

# PUBLIC DISCLOSURE COPY

Form **990**

## 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

2012

Department of the Treasury  
Internal Revenue Service

▶ The organization may have to use a copy of this return to satisfy state reporting requirements.

Open to Public Inspection

<b>A For the 2012 calendar year, or tax year beginning and ending</b>																																	
<b>B</b> Check if applicable:  <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td colspan="2"><b>C Name of organization</b> <b>CYSTINOSIS RESEARCH NETWORK, INC.</b></td> <td rowspan="2"><b>D Employer identification number</b>  04-3323789</td> </tr> <tr> <td colspan="2">Doing Business As</td> </tr> <tr> <td>Number and street (or P.O. box if mail is not delivered to street address)</td> <td>Room/suite</td> <td rowspan="2"><b>E Telephone number</b>  866-276-3669</td> </tr> <tr> <td colspan="2"><b>302 WHYTEGATE COURT</b></td> </tr> <tr> <td colspan="2">City, town, or post office, state, and ZIP code</td> <td rowspan="2"><b>G Gross receipts \$</b> 370,984.</td> </tr> <tr> <td colspan="2"><b>LAKE FOREST, IL 60045</b></td> </tr> <tr> <td colspan="2"><b>F Name and address of principal officer: CHRISTY GREELEY</b></td> <td rowspan="2"><b>H(a) Is this a group return for affiliates?</b> <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No</td> </tr> <tr> <td colspan="2"><b>SAME AS C ABOVE</b></td> </tr> <tr> <td colspan="2"><b>I Tax-exempt status:</b> <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) ( ) ◀ (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527</td> <td><b>H(b) Are all affiliates included?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No</td> </tr> <tr> <td colspan="2"><b>J Website:</b> ▶ WWW.CYSTINOSIS.ORG</td> <td>If "No," attach a list. (see instructions)</td> </tr> <tr> <td colspan="2"><b>K Form of organization:</b> <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶</td> <td><b>H(c) Group exemption number</b> ▶</td> </tr> <tr> <td colspan="2"><b>L Year of formation:</b> 1996</td> <td><b>M State of legal domicile:</b> MA</td> </tr> </table>	<b>C Name of organization</b> <b>CYSTINOSIS RESEARCH NETWORK, INC.</b>		<b>D Employer identification number</b>  04-3323789	Doing Business As		Number and street (or P.O. box if mail is not delivered to street address)	Room/suite	<b>E Telephone number</b>  866-276-3669	<b>302 WHYTEGATE COURT</b>		City, town, or post office, state, and ZIP code		<b>G Gross receipts \$</b> 370,984.	<b>LAKE FOREST, IL 60045</b>		<b>F Name and address of principal officer: CHRISTY GREELEY</b>		<b>H(a) Is this a group return for affiliates?</b> <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	<b>SAME AS C ABOVE</b>		<b>I Tax-exempt status:</b> <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) ( ) ◀ (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527		<b>H(b) Are all affiliates included?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No	<b>J Website:</b> ▶ WWW.CYSTINOSIS.ORG		If "No," attach a list. (see instructions)	<b>K Form of organization:</b> <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶		<b>H(c) Group exemption number</b> ▶	<b>L Year of formation:</b> 1996		<b>M State of legal domicile:</b> MA
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<b>Part I Summary</b>		
	1 Briefly describe the organization's mission or most significant activities: <u>SEE SCHEDULE O</u>	
Activities & Governance	2 Check this box <input type="checkbox"/> 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 17
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4 17
	5 Total number of individuals employed in calendar year 2012 (Part V, line 2a)	5 0
	6 Total number of volunteers (estimate if necessary)	6 17
	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	8 Contributions and grants (Part VIII, line 1h)	Prior Year 323,360. Current Year 370,565.
	9 Program service revenue (Part VIII, line 2g)	0. 0.
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	1,677. 419.
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	4,950. 0.
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	329,987. 370,984.
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	233,651. 325,078.
	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) ▶ 28,358.	
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	259,625. 143,670.	
18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	493,276. 468,748.	
19 Revenue less expenses. Subtract line 18 from line 12	-163,289. -97,764.	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year 214,241. End of Year 128,654.
	21 Total liabilities (Part X, line 26)	23,606. 35,783.
	22 Net assets or fund balances. Subtract line 21 from line 20	190,635. 92,871.

<b>Part II Signature Block</b>				
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	Date		
	▶ <b>JEFF LARIMORE, PRESIDENT</b>	Type or print name and title		
Paid Preparer Use Only	Print/Type preparer's name	Preparer's signature	Date	Check if self-employed <input type="checkbox"/> PTIN
	<b>JAMES G. QUAID</b>			<b>P00641738</b>
	Firm's name ▶ <b>OSTROW REISIN BERK &amp; ABRAMS, LTD.</b>	Firm's EIN ▶ <b>36-2938874</b>		
	Firm's address ▶ <b>455 N. CITYFRONT PLAZA DRIVE, SUITE 1500 CHICAGO, IL 60611-5313</b>	Phone no. <b>312-670-7444</b>		

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

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? Yes No

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 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 \$ 325,125. including grants of \$ 325,078. ) (Revenue \$ ) THE ORGANIZATION ESTABLISHES AND FUNDS FELLOWSHIPS AND RESEARCH GRANTS FOCUSING ON CLINICAL AND RESEARCH TRAINING IN CYSTINOSIS.

4b (Code: ) (Expenses \$ 80,591. 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 \$ 4,217. 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 409,933.

**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> .....	X	
2	Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ? .....	X	
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> .....		X
4	<b>Section 501(c)(3) organizations.</b> 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> .....		X
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> .....		X
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> .....		X
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> .....		X
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> .....		X
9	Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; 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> .....		X
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> .....		X
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> .....		X
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> .....		X
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> .....		X
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> .....		X
e	Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i> .....		X
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> .....		X
12a	Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i> .....	X	
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 and XII is optional</i> .....		X
13	Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i> .....		X
14a	Did the organization maintain an office, employees, or agents outside of the United States? .....		X
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, Parts I and IV</i> .....	X	
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 United States? <i>If "Yes," complete Schedule F, Parts II and IV</i> .....		X
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 United States? <i>If "Yes," complete Schedule F, Parts III and IV</i> .....	X	
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> .....		X
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> .....		X
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> .....		X
20a	Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i> .....		X
b	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? .....		

**Part IV Checklist of Required Schedules** (continued)

	Yes	No
<b>21</b> Did the organization report more than \$5,000 of grants and other assistance to any government or organization in the United States on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i> .....		X
<b>22</b> 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> .....	X	
<b>23</b> Did the organization answer "Yes" to Part VII, Section A, line 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> .....		X
<b>24a</b> 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 lines 24b through 24d and complete Schedule K. If "No," go to line 25</i> .....		X
<b>b</b> Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? .....		
<b>c</b> Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds? .....		
<b>d</b> Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? .....		
<b>25a Section 501(c)(3) and 501(c)(4) organizations.</b> 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> .....		X
<b>b</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> .....		X
<b>26</b> Was a loan to or by a current or former officer, director, trustee, key employee, highest 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> .....		X
<b>27</b> Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i> .....		X
<b>28</b> 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):		
<b>a</b> A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i> .....		X
<b>b</b> A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i> .....		X
<b>c</b> 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 direct or indirect owner? <i>If "Yes," complete Schedule L, Part IV</i> .....		X
<b>29</b> Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i> .....		X
<b>30</b> Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i> .....		X
<b>31</b> Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i> .....		X
<b>32</b> 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> .....		X
<b>33</b> 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> .....		X
<b>34</b> Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i> .....		X
<b>35a</b> Did the organization have a controlled entity within the meaning of section 512(b)(13)? .....		X
<b>b</b> If "Yes" to line 35a, 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> .....		
<b>36 Section 501(c)(3) organizations.</b> Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i> .....		X
<b>37</b> 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> .....		X
<b>38</b> Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? .....	X	

**Note.** All Form 990 filers are required to complete Schedule O .....

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

Input box for Schedule O response

Main table with columns for question ID, description, and Yes/No responses. Includes questions 1a through 14b regarding Form 1096, Form W-2G, backup withholding, Form W-3, foreign accounts, prohibited tax shelter transactions, and 501(c)(7), (12), and (29) organizations.

**Part VI Governance, Management, and Disclosure** For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 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
<b>1a</b>	Enter the number of voting members of the governing body at the end of the tax year ..... If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O.	17	
<b>b</b>	Enter the number of voting members included in line 1a, above, who are independent .....	17	
<b>2</b>	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? .....		X
<b>3</b>	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? .....		X
<b>4</b>	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? .....		X
<b>5</b>	Did the organization become aware during the year of a significant diversion of the organization's assets? .....		X
<b>6</b>	Did the organization have members or stockholders? .....		X
<b>7a</b>	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? .....		X
<b>b</b>	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? .....		X
<b>8</b>	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
<b>a</b>	The governing body? .....	X	
<b>b</b>	Each committee with authority to act on behalf of the governing body? .....		X
<b>9</b>	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 .....		X

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

		Yes	No
<b>10a</b>	Did the organization have local chapters, branches, or affiliates? .....		X
<b>b</b>	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? .....		
<b>11a</b>	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? .....	X	
<b>b</b>	Describe in Schedule O the process, if any, used by the organization to review this Form 990. ....		
<b>12a</b>	Did the organization have a written conflict of interest policy? If "No," go to line 13 .....		X
<b>b</b>	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? .....		
<b>c</b>	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done .....		
<b>13</b>	Did the organization have a written whistleblower policy? .....		X
<b>14</b>	Did the organization have a written document retention and destruction policy? .....		X
<b>15</b>	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?		
<b>a</b>	The organization's CEO, Executive Director, or top management official .....		X
<b>b</b>	Other officers or key employees of the organization .....		X
	If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions). ....		
<b>16a</b>	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? .....		X
<b>b</b>	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 Forms 1023 (or 1024 if applicable), 990, and 990-T (Section 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     Other (explain in Schedule O)
- 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 during the tax year.
- 20** State the name, physical address, and telephone number of the person who possesses the books and records of the organization: **LISA KOVAR - 815-468-0172**  
**7784 5000E ROAD, MANTENO, IL 60950**

**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. 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, and 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 organization compensated any current officer, director, or trustee.

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below line)	(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) JEFF LARIMORE PRESIDENT	20.00	X		X			0.	0.	0.	
(2) COLLEEN HAMMOND VICE PRESIDENT, RESEARCH	10.00	X		X			0.	0.	0.	
(3) JESSICA JONDLE VICE PRESIDENT, AWARENESS	5.00	X		X			0.	0.	0.	
(4) JOSE MORALES VICE PRESIDENT, DEVELOPMENT	5.00	X		X			0.	0.	0.	
(5) PAM WOODWARD VICE PRESIDENT, FAMILY SUPPORT	5.00	X		X			0.	0.	0.	
(6) JENNI SEXSTONE TREASURER	5.00	X		X			0.	0.	0.	
(7) TERRI SCHLEUDER SECRETARY	5.00	X		X			0.	0.	0.	
(8) CHRISTY GREELEY EXECUTIVE DIRECTOR	20.00	X		X			0.	0.	0.	
(9) RACHEL DELOMBA DIRECTOR	5.00	X					0.	0.	0.	
(10) RICH JORDAN DIRECTOR	5.00	X					0.	0.	0.	
(11) MARYBETH KRUMMENACKER DIRECTOR	5.00	X					0.	0.	0.	
(12) BRITTNEY LEBEAU DIRECTOR	5.00	X					0.	0.	0.	
(13) JOHN MACCARONE DIRECTOR	5.00	X					0.	0.	0.	
(14) KATHY M. MANDREL DIRECTOR	5.00	X					0.	0.	0.	
(15) DEB REED DIRECTOR	5.00	X					0.	0.	0.	
(16) LYNN THOMAS DIRECTOR	5.00	X					0.	0.	0.	
(17) TAHNIE WOODWARD DIRECTOR	5.00	X					0.	0.	0.	

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

Table with 6 main columns: (A) Name and title, (B) Average hours per week, (C) Position (Individual trustee or director, Institutional trustee, Officer, Key employee, Highest compensated employee, Former), (D) Reportable compensation from the organization, (E) Reportable compensation from related organizations, (F) Estimated amount of other compensation. Includes sub-totals for 1b, 1c, and 1d.

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

Table with 3 columns: Question number, Question text, Yes/No columns. Questions 3, 4, and 5 regarding compensation reporting.

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.

Table with 3 columns: (A) Name and business address, (B) Description of services, (C) Compensation. Row 1 contains 'NONE' in column A.

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**

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

		(A)	(B)	(C)	(D)	
		Total revenue	Related or exempt function revenue	Unrelated business revenue	Revenue excluded from tax under sections 512, 513, or 514	
Contributions, Gifts, Grants and Other Similar Amounts	1 a 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 370,565.				
	g Noncash contributions included in lines 1a-1f: \$					
	h Total. Add lines 1a-1f	▶ 370,565.				
	Program Service Revenue	Business Code				
2 a						
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)	▶	419.		419.	
	4 Income from investment of tax-exempt bond proceeds	▶				
	5 Royalties	▶				
	6 a Gross rents	(i) Real				
		(ii) Personal				
		b Less: rental expenses				
		c Rental income or (loss)				
	d Net rental income or (loss)	▶				
	7 a 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)	▶				
	8 a 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		▶				
9 a Gross income from gaming activities. See Part IV, line 19	a					
	b Less: direct expenses	b				
	c Net income or (loss) from gaming activities	▶				
10 a 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				
11 a						
	b					
	c					
	d All other revenue					
	e Total. Add lines 11a-11d	▶				
12 Total revenue. See instructions.	▶	370,984.	0.	0.	419.	

**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).

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
<b>1</b> Grants and other assistance to governments and organizations in the United States. See Part IV, line 21				
<b>2</b> Grants and other assistance to individuals in the United States. See Part IV, line 22	229,790.	229,790.		
<b>3</b> Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16	95,288.	95,288.		
<b>4</b> Benefits paid to or for members				
<b>5</b> Compensation of current officers, directors, trustees, and key employees				
<b>6</b> Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
<b>7</b> Other salaries and wages				
<b>8</b> Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
<b>9</b> Other employee benefits				
<b>10</b> Payroll taxes				
<b>11</b> Fees for services (non-employees):				
<b>a</b> Management				
<b>b</b> Legal				
<b>c</b> Accounting	16,300.		16,300.	
<b>d</b> Lobbying				
<b>e</b> Professional fundraising services. See Part IV, line 17				
<b>f</b> Investment management fees				
<b>g</b> Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Sch O.)	7,510.		3,755.	3,755.
<b>12</b> Advertising and promotion	33,000.	26,400.		6,600.
<b>13</b> Office expenses	12,339.	2,745.	5,455.	4,139.
<b>14</b> Information technology				
<b>15</b> Royalties				
<b>16</b> Occupancy	3,040.			3,040.
<b>17</b> Travel	19,353.	16,224.	441.	2,688.
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials				
<b>19</b> Conferences, conventions, and meetings	5,124.	5,124.		
<b>20</b> Interest				
<b>21</b> Payments to affiliates				
<b>22</b> Depreciation, depletion, and amortization				
<b>23</b> Insurance	3,037.		3,037.	
<b>24</b> Other expenses. Itemize expenses not covered above. (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
<b>a</b> PRINTING & COPYING	31,561.	28,862.	426.	2,273.
<b>b</b> MISCELLANEOUS	6,906.		1,043.	5,863.
<b>c</b> SPONSORSHIPS	5,500.	5,500.		
<b>d</b>				
<b>e</b> All other expenses				
<b>25</b> Total functional expenses. Add lines 1 through 24e	468,748.	409,933.	30,457.	28,358.
<b>26</b> Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.				

Check here  if following SOP 98-2 (ASC 958-720)

**Part X Balance Sheet**

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

		(A) Beginning of year		(B) End of year
<b>Assets</b>	<b>1</b> Cash - non-interest-bearing .....	67,218.	<b>1</b>	12,606.
	<b>2</b> Savings and temporary cash investments .....	145,001.	<b>2</b>	90,048.
	<b>3</b> Pledges and grants receivable, net .....		<b>3</b>	20,000.
	<b>4</b> Accounts receivable, net .....		<b>4</b>	
	<b>5</b> Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L .....		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instr). Complete Part II of Sch L .....		<b>6</b>	
	<b>7</b> Notes and loans receivable, net .....		<b>7</b>	
	<b>8</b> Inventories for sale or use .....		<b>8</b>	
	<b>9</b> Prepaid expenses and deferred charges .....	2,022.	<b>9</b>	
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D .....	<b>10a</b>		
	<b>b</b> Less: accumulated depreciation .....	<b>10b</b>	<b>10c</b>	
	<b>11</b> Investments - publicly traded securities .....		<b>11</b>	
	<b>12</b> Investments - other securities. See Part IV, line 11 .....		<b>12</b>	
	<b>13</b> Investments - program-related. See Part IV, line 11 .....		<b>13</b>	
	<b>14</b> Intangible assets .....		<b>14</b>	
	<b>15</b> Other assets. See Part IV, line 11 .....	0.	<b>15</b>	6,000.
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 34) .....	214,241.	<b>16</b>	128,654.	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses .....	7,039.	<b>17</b>	14,318.
	<b>18</b> Grants payable .....		<b>18</b>	21,465.
	<b>19</b> Deferred revenue .....	16,567.	<b>19</b>	
	<b>20</b> Tax-exempt bond liabilities .....		<b>20</b>	
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D .....		<b>21</b>	
	<b>22</b> Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L .....		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties .....		<b>23</b>	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties .....		<b>24</b>	
	<b>25</b> 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 .....		<b>25</b>	
	<b>26 Total liabilities.</b> Add lines 17 through 25 .....	23,606.	<b>26</b>	35,783.
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow SFAS 117 (ASC 958), check here</b> <input checked="" type="checkbox"/> <b>and complete lines 27 through 29, and lines 33 and 34.</b>			
	<b>27</b> Unrestricted net assets .....	190,635.	<b>27</b>	92,871.
	<b>28</b> Temporarily restricted net assets .....		<b>28</b>	
	<b>29</b> Permanently restricted net assets .....		<b>29</b>	
	<b>Organizations that do not follow SFAS 117 (ASC 958), check here</b> <input type="checkbox"/> <b>and complete lines 30 through 34.</b>			
	<b>30</b> Capital stock or trust principal, or current funds .....		<b>30</b>	
	<b>31</b> Paid-in or capital surplus, or land, building, or equipment fund .....		<b>31</b>	
	<b>32</b> Retained earnings, endowment, accumulated income, or other funds .....		<b>32</b>	
<b>33</b> Total net assets or fund balances .....	190,635.	<b>33</b>	92,871.	
<b>34</b> Total liabilities and net assets/fund balances .....	214,241.	<b>34</b>	128,654.	

**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	370,984.
2	Total expenses (must equal Part IX, column (A), line 25)	2	468,748.
3	Revenue less expenses. Subtract line 2 from line 1	3	-97,764.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	190,635.
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	92,871.

**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: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> 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? If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		X
2b	Were the organization's financial statements audited by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	X	
2c	If "Yes" to line 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.	X	
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?		X
3b	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		

Form 990 (2012)

SCHEDULE A
(Form 990 or 990-EZ)

Public Charity Status and Public Support

OMB No. 1545-0047

2012

Department of the Treasury
Internal Revenue Service

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.

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 described in 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 [X] 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. See 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 - Non-functionally integrated
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 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).

Table with 3 columns: Question (11g(i), 11g(ii), 11g(iii)), Yes, No. All cells are empty.

Table with 7 main columns: (i) Name of supported organization, (ii) EIN, (iii) Type of organization, (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 monetary support. Includes a Total row at the bottom.

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ. Schedule A (Form 990 or 990-EZ) 2012

**Part II Support Schedule for Organizations Described in Sections 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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....	357,784.	444,207.	294,213.	323,360.	370,565.	1790129.
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 <b>Total.</b> Add lines 1 through 3 .....	357,784.	444,207.	294,213.	323,360.	370,565.	1790129.
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) .....						106,863.
6 <b>Public support.</b> Subtract line 5 from line 4.						1683266.

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
7 Amounts from line 4 .....	357,784.	444,207.	294,213.	323,360.	370,565.	1790129.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources .....	9,365.	3,666.	1,931.	1,677.	419.	17,058.
9 Net income from unrelated business activities, whether or not the business is regularly carried on .....						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.) .....		500.		4,950.		5,450.
11 <b>Total support.</b> Add lines 7 through 10						1812637.
12 Gross receipts from related activities, etc. (see instructions) .....					12	
13 <b>First five years.</b> If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and <b>stop here</b> .....	<input type="checkbox"/>					

**Section C. Computation of Public Support Percentage**

14 Public support percentage for 2012 (line 6, column (f) divided by line 11, column (f)) .....	14	92.86	%
15 Public support percentage from 2011 Schedule A, Part II, line 14 .....	15	91.45	%
16a <b>33 1/3% support test - 2012.</b> If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and <b>stop here.</b> The organization qualifies as a publicly supported organization .....	<input checked="" type="checkbox"/>		
b <b>33 1/3% support test - 2011.</b> If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and <b>stop here.</b> The organization qualifies as a publicly supported organization .....	<input type="checkbox"/>		
17a <b>10% -facts-and-circumstances test - 2012.</b> 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 <b>stop here.</b> Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization .....	<input type="checkbox"/>		
b <b>10% -facts-and-circumstances test - 2011.</b> 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 <b>stop here.</b> Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization .....	<input type="checkbox"/>		
18 <b>Private foundation.</b> If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions .....	<input type="checkbox"/>		

**Part III Support Schedule for Organizations Described in Section 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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....						
<b>2</b> 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 .....						
<b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513 .....						
<b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf .....						
<b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge .....						
<b>6 Total.</b> Add lines 1 through 5 .....						
<b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons .....						
<b>b</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 .....						
<b>c</b> Add lines 7a and 7b .....						
<b>8 Public support.</b> (Subtract line 7c from line 6.)						

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
<b>9</b> Amounts from line 6 .....						
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources .....						
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 .....						
<b>c</b> Add lines 10a and 10b .....						
<b>11</b> Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on .....						
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.) .....						
<b>13 Total support.</b> (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 section 501(c)(3) organization, check this box and **stop here**

**Section C. Computation of Public Support Percentage**

<b>15</b> Public support percentage for 2012 (line 8, column (f) divided by line 13, column (f)) .....	<b>15</b>	%
<b>16</b> Public support percentage from 2011 Schedule A, Part III, line 15 .....	<b>16</b>	%

**Section D. Computation of Investment Income Percentage**

<b>17</b> Investment income percentage for 2012 (line 10c, column (f) divided by line 13, column (f)) .....	<b>17</b>	%
<b>18</b> Investment income percentage from 2011 Schedule A, Part III, line 17 .....	<b>18</b>	%

**19a 33 1/3% support tests - 2012.** 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 - 2011.** 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

**SCHEDULE D**  
**(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Supplemental Financial Statements**

▶ Complete if the organization answered "Yes," to Form 990,  
Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.

▶ Attach to Form 990. ▶ See separate instructions.

OMB No. 1545-0047

**2012**

Open to Public  
Inspection

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? .....		<input type="checkbox"/> Yes <input type="checkbox"/> No
6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can 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? .....		<input type="checkbox"/> Yes <input type="checkbox"/> 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 education)       Preservation of an historically important land area

Protection of natural habitat       Preservation of a certified historic structure

Preservation of open space

2 Complete lines 2a through 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 Tax Year
a Total number of conservation easements .....	2a
b Total acreage restricted by conservation easements .....	2b
c Number of conservation easements on a certified historic structure included in (a) .....	2c
d Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register .....	2d

3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax 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 section 170(h)(4)(B)(ii)? .....

Yes  No

9 In Part XIII, 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 (ASC 958), 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 XIII, the text of the footnote to its financial statements that describes these items.

b If the organization elected, as permitted under SFAS 116 (ASC 958), 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 (ASC 958) 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 acquisition, 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 XIII.
- 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 XIII and complete the following table:

	Amount
c Beginning balance	<b>1c</b>
d Additions during the year	<b>1d</b>
e Distributions during the year	<b>1e</b>
f Ending balance	<b>1f</b>

- 2a Did the organization include an amount on Form 990, Part X, line 21?  Yes  No

b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII

**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 Net investment earnings, gains, and 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 current year end balance (line 1g, column (a)) held as:

- a Board designated or quasi-endowment  \_\_\_\_\_ %
- b Permanent endowment  \_\_\_\_\_ %
- c Temporarily restricted endowment  \_\_\_\_\_ %

The percentages in lines 2a, 2b, and 2c should equal 100%.

3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:

- (i) unrelated organizations
- (ii) related organizations

	Yes	No
3a(i)		
3a(ii)		
3b		

b If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?

4 Describe in Part XIII 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 through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).)  0.

Part VII Investments - Other Securities. See Form 990, Part X, line 12.

Table with 3 columns: (a) Description of security or category, (b) Book value, (c) Method of valuation. Rows include Financial derivatives, Closely-held equity interests, and Other (A-I).

Part VIII Investments - Program Related. See Form 990, Part X, line 13.

Table with 3 columns: (a) Description of investment type, (b) Book value, (c) Method of valuation. Rows numbered 1 through 10.

Part IX Other Assets. See Form 990, Part X, line 15.

Table with 2 columns: (a) Description, (b) Book value. Rows numbered 1 through 10.

Part X Other Liabilities. See Form 990, Part X, line 25.

Table with 2 columns: (a) Description of liability, (b) Book value. Rows include Federal income taxes and rows 2-11.

2. FIN 48 (ASC 740) Footnote. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII

**Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return**

<b>1</b>	Total revenue, gains, and other support per audited financial statements	<b>1</b>	390,984.
<b>2</b>	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
<b>a</b>	Net unrealized gains on investments	<b>2a</b>	
<b>b</b>	Donated services and use of facilities	<b>2b</b>	20,000.
<b>c</b>	Recoveries of prior year grants	<b>2c</b>	
<b>d</b>	Other (Describe in Part XIII.)	<b>2d</b>	
<b>e</b>	Add lines <b>2a</b> through <b>2d</b>	<b>2e</b>	20,000.
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b>	<b>3</b>	370,984.
<b>4</b>	Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b	<b>4a</b>	
<b>b</b>	Other (Describe in Part XIII.)	<b>4b</b>	
<b>c</b>	Add lines <b>4a</b> and <b>4b</b>	<b>4c</b>	0.
<b>5</b>	Total revenue. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 12.)	<b>5</b>	370,984.

**Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return**

<b>1</b>	Total expenses and losses per audited financial statements	<b>1</b>	488,748.
<b>2</b>	Amounts included on line 1 but not on Form 990, Part IX, line 25:		
<b>a</b>	Donated services and use of facilities	<b>2a</b>	20,000.
<b>b</b>	Prior year adjustments	<b>2b</b>	
<b>c</b>	Other losses	<b>2c</b>	
<b>d</b>	Other (Describe in Part XIII.)	<b>2d</b>	
<b>e</b>	Add lines <b>2a</b> through <b>2d</b>	<b>2e</b>	20,000.
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b>	<b>3</b>	468,748.
<b>4</b>	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b	<b>4a</b>	
<b>b</b>	Other (Describe in Part XIII.)	<b>4b</b>	
<b>c</b>	Add lines <b>4a</b> and <b>4b</b>	<b>4c</b>	0.
<b>5</b>	Total expenses. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 18.)	<b>5</b>	468,748.

**Part XIII 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, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

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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

**2012**

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 its grants and other 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 its grants and other assistance outside the United States.

**3 Activities per Region.** (The following Part I, line 3 table can be duplicated if additional space is needed.)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in region	(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 and investments in region
EUROPE (INCLUDING ICELAND & GREENLAND)	0	0	GRANTS TO RECIPIENTS		95,288.
<b>3 a</b> Sub-total .....	0	0			95,288.
<b>b</b> Total from continuation sheets to Part I .....	0	0			0.
<b>c Totals</b> (add lines 3a and 3b) .....	0	0			95,288.

Part II Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

Table with 9 columns: (a) Name of organization, (b) IRS code section and EIN (if applicable), (c) Region, (d) Purpose of grant, (e) Amount of cash grant, (f) Manner of cash disbursement, (g) Amount of non-cash assistance, (h) Description of non-cash assistance, (i) Method of valuation (book, FMV, appraisal, other). The table contains 8 empty rows.

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter
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.

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of non-cash assistance	(g) Description of non-cash assistance	(h) Method of valuation (book, FMV, appraisal, other)
MEDICAL RESEARCH	EUROPE (INCLUDING ICELAND & GREENLAND) -	2	95,288.	CHECK	0.		

**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, Return by a U.S. Transferor of Property to a Foreign Corporation (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, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (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, Information 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

Schedule F (Form 990) 2012

**Part V** Supplemental Information

Complete this part to provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information.

SCHEDULE F, 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.

Multiple horizontal lines for supplemental information.



**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

**2012**

**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. Part II can be duplicated if additional space is needed.

<b>1 (a)</b> Name and address of organization or government	<b>(b)</b> EIN	<b>(c)</b> IRC section if applicable	<b>(d)</b> Amount of cash grant	<b>(e)</b> Amount of non-cash assistance	<b>(f)</b> Method of valuation (book, FMV, appraisal, other)	<b>(g)</b> Description of non-cash assistance	<b>(h)</b> 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 ▶ \_\_\_\_\_

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule I (Form 990) (2012)

**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.  
Part III can be duplicated 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
RESEARCH GRANTS	5	229,790.	0.		

**Part IV** Supplemental Information. Complete this part to provide the information required in Part I, line 2, Part III, column (b), and any other additional information.

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 990-EZ or to provide any additional information.  
▶ Attach to Form 990 or 990-EZ.

OMB No. 1545-0047

**2012**

Open to Public  
Inspection

Name of the organization

CYSTINOSIS RESEARCH NETWORK, INC.

Employer identification number

04-3323789

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION 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.

FORM 990, PART VI, SECTION A, LINE 8B: THE ORGANIZATION DOES NOT HAVE COMMITTEES WITH AUTHORITY TO ACT ON BEHALF OF THE GOVERNING BODY.

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.

FORM 990, PART XII, LINE 2C:

THE ORGANIZATION HAS A COMMITTEE THAT ASSUMES RESPONSIBILITY FOR OVERSIGHT OF THE AUDIT OF ITS FINANCIAL STATEMENTS AND SELECTION OF AN INDEPENDENT ACCOUNTANT.