizations in the United States See Part IV, line 21				
2	Grants and other assistance to individuals in the United States See Part IV, line 22	167,566	167,566		
3	Grants and other assistance to governments, organizations, and individuals outside the United States See Part IV, lines 15 and 16	66,085	66,085		
4	Benefits paid to or for members				
5	Compensation of current officers, directors, trustees, and key employees				
6	Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7	Other salaries and wages				
8	Pension plan contributions (include section 401(k) and section 403(b) employer contributions)				
9	Other employee benefits				
10	Payroll taxes				
11	Fees for services (non-employees)				
a	Management				
b	Legal				
c	Accounting	20,560		20,560	
d	Lobbying				
e	Professional fundraising See Part IV, line 17				
f	Investment management fees				
g	Other	16,178		8,089	8,089
12	Advertising and promotion				
13	Office expenses	19,510	11,406	5,915	2,189
14	Information technology				
15	Royalties				
16	Occupancy	3,610			3,610
17	Travel	45,201	38,594		6,607
18	Payments of travel or entertainment expenses for any federal, state, or local public officials				
19	Conferences, conventions, and meetings	112,288	112,288		
20	Interest				
21	Payments to affiliates				
22	Depreciation, depletion, and amortization				
23	Insurance	1,913		1,913	
24	Other expenses Itemize expenses not covered above (List miscellaneous expenses in line 24f If line 24f amount exceeds 10% of line 25, column (A) amount, list line 24f expenses on Schedule O)				
a	PRINTING & COPYING	21,043	21,043		
b	SPONSORSHIPS	8,800	8,800		
c	MISCELLANEOUS	5,346	1,340	474	3,532
d	EQUIPMENT RENTAL	5,176	5,086		90
e					
f	All other expenses				
25	Total functional expenses. Add lines 1 through 24f	493,276	432,208	36,951	24,117
26	Joint costs. Check here ☒ if following SOP 98-2 (ASC 958-720) Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation				

Part X

Balance Sheet

					(A)		(B)
					Beginning of year		End of year
Assets	1	Cash—non-interest-bearing			103,266	1	67,218
	2	Savings and temporary cash investments			374,062	2	145,001
	3	Pledges and grants receivable, net				3	
	4	Accounts receivable, net				4	
	5	Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L				5	
	6	Receivables from other disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) Complete Part II of Schedule L				6	
	7	Notes and loans receivable, net				7	
	8	Inventories for sale or use				8	
	9	Prepaid expenses and deferred charges			13,400	9	2,022
	10a	Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	10a			10c	
	b	Less accumulated depreciation	10b				
	11	Investments—publicly traded securities				11	
	12	Investments—other securities See Part IV, line 11				12	
	13	Investments—program-related See Part IV, line 11				13	
	14	Intangible assets				14	
	15	Other assets See Part IV, line 11				15	
	16	Total assets. Add lines 1 through 15 (must equal line 34)			490,728	16	214,241
Liabilities	17	Accounts payable and accrued expenses				17	7,039
	18	Grants payable			136,804	18	
	19	Deferred revenue				19	16,567
	20	Tax-exempt bond liabilities				20	
	21	Escrow or custodial account liability Complete Part IV of Schedule D				21	
	22	Payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons Complete Part II of Schedule L				22	
	23	Secured mortgages and notes payable to unrelated third parties				23	
	24	Unsecured notes and loans payable to unrelated third parties				24	
	25	Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24) Complete Part X of Schedule D				25	
	26	Total liabilities. Add lines 17 through 25			136,804	26	23,606
Net Assets or Fund Balances	Organizations that follow SFAS 117, check here ☒ and complete lines 27 through 29, and lines 33 and 34.						
	27	Unrestricted net assets			353,924	27	190,635
	28	Temporarily restricted net assets				28	
	29	Permanently restricted net assets				29	
	Organizations that do not follow SFAS 117, check here ☐ and complete lines 30 through 34.						
	30	Capital stock or trust principal, or current funds				30	
	31	Paid-in or capital surplus, or land, building or equipment fund				31	
	32	Retained earnings, endowment, accumulated income, or other funds				32	
	33	Total net assets or fund balances			353,924	33	190,635
	34	Total liabilities and net assets/fund balances			490,728	34	214,241

Part XI Reconciliation of Net Assets

Check if Schedule O contains a response to any question in this Part XI

1	Total revenue (must equal Part VIII, column (A), line 12)	1	329,987
2	Total expenses (must equal Part IX, column (A), line 25)	2	493,276
3	Revenue less expenses Subtract line 2 from line 1	3	-163,289
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	353,924
5	Other changes in net assets or fund balances (explain in Schedule O)	5	0
6	Net assets or fund balances at end of year Combine lines 3, 4, and 5 (must equal Part X, line 33, column (B))	6	190,635

Part XII Financial Statements and Reporting

Check if Schedule O contains a response to any question in this Part XII

		Yes	No
1	Accounting method used to prepare the Form 990 ☐ Cash ☒ Accrual ☐ Other If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O		
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?		No
b	Were the organization's financial statements audited by an independent accountant?	Yes	
c	If "Yes," to 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O	Yes	
d	If "Yes" to line 2a or 2b, check a box below to indicate whether the financial statements for the year were issued on a separate basis, consolidated basis, or both ☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separated basis		
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		No
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits		

SCHEDULE A

(Form 990 or 990EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.

▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

OMB No 1545-0047

2011

Open to Public
Inspection

Name of the organization CYSTINOSIS RESEARCH NETWORK INC	Employer identification number 04-3323789
---	--

Part I Reason for Public Charity Status (All organizations must complete this part.) See instructions

The organization is not a private foundation because it is (For lines 1 through 11, check only one box)

- 1

☐

A church, convention of churches, or association of churches **section 170(b)(1)(A)(i).**
- 2

☐

A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E)
- 3

☐

A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**
- 4

☐

A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state
- 5

☐

An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv).** (Complete Part II)
- 6

☐

A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**
- 7

☒

An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)** (Complete Part II)
- 8

☐

A community trust described in **section 170(b)(1)(A)(vi)** (Complete Part II)
- 9

☐

An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975 See **section 509(a)(2).** (Complete Part III)
- 10

☐

An organization organized and operated exclusively to test for public safety Se**section 509(a)(4).**
- 11

☐

An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2) See **section 509(a)(3).** Check the box that describes the type of supporting organization and complete lines 11e through 11h

a

☐

Type I

b

☐

Type II

c

☐

Type III - Functionally integrated

d

☐

Type III - Other

e

☐

By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2)

f

☐

If the organization received a written determination from the IRS that it is a Type I, Type II or Type III supporting organization, check this box

g

☐

Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?

(i)

a person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the the supported organization?

(ii)

a family member of a person described in (i) above?

(iii)

a 35% controlled entity of a person described in (i) or (ii) above?

h

☐

Provide the following information about the supported organization(s)

	Yes	No
11g(i)		
11g(ii)		
11g(iii)		

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 9 above or IRC section (see instructions))	(iv) Is the organization in col (i) listed in your governing document?		(v) Did you notify the organization in col (i) of your support?		(vi) Is the organization in col (i) organized in the U S ?		(vii) Amount of support?
			Yes	No	Yes	No	Yes	No	
Total									

Part II

Support Schedule for Organizations Described in IRC 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)
(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")	313,363	357,784	444,207	294,213	323,360	1,732,927
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	313,363	357,784	444,207	294,213	323,360	1,732,927
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						125,781
6 Public Support. Subtract line 5 from line 4						1,607,146

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
7 Amounts from line 4	313,363	357,784	444,207	294,213	323,360	1,732,927
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	2,371	9,365	3,666	1,931	1,677	19,010
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income (Explain in Part IV) Do not include gain or loss from the sale of capital assets			500		4,950	5,450
11 Total support (Add lines 7 through 10)						1,757,387

12 Gross receipts from related activities, etc (See instructions)

12

13 First Five Years If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here

Section C. Computation of Public Support Percentage

14 Public Support Percentage for 2011 (line 6 column (f) divided by line 11 column (f))	14	91 450 %
15 Public Support Percentage for 2010 Schedule A, Part II, line 14	15	98 680 %

16a 33 1/3% support test—2011. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization

b 33 1/3% support test—2010. If the organization did not check the box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization

17a 10%-facts-and-circumstances test—2011. If the organization did not check a box on line 13, 16a, or 16b and line 14 is 10% or more, and if the organization meets the "facts and circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts and circumstances" test The organization qualifies as a publicly supported organization

b 10%-facts-and-circumstances test—2010. If the organization did not check a box on line 13, 16a, 16b, or 17a and line 15 is 10% or more, and if the organization meets the "facts and circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts and circumstances" test The organization qualifies as a publicly supported organization

18 Private Foundation If the organization did not check a box on line 13, 16a, 16b, 17a or 17b, check this box and see instructions

Part IIIPart III

Support Schedule for Organizations Described in IRC 509(a)(2)
(Complete only if you checked the box on line 9 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support						
Calendar year (or fiscal year beginning in)	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public Support (Subtract line 7c from line 6)						

Section B. Total Support						
Calendar year (or fiscal year beginning in)	(a) 2007	(b) 2008	(c) 2009	(d) 2010	(e) 2011	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total support (Add lines 9, 10c, 11 and 12.)						
14 First Five Years If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here						

Section C. Computation of Public Support Percentage		
15 Public Support Percentage for 2011 (line 8 column (f) divided by line 13 column (f))	15	
16 Public support percentage from 2010 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage		
17 Investment income percentage for 2011 (line 10c column (f) divided by line 13 column (f))	17	
18 Investment income percentage from 2010 Schedule A, Part III, line 17	18	
19a 33 1/3% support tests—2011. If the organization did not check the box on line 14, and line 15 is more than 33 1/3% and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization		
b 33 1/3% support tests—2010. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization		
20 Private Foundation If the organization did not check a box on line 14, 19a or 19b, check this box and see instructions		

Part IV **Supplemental Information.** Supplemental Information. Complete this part to provide the explanation required by Part II, line 10; Part II, line 17a or 17b; or Part III, line 12. Also complete this part for any additional information. (See instructions).

Facts And Circumstances Test

Explanation

Additional Data

Software ID:
Software Version:
EIN: 04-3323789
Name: CYSTINOSIS RESEARCH NETWORK INC

Form 990, Special Condition Description:

Special Condition Description

SCHEDULE D
(Form 990)

Supplemental Financial Statements

Department of the Treasury
Internal Revenue Service

OMB No 1545-0047

2011

Open to Public Inspection

Complete if the organization answered "Yes," to Form 990, Part IV, line 6, 7, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b

Attach to Form 990. See separate instructions.

Name of the organization
CYSTINOSIS RESEARCH NETWORK INC

Employer identification number
04-3323789

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts. Complete if the organization answered "Yes" to Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1	Total number at end of year	
2	Aggregate contributions to (during year)	
3	Aggregate grants from (during year)	
4	Aggregate value at end of year	
5	Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control?	
	Yes No	
6	Did the organization inform all grantees, donors, and donor advisors in writing that grant funds may be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit	
	Yes No	

Part II Conservation Easements. Complete if the organization answered "Yes" to Form 990, Part IV, line 7.

1

Purpose(s) of conservation easements held by the organization (check all that apply)

Preservation of land for public use (e g , recreation or pleasure)

Protection of natural habitat

Preservation of open space

Preservation of an historically importantly land area

Preservation of a certified historic structure

2

Complete lines 2a–2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year

	Held at the End of the Year
a	Total number of conservation easements
b	Total acreage restricted by conservation easements
c	Number of conservation easements on a certified historic structure included in (a)
d	Number of conservation easements included in (c) acquired after 8/17/06

3

Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the taxable year

4

Number of states where property subject to conservation easement is located

5

Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?

Yes

No

6

Staff and volunteer hours devoted to monitoring, inspecting and enforcing conservation easements during the year

7

Amount of expenses incurred in monitoring, inspecting, and enforcing conservation easements during the year

\$

8

Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and 170(h)(4)(B)(ii)?

Yes

No

9

In Part XIV, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Complete if the organization answered "Yes" to Form 990, Part IV, line 8.

1a

If the organization elected, as permitted under SFAS 116, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education or research in furtherance of public service, provide, in Part XIV, the text of the footnote to its financial statements that describes these items

b

If the organization elected, as permitted under SFAS 116, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items

(i)

Revenues included in Form 990, Part VIII, line 1

\$

(ii)

Assets included in Form 990, Part X

\$

2

If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 relating to these items

a

Revenues included in Form 990, Part VIII, line 1

\$

b

Assets included in Form 990, Part X

\$

Part III

Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets (continued)

3

Using the organization's accession and other records, check any of the following that are a significant use of its collection items (check all that apply)

a

☐

Public exhibition

b

☐

Scholarly research

c

☐

Preservation for future generations

d

☐

Loan or exchange programs

e

☐

Other

4

Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIV

5

During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?

☐ Yes

☐ No

Part IV

Escrow and Custodial Arrangements. Complete if the organization answered "Yes" to Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

1a

Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?

☐ Yes

☐ No

b

If "Yes," explain the arrangement in Part XIV and complete the following table

	Amount
1c	
1d	
1e	
1f	

2a

Did the organization include an amount on Form 990, Part X, line 21?

☐ Yes

☐ No

b

If "Yes," explain the arrangement in Part XIV

Part V

Endowment Funds. Complete if the organization answered "Yes" to Form 990, Part IV, line 10.

	(a)Current Year	(b)Prior Year	(c)Two Years Back	(d)Three Years Back	(e)Four Years Back
1a	Beginning of year balance				
b	Contributions				
c	Investment earnings or losses				
d	Grants or scholarships				
e	Other expenditures for facilities and programs				
f	Administrative expenses				
g	End of year balance				

2

Provide the estimated percentage of the year end balance held as

a

Board designated or quasi-endowment ▶

b

Permanent endowment ▶

c

Term endowment ▶

3a

Are there endowment funds not in the possession of the organization that are held and administered for the organization by

	Yes	No
(i) unrelated organizations	3a(i)	
(ii) related organizations	3a(ii)	
b If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?	3b	

4

Describe in Part XIV the intended uses of the organization's endowment funds

Part VI

Land, Buildings, and Equipment. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b)Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment				
e Other				
Total. Add lines 1a-1e (Column (d) should equal Form 990, Part X, column (B), line 10(c).) ▶				0

Part XI Reconciliation of Change in Net Assets from Form 990 to Financial Statements

1	Total revenue (Form 990, Part VIII, column (A), line 12)	1	329,987
2	Total expenses (Form 990, Part IX, column (A), line 25)	2	493,276
3	Excess or (deficit) for the year Subtract line 2 from line 1	3	-163,289
4	Net unrealized gains (losses) on investments	4	
5	Donated services and use of facilities	5	
6	Investment expenses	6	
7	Prior period adjustments	7	
8	Other (Describe in Part XIV)	8	
9	Total adjustments (net) Add lines 4 - 8	9	
10	Excess or (deficit) for the year per financial statements Combine lines 3 and 9	10	-163,289

Part XII Reconciliation of Revenue per Audited Financial Statements With Revenue per Return

1	Total revenue, gains, and other support per audited financial statements	1	370,537
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12		
a	Net unrealized gains on investments	2a	
b	Donated services and use of facilities	2b	40,550
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIV)	2d	
e	Add lines 2a through 2d	2e	40,550
3	Subtract line 2e from line 1	3	329,987
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIV)	4b	
c	Add lines 4a and 4b	4c	0
5	Total Revenue Add lines 3 and 4c . (This should equal Form 990, Part I, line 12)	5	329,987

Part XIII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return

1	Total expenses and losses per audited financial statements	1	533,826
2	Amounts included on line 1 but not on Form 990, Part IX, line 25		
a	Donated services and use of facilities	2a	40,550
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIV)	2d	
e	Add lines 2a through 2d	2e	40,550
3	Subtract line 2e from line 1	3	493,276
4	Amounts included on Form 990, Part IX, line 25, but not on line 1 :		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIV)	4b	
c	Add lines 4a and 4b	4c	0
5	Total expenses Add lines 3 and 4c . (This should equal Form 990, Part I, line 18)	5	493,276

Part XIV Supplemental Information

Complete this part to provide the descriptions required for Part II, lines 3, 5, and 9, Part III, lines 1a and 4, Part IV, lines 1b and 2b, Part V, line 4, Part X, Part XI, line 8, Part XII, lines 2d and 4b, and Part XIII, lines 2d and 4b. Also complete this part to provide any additional information.

Identifier	Return Reference	Explanation
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SCHEDULE F
(Form 990)

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

► Complete if the organization answered "Yes" to Form 990,
Part IV, line 14b, 15, or 16.
► Attach to Form 990. ► See separate instructions.

OMB No 1545-0047

2011

Open to Public
Inspection

Name of the organization
CYSTINOSIS RESEARCH NETWORK INC

Employer identification number
04-3323789

Part I

General Information on Activities Outside the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 14b.

- 1 For grantmakers. Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? ☒ Yes ☐ No
- 2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of grant funds outside the United States
- 3 Activites per Region (Use Part V if additional space is needed)

(a) Region	(b) Number of offices in the region	(c) Number of employees or agents in region or independent contractors	(d) Activities conducted in region (by type) (e g , fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for region/investments in region
EUROPE (INCLUDING ICELAND & GREENLAND) -	0	0	GRANTS TO RECIPIENTS		66,085
3a Sub-total	0	0			66,085
b Total from continuation sheets to Part I	0	0			0
c Totals (add lines 3a and 3b)	0	0			66,085

[illegible]

3 Enter total number of other organizations or entities ►

Part III **Grants and Other Assistance to Individuals Outside the United States.** Complete if the organization answered "Yes" to Form 990, Part IV, line 16.
Use Part V if additional space is needed.

[illegible]

Part IV Foreign Forms

- 1

Was the organization a U S transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926 (see instructions for Form 926)*

☐

Yes

☒

No
- 2

Did the organization have an interest in a foreign trust during the tax year? *If " Yes," the organization may be required to file Form 3520 and/or Form 3520-A. (see instructions for Forms 3520 and 3520-A)*

☐

Yes

☒

No
- 3

Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons with respect to Certain Foreign Corporations. (see instructions for Form 5471)*

☐

Yes

☒

No
- 4

Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see instructions for Form 8621)*

☐

Yes

☒

No
- 5

Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons with respect to Certain Foreign Partnerships. (see instructions for Form 8865)*

☐

Yes

☒

No
- 6

Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to file Form 5713, International Boycott Report (see instructions for Form 5713).*

☐

Yes

☒

No

Supplemental Information
Complete this part to provide the information (see instructions) required in Part I, line 2, and any additional information.

Schedule F (Form 990) 2011

Schedule I
(Form 990)

Department of the Treasury
Internal Revenue Service

Grants and Other Assistance to Organizations,
Governments and Individuals in the United States

Complete if the organization answered "Yes," to Form 990, Part IV, line 21 or 22.
▶ Attach to Form 990

OMB No 1545-0047

2011

Open to Public
Inspection

Name of the organization
CYSTINOSIS RESEARCH NETWORK INC

Employer identification number
04-3323789

Part I

General Information on Grants and Assistance

- 1

Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?

☒ Yes ☐ No
- 2

Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States

Part II

Grants and Other Assistance to Governments and Organizations in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 21 for any recipient that received more than \$5,000. Check this box if no one recipient received more than \$5,000. Use Part IV and Schedule I-1 (Form 990) if additional space is needed ▶ ☐

(a) Name and address of organization or government	(b) EIN	(c) IRC Code section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance

2

Enter total number of section 501(c)(3) and government organizations listed in the line 1 table ▶

3

Enter total number of other organizations listed in the line 1 table ▶

Part III

Grants and Other Assistance to Individuals in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 22.
Use Schedule I-1 (Form 990) if additional space is needed.

(a)Type of grant or assistance	(b)Number of recipients	(c)Amount of cash grant	(d)Amount of non-cash assistance	(e)Method of valuation (book, FMV, appraisal, other)	(f)Description of non-cash assistance
(1) RESEARCH GRANTS	2	167,566			

Part IV

Supplemental Information. Complete this part to provide the information required in Part I, line 2, and any other additional information.

Identifier	Return Reference	Explanation
PROCEDURE FOR MONITORING GRANTS IN THE U S	PART I, LINE 2	SCHEDULE I, PART I, LINE 2 ALL GRANTS ARE REVIEWED BY A SCIENTIFIC REVIEW BOARD OF PHYSICIANS FAMILIAR WITH CYSTINOSIS PER GRANT AGREEMENT, RESEARCHERS ARE TO PROVIDE PERIODIC PROGRESS REPORTS SHOWING RESEARCH PROGRESS AND EXPENSES INCURRED THUS FAR

SCHEDULE O

(Form 990 or 990-EZ)

Department of the Treasury

Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

Complete to provide information for responses to specific questions on

Form 990 or to provide any additional information.

▶ Attach to Form 990 or 990-EZ.

OMB No 1545-0047

2011

Open to Public

Inspection

Name of the organization

CYSTINOSIS RESEARCH NETWORK INC

Employer identification number

04-3323789

Identifier	Return Reference	Explanation
	FORM 990, PART VI, SECTION B, LINE 11	THE DRAFT COPY OF FORM 990 IS REVIEWED BY THE TREASURER AND REQUESTS TO REVIEW WILL BE MADE TO THE EXECUTIVE COMMITTEE PRIOR TO SIGNATURE BY THE TREASURER OR EXECUTIVE DIRECTOR A COPY OF THE FINAL FORM 990 IS PROVIDED TO ALL BOARD MEMBERS PRIOR TO FILING
	FORM 990, PART VI, SECTION C, LINE 19	ALL AVAILABLE UPON REQUEST OF EXECUTIVE DIRECTOR
	FORM 990, PART VI, SECTION B, LINE 15	THE ORGANIZATION DID NOT COMPENSATE ANY INDIVIDUALS DURING THE YEAR