

**Short Form
Return of Organization Exempt From Income Tax**

2009

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code
(except black lung benefit trust or private foundation)

▶ Sponsoring organizations of donor advised funds and controlling organizations as defined in section 512(b)(13) must file Form 990. All other organizations with gross receipts less than \$500,000 and total assets less than \$1,250,000 at the end of the year may use this form.

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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

A For the 2009 calendar year, or tax year beginning , 2009, and ending

<p>B Check if applicable:</p> <p><input type="checkbox"/> Address change</p> <p><input type="checkbox"/> Name change</p> <p><input type="checkbox"/> Initial return</p> <p><input type="checkbox"/> Termination</p> <p><input type="checkbox"/> Amended return</p> <p><input type="checkbox"/> Application pending</p>	<p>C</p> <p>Please use IRS label or print or type. See Specific Instructions.</p> <p>CYSTINOSIS RESEARCH NETWORK, INC. 302 WHYTEGATE COURT LAKE FOREST, IL 60045</p>	<p>D Employer identification number</p> <p>04-3323789</p>	<p>E Telephone number</p> <p>866 276 3669</p>	<p>F Group Exemption Number</p>
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• Section 501(c)(3) organizations and 4947(a)(1) nonexempt charitable trusts must attach a completed Schedule A (Form 990 or 990-EZ).

G Accounting method: Cash Accrual
Other (specify) ▶

I Website: ▶ WWW.CYSTINOSIS.ORG

H Check if the organization is not required to attach Schedule B (Form 990, 990-EZ, or 990-PF).

J Tax-exempt status (check only one) — 501(c) (3) (insert no.) 4947(a)(1) or 527

K Check if the organization is not a section 509(a)(3) supporting organization and its gross receipts are normally not more than \$25,000. A Form 990-EZ or Form 990 return is not required, but if the organization chooses to file a return, be sure to file a complete return.

L Add lines 5b, 6b, and 7b, to line 9 to determine gross receipts; if \$500,000 or more, file Form 990 instead of Form 990-EZ ▶ \$ 494,044.

Part I Revenue, Expenses, and Changes in Net Assets or Fund Balances (See the instructions for Part I.)

R E V E N U E	1	Contributions, gifts, grants, and similar amounts received		1	165,961.
	2	Program service revenue including government fees and contracts		2	
	3	Membership dues and assessments		3	
	4	Investment income		4	3,666.
	5a	Gross amount from sale of assets other than inventory	5a		
	5b	Less: cost or other basis and sales expenses	5b		
	5c	Gain or (loss) from sale of assets other than inventory (Subtract line 5b from line 5a)	5c		
	6	Special events and activities (complete applicable parts of Schedule G). If any amount is from gaming, check here <input type="checkbox"/>			
	6a	Gross revenue (not including \$ _____ of contributions reported on line 1)	323,917.	6a	
6b	Less: direct expenses other than fundraising expenses	45,671.	6b		
6c	Net income or (loss) from special events and activities (Subtract line 6b from line 6a)		6c	278,246.	
7a	Gross sales of inventory, less returns and allowances		7a		
7b	Less: cost of goods sold		7b		
7c	Gross profit or (loss) from sales of inventory (Subtract line 7b from line 7a)		7c		
8	Other revenue (describe ▶ SEE STATEMENT 1)		8	500.	
9	Total revenue. Add lines 1, 2, 3, 4, 5c, 6c, 7c, and 8		9	448,373.	
E X P E N D I T U R E S	10	Grants and similar amounts paid (attach schedule)	SEE STATEMENT 2	10	244,972.
	11	Benefits paid to or for members		11	
	12	Salaries, other compensation, and employee benefits		12	
	13	Professional fees and other payments to independent contractors		13	11,528.
	14	Occupancy, rent, utilities, and maintenance		14	66,861.
	15	Printing, publications, postage, and shipping		15	10,991.
	16	Other expenses (describe ▶ SEE STATEMENT 3)		16	38,842.
	17	Total expenses. Add lines 10 through 16		17	373,194.
A S S E T S	18	Excess or (deficit) for the year (Subtract line 17 from line 9)		18	75,179.
	19	Net assets or fund balances at beginning of year (from line 27, column (A)) (must agree with end-of-year figure reported on prior year's return)		19	393,908.
	20	Other changes in net assets or fund balances (attach explanation)		20	
	21	Net assets or fund balances at end of year. Combine lines 18 through 20		21	469,087.

Part II Balance Sheets. If Total assets on line 25, column (B) are \$1,250,000 or more, file Form 990 instead of Form 990-EZ.

		(See the instructions for Part II.)		(A) Beginning of year	(B) End of year
22	Cash, savings, and investments	319,876.	22	461,841.	
23	Land and buildings		23		
24	Other assets (describe ▶ SEE STATEMENT 4)	81,258.	24	35,219.	
25	Total assets	401,134.	25	497,060.	
26	Total liabilities (describe ▶ SEE STATEMENT 5)	7,226.	26	27,973.	
27	Net assets or fund balances (line 27 of column (B) must agree with line 21)	393,908.	27	469,087.	

BAA For Privacy Act and Paperwork Reduction Act Notice, see separate instructions.

Part III Statement of Program Service Accomplishments (See the instructions.)

What is the organization's primary exempt purpose? SEE STATEMENT 6
Describe what was achieved in carrying out the organization's exempt purposes. In a clear and concise manner, describe the services provided, the number of persons benefited, or other relevant information for each program title.

Expenses
(Required for section 501(c)(3) and (4) organizations and section 4947(a)(1) trusts; optional for others.)

Table with 3 columns: Program Title, Expense Code, Expense Amount. Rows include: 28 CYSTINOSIS RESEARCH (28a, 244,972), 29 CYSTINOSIS EDUCATION & AWARENESS (29a, 101,933), 31 Other program services (31a), 32 Total program service expenses (32, 346,905).

Part IV List of Officers, Directors, Trustees, and Key Employees. List each one even if not compensated. (See the instrs.)

Table with 5 columns: (a) Name and address, (b) Title and average hours per week devoted to position, (c) Compensation (if not paid, enter -0-), (d) Contributions to employee benefit plans and deferred compensation, (e) Expense account and other allowances. Row 1: SEE STATEMENT 7, 0, 0, 0.

Part V Other Information (Note the statement requirements in the instrs for Part V.) **SEE STATEMENT 8**

		Yes	No
33	Did the organization engage in any activity not previously reported to the IRS? If 'Yes,' attach a detailed description of each activity.		X
34	Were any changes made to the organizing or governing documents? If 'Yes,' attach a conformed copy of the changes.		X
35	If the organization had income from business activities, such as those reported on lines 2, 6a, and 7a (among others), but not reported on Form 990-T, attach a statement explaining why the organization did not report the income on Form 990-T.		
35a	Did the organization have unrelated business gross income of \$1,000 or more or was it subject to section 6033(e) notice, reporting, and proxy tax requirements?		X
35b	If 'Yes,' has it filed a tax return on Form 990-T for this year?		
36	Did the organization undergo a liquidation, dissolution, termination, or significant disposition of net assets during the year? If 'Yes,' complete applicable parts of Schedule N.		X
37a	Enter amount of political expenditures, direct or indirect, as described in the instructions. ▶ 37a 0.		
37b	Did the organization file Form 1120-POL for this year?		X
38a	Did the organization borrow from, or make any loans to, any officer, director, trustee, or key employee or were any such loans made in a prior year and still outstanding at the end of the period covered by this return?		X
38b	If 'Yes,' complete Schedule L, Part II and enter the total amount involved. N/A		
39	Section 501(c)(7) organizations. Enter:		
39a	Initiation fees and capital contributions included on line 9. N/A		
39b	Gross receipts, included on line 9, for public use of club facilities. N/A		
40a	Section 501(c)(3) organizations. Enter amount of tax imposed on the organization during the year under: section 4911 ▶ 0.; section 4912 ▶ 0.; section 4955 ▶ 0.		
40b	Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in any section 4958 excess benefit transaction during the year or is it 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? If 'Yes,' complete Schedule L, Part I.		X
40c	Section 501(c)(3) and 501(c)(4) organizations. Enter amount of tax imposed on organization managers or disqualified persons during the year under sections 4912, 4955, and 4958. ▶ 0.		
40d	Section 501(c)(3) and 501(c)(4) organizations. Enter amount of tax on line 40c reimbursed by the organization. ▶ 0.		
40e	All organizations. At any time during the tax year, was the organization a party to a prohibited tax shelter transaction? If 'Yes,' complete Form 8886-T.		X
41	List the states with which a copy of this return is filed ▶ <u>NONE</u>		

42a The organization's books are in care of ▶ SUSAN S. LEWIS, LTD. Telephone no. ▶ 630 548-9600
 Located at ▶ 1064 104TH STREET NAPERVILLE IL ZIP + 4 ▶ 60564

		Yes	No
42b	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, securities account, or other financial account)? If 'Yes,' enter the name of the foreign country: ... ▶ _____		X
See the instructions for exceptions and filing requirements for Form TD F 90-22.1, Report of a Foreign Bank and Financial Accounts.			
42c	At any time during the calendar year, did the organization maintain an office outside of the U.S.? If 'Yes,' enter the name of the foreign country: ... ▶ _____		X

43 Section 4947(a)(1) nonexempt charitable trusts filing Form 990-EZ in lieu of **Form 1041** — Check here N/A
 and enter the amount of tax-exempt interest received or accrued during the tax year. ▶ **43** N/A

		Yes	No
44	Did the organization maintain any donor advised funds? If 'Yes,' Form 990 must be completed instead of Form 990-EZ.		X
45	Is any related organization a controlled entity of the organization within the meaning of section 512(b)(13)? If 'Yes,' Form 990 must be completed instead of Form 990-EZ.		X

Part VI Section 501(c)(3) organizations and section 4947(a)(1) nonexempt charitable trusts only. All section 501(c)(3) organizations and section 4947(a)(1) nonexempt charitable trusts must answer questions 46-49b and complete the tables for lines 50 and 51.

	Yes	No
46 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If 'Yes,' complete Schedule C, Part I.....	<input type="checkbox"/>	<input checked="" type="checkbox"/>
47 Did the organization engage in lobbying activities? If 'Yes,' complete Schedule C, Part II.....	<input type="checkbox"/>	<input checked="" type="checkbox"/>
48 Is the organization a school as described in section 170(b)(1)(A)(ii)? If 'Yes,' complete Schedule E.....	<input type="checkbox"/>	<input checked="" type="checkbox"/>
49a Did the organization make any transfers to an exempt non-charitable related organization?.....	<input type="checkbox"/>	<input checked="" type="checkbox"/>
b If 'Yes,' was the related organization a section 527 organization?.....	<input type="checkbox"/>	<input type="checkbox"/>

50 Complete this table for the organization's five highest compensated employees (other than officers, directors, trustees and key employees) who each received more than \$100,000 of compensation from the organization. If there is none, enter 'None.'

(a) Name and address of each employee paid more than \$100,000	(b) Title and average hours per week devoted to position	(c) Compensation	(d) Contributions to employee benefit plans and deferred compensation	(e) Expense account and other allowances
NONE				

f Total number of other employees paid over \$100,000..... ▶

51 Complete this table for the organization's five highest compensated independent contractors who each received more than \$100,000 of compensation from the organization. If there is none, enter 'None.'

(a) Name and address of each independent contractor paid more than \$100,000	(b) Type of service	(c) Compensation
NONE		

d Total number of other independent contractors each receiving over \$100,000..... ▶

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

Type or print name and title.

Paid Preparer's Use Only

Preparer's signature

SUSAN S. LEWIS

Date

Check if self-employed

Preparer's Identifying Number (See Instructions)
N/A

Firm's name (or yours if self-employed), address, and ZIP + 4

SUSAN S. LEWIS, LTD.
1064 104TH STREET
NAPERVILLE, IL 60564

EIN

N/A

Phone no.

630-548-9600

May the IRS discuss this return with the preparer shown above? See instructions. ▶ Yes No

SCHEDULE A
(Form 990 or 990-EZ)

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.

OMB No. 1545-0047

2009

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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

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 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. See **section 509(a)(4)**.
- 11 An organization organized and operated exclusively for the benefit of, to perform the functions of, or 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 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?

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

h Provide the following information about the supported organizations.

(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 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.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
1 Gifts, grants, contributions and membership fees received. (Do not include "unusual grants.")...	253,281.	198,456.	313,363.	357,784.	444,207.	1,567,091.
2 Tax revenues levied for the organization's benefit and either paid to it or expended on its behalf.....						0.
3 The value of services or facilities furnished to the organization by a governmental unit without charge. Do not include the value of services or facilities generally furnished to the public without charge.....						0.
4 Total. Add lines 1-through 3.	253,281.	198,456.	313,363.	357,784.	444,207.	1,567,091.
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)....						0.
6 Public support. Subtract line 5 from line 4.....						1,567,091.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
7 Amounts from line 4.....	253,281.	198,456.	313,363.	357,784.	444,207.	1,567,091.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources.....	1,170.	3,621.	2,371.	9,365.	3,666.	20,193.
9 Net income from unrelated business activities, whether or not the business is regularly carried on.....						0.
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.) SEE PART IV.....					500.	500.
11 Total support. Add lines 7 through 10.....						1,587,784.
12 Gross receipts from related activities, etc. (see instructions).....					12	0.
13 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..... ▶ <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

14 Public support percentage for 2009 (line 6, column (f) divided by line 11, column (f)).....	14	98.7 %
15 Public support percentage from 2008 Schedule A, Part II, line 14.....	15	98.7 %
16a 33-1/3 support test – 2009. If the organization did not check the box on line 13, and the line 14 is 33-1/3 % or more, check this box and stop here. The organization qualifies as a publicly supported organization..... ▶ <input checked="" type="checkbox"/>		
b 33-1/3 support test – 2008. 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 stop here. The organization qualifies as a publicly supported organization..... ▶ <input type="checkbox"/>		
17a 10%-facts-and-circumstances test – 2009 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..... ▶ <input type="checkbox"/>		
b 10%-facts-and-circumstances test – 2008. 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..... ▶ <input type="checkbox"/>		
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... ▶ <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.)

Section A. Public Support

Calendar year (or fiscal yr beginning in) ▶	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
1 Gifts, grants, contributions and membership fees received. (Do not include 'unusual grants.')...						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in a 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, 3 received from disqualified persons.						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of 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 yr beginning in) ▶	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(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 lns 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

15 Public support percentage for 2009 (line 8, column (f) divided by line 13, column (f)).	15	%
16 Public support percentage from 2008 Schedule A, Part III, line 15.	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2009 (line 10c, column (f) divided by line 13, column (f)).	17	%
18 Investment income percentage from 2008 Schedule A, Part III, line 17.	18	%

19a 33-1/3 support tests — 2009. 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 — 2008. If the organization did not check a box on line 14 or 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.

8/11/10

04:08PM

PART II, LINE 10 - OTHER INCOME

NATURE AND SOURCE	2009	2008	2007	2006	2005
MISCELLANEOUS INCOME	500.				
TOTAL	<u>\$ 500.</u>	<u>\$ 0.</u>	<u>\$ 0.</u>	<u>\$ 0.</u>	<u>\$ 0.</u>

Part II Fundraising Events. Complete if the organization answered 'Yes' to Form 990, Part IV, line 18, or reported more than \$15,000 on Form 990-EZ, line 6a. List events with gross receipts greater than \$5,000.

REVENUE		(a) Event #1	(b) Event #2	(c) Other Events	(d) Total Events	
		(event type)	(event type)	(total number)	(Add col. (a) through col. (c))	
REVENUE	1	Gross receipts	323,917.		323,917.	
	2	Less: Charitable contributions				
	3	Gross income (line 1 minus line 2)	323,917.		323,917.	
DIRECT EXPENSES	4	Cash prizes				
	5	Noncash prizes				
	6	Rent/facility costs				
	7	Food and beverages				
	8	Entertainment				
	9	Other direct expenses	45,671.		45,671.	
	10	Direct expense summary. Add lines 4- through 9 in column (d)				45,671.
	11	Net income summary. Combine lines 3, column (d) and line 10.				278,246.

Part III Gaming. Complete if the organization answered 'Yes' to Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

REVENUE		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming	
		(Add col. (a) through col. (c))				
REVENUE	1	Gross revenue				
DIRECT EXPENSES	2	Cash prizes				
	3	Non-cash prizes				
	4	Rent/facility costs				
	5	Other direct expenses				
	6	Volunteer labor	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ %	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ %	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No _____ %	
	7	Direct expense summary. Add lines 2 through 5 in column (d)				
	8	Net gaming income summary. Combine lines 1, column (d) and line 7.				

	YES	NO
9 Enter the state(s) in which the organization operates gaming activities: _____		
a Is the organization licensed to operate gaming activities in each of these states? _____	9a	
b If 'No,' explain: _____		
10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? _____	10a	
b If 'Yes,' explain: _____		
11 Does the organization operate gaming activities with nonmembers? _____	11	
12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming? _____	12	

		YES	NO
13 Indicate the percentage of gaming activity operated in:			
a The organization's facility	13a %		
b An outside facility	13b %		
14 Enter the name and address of the person who prepares the organization's gaming/special events books and records:			
Name: ▶ -----			
Address: ▶ -----			
15a Does the organization have a contact with a third party from whom the organization receives gaming revenue?		15a	
b If 'Yes,' enter the amount of gaming revenue received by the organization \$ _____ and the amount of gaming revenue retained by the third party \$ _____.			
c If 'Yes,' enter name and address of the third party:			
Name: ▶ -----			
Address: ▶ -----			
16 Gaming manager information			
Name: ▶ -----			
Gaming manager compensation ▶ \$ _____			
Description of services provided: ▶ -----			
<input type="checkbox"/> Director/officer <input type="checkbox"/> Employee <input type="checkbox"/> Independent contractor			
17 Mandatory distributions			
a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license?		17a	
b Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year: ▶ \$ _____			

CLIENT 07102

CYSTINOSIS RESEARCH NETWORK, INC.

04-3323789

8/11/10

04:08PM

STATEMENT 1
FORM 990-EZ, PART I, LINE 8
OTHER REVENUE

..... \$ 500.
TOTAL \$ 500.

STATEMENT 2
FORM 990-EZ, PART I, LINE 10
GRANTS AND SIMILAR AMOUNTS PAID

DONEE'S NAME:	DONALD CAIRNS, PHD		
DONEE'S ADDRESS:	ROBERT GORDON UNIVERSITY		
CASH AMOUNT GIVEN:		\$	32,643.
DONEE'S NAME:	CATHERINE TULEU, PHD		
DONEE'S ADDRESS:	UNIVERSITY OF LONDON		
CASH AMOUNT GIVEN:		\$	952.
DONEE'S NAME:	VIVI KALATZOS, PHD		
DONEE'S ADDRESS:	INSTITUT GENETIQUE MOLECULAIRE		
CASH AMOUNT GIVEN:		\$	26,436.
DONEE'S NAME:	NIH FELLOWSHIP		
DONEE'S ADDRESS:	5625 FISHERS LANE BETHESDA, MD		
CASH AMOUNT GIVEN:		\$	75,000.
DONEE'S NAME:	FRANCESCO EMMA, M.D.		
DONEE'S ADDRESS:	PIAZZA S. ONOFRIO 4		
CASH AMOUNT GIVEN:		\$	21,465.
DONEE'S NAME:	DR. H. J. BLOM		
DONEE'S ADDRESS:	THE ROBERT GORDON UNIVERSITY		
CASH AMOUNT GIVEN:		\$	15,380.
DONEE'S NAME:	DR. EWA ELENBERG		
DONEE'S ADDRESS:	BAYLOR COLLEGE OF MEDICINE HOUSTON, TX 77030		
CASH AMOUNT GIVEN:		\$	5,250.
DONEE'S NAME:	DR. JESS THOENE		
DONEE'S ADDRESS:	UNIVERSITY OF MICHIGAN ANN ARBOR, MI 48109		
CASH AMOUNT GIVEN:		\$	27,622.
DONEE'S NAME:	DORIS TRAUNER, M.D.		
DONEE'S ADDRESS:	UC REGENTS OAKLAND, CA 94607		
CASH AMOUNT GIVEN:		\$	31,224.
DONEE'S NAME:	DR. PAUL GOODYER		
DONEE'S ADDRESS:	MCGILL UNIVERSITY HEALTH CENTE		
CASH AMOUNT GIVEN:		\$	9,000.

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CYSTINOSIS RESEARCH NETWORK, INC.

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**STATEMENT 3
FORM 990-EZ, PART I, LINE 16
OTHER EXPENSES**

BOOKS AND PUBLICATIONS.....	\$	300.
EQUIPMENT RENTAL.....		4,500.
INSURANCE.....		1,990.
LICENSES AND REGISTRATION.....		205.
MEETINGS.....		2,999.
SCHOLARSHIPS.....		1,000.
SUNDRY.....		1,127.
SUPPLIES.....		7,203.
TELEPHONE.....		7,768.
TRAVEL AND TRANSPORTATION.....		11,750.
TOTAL	\$	<u>38,842.</u>

**STATEMENT 4
FORM 990-EZ, PART II, LINE 24
OTHER ASSETS**

	<u>BEGINNING</u>	<u>ENDING</u>
PLEDGES AND GRANTS RECEIVABLE.....	\$ 50,361.	\$ 12,000.
PREPAID EXPENSES AND DEFERRED CHARGES.....	30,897.	23,219.
TOTAL	\$ <u>81,258.</u>	\$ <u>35,219.</u>

**STATEMENT 5
FORM 990-EZ, PART II, LINE 26
TOTAL LIABILITIES**

	<u>BEGINNING</u>	<u>ENDING</u>
ACCOUNTS PAYABLE AND ACCRUED EXPENSES.....	\$ 7,226.	\$ 1,173.
DEFERRED REVENUE.....	0.	12,550.
GRANTS PAYABLE.....	0.	14,250.
TOTAL	\$ <u>7,226.</u>	\$ <u>27,973.</u>

**STATEMENT 6
FORM 990-EZ, PART III
ORGANIZATION'S PRIMARY EXEMPT PURPOSE**

CYSTINOSIS RESEARCH NETWORK, INC. SUPPORTS AND ADVOCATES RESEARCH INTO CYSTINOSIS, PROVIDES FAMILY SUPPORT, AND PROMOTES EDUCATION AND AWARENESS OF CYSTINOSIS.

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STATEMENT 7
FORM 990-EZ, PART IV
LIST OF OFFICERS, DIRECTORS, TRUSTEES, AND KEY EMPLOYEES

NAME AND ADDRESS	TITLE AND AVERAGE HOURS PER WEEK DEVOTED	COMPEN- SATION	CONTRI- BUTION TO EBP & DC	EXPENSE ACCOUNT/ OTHER
ELVA S SMITH 417 CLAIREMONT AVENUE, #209 DECATUR, GA 30030	VP-RESEARCH 0	\$ 0.	\$ 0.	\$ 0.
CHRISTY GREELEY 302 WHYTEGATE COURT LAKE FOREST, IL 60045	PRESIDENT 0	0.	0.	0.
JILL MORRILL 974 PRINCETON BLVD, SE GRAND RAPIDS, MI 49506	DIRECTOR 0	0.	0.	0.
BRITTNEY LEBEAU 3358 CHARLEMAINE AURORA, IL 60504	TREASURER 0	0.	0.	0.
KAREN GLEDHILL 39 ASPEN DRIVE ROCHESTER, NY 14625	SECRETARY 0	0.	0.	0.
TAHNIE WOODWARD 575 S 360 E AMERICAN FORK, UT 84003	DIRECTOR 0	0.	0.	0.
PAULA SHAL 1718 BRIARWOOD DRIVE JOHNSBURG, IL 60051	VP-EDUC & AWARE 0	0.	0.	0.
CHERI FRIEND 4027 WYNDHAM HILL DRIVE SUWANEE, GA 30024	VP - FAMILY SUP 0	0.	0.	0.
KATHY MANDREL 1741 NEW JAMESTOWN RD ST LOUIS, MO 63138	DIRECTOR 0	0.	0.	0.
LORNA SMITH 1356 HILLANDALE RD LAWRENCEVILLE, GA 30045	DIRECTOR 0	0.	0.	0.
JEN WYMAN 6375 WEST SURREY RD BLOOMFIELD HILLS, MI 48301	VP-DEVELOPMENT 0	0.	0.	0.
DAN JULIAN 24010 BURR OAK LANE ATHENS, IL 62613	DIRECTOR 0	0.	0.	0.

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**STATEMENT 7 (CONTINUED)
FORM 990-EZ, PART IV
LIST OF OFFICERS, DIRECTORS, TRUSTEES, AND KEY EMPLOYEES**

<u>NAME AND ADDRESS</u>	<u>TITLE AND AVERAGE HOURS PER WEEK DEVOTED</u>	<u>COMPEN- SATION</u>	<u>CONTRI- BUTION TO EBP & DC</u>	<u>EXPENSE ACCOUNT/ OTHER</u>
MARY BETH KRUMMENACKER 54 SMITH STREET HICKSVILLE, NY 11801	DIRECTOR 0	\$ 0.	\$ 0.	\$ 0.
FRANKIE MCGINNIS 214 SPRINGS CROSSING CIRCLE GREER, SC 29650	DIRECTOR 0	0.	0.	0.
JOHN SHEPPARD 302 W KINGS HWY SAN ANTONIO, TX 78212	DIRECTOR 0	0.	0.	0.
MACK MAXWELL 5198 HOPPER ROAD BURLESON, TX 76028	DIRECTOR 0	0.	0.	0.
JOSE MORALES 27 CHIEFTANS ROAD GREENWICH, CT 06831	DIRECTOR 0	0.	0.	0.
JOHN MACCARONE 11 WAYLOR LANE SYOSSET, NY 11791	DIRECTOR 0	0.	0.	0.
TOTAL		\$ 0.	\$ 0.	\$ 0.

**STATEMENT 8
FORM 990-EZ, PART V
REGARDING TRANSFERS ASSOCIATED WITH PERSONAL BENEFIT CONTRACTS**

(A) DID THE ORGANIZATION, DURING THE YEAR, RECEIVE ANY FUNDS, DIRECTLY OR INDIRECTLY, TO PAY PREMIUMS ON A PERSONAL BENEFIT CONTRACT?..... NO

(B) DID THE ORGANIZATION, DURING THE YEAR, PAY PREMIUMS, DIRECTLY OR INDIRECTLY, ON A PERSONAL BENEFIT CONTRACT?..... NO

For Office Use Only

PMT # _____
AMT _____
INIT _____

Illinois Charitable Organization Annual Report
 Attorney General **Lisa Madigan** State of Illinois
 Charitable Trust Bureau, 100 West Randolph
 11th Floor, Chicago, Illinois 60601

Form AG990-IL
Revised 3/05 ID: 28N

CO# 01050724

Report for the Fiscal Period:
 Beginning 1/01/09
 & Ending 12/31/09
MO DAY YR

Check all items attached:

<input type="checkbox"/>	Copy of IRS Return
<input type="checkbox"/>	Audited Financial Statements
<input type="checkbox"/>	Copy of Form IFC
<input checked="" type="checkbox"/>	\$15.00 Annual Report Filing Fee
<input type="checkbox"/>	\$100.00 Late Report Filing Fee

Make Checks Payable to the Illinois Charity Bureau Fund

Federal ID # 04-3323789

Are contributions to the organization tax deductible? Yes No

Date Organization was created: 8/06/1996
MO DAY YR

LEGAL NAME CYSTINOSIS RESEARCH NETWORK, INC.	Year-end amounts	
MAIL ADDRESS 302 WHYTEGATE COURT	A ASSETS	A\$ 497,060.
CITY, STATE ZIP CODE LAKE FOREST, IL 60045	B LIABILITIES	B\$ 27,973.
	C NET ASSETS	C\$ 469,087.

I SUMMARY OF ALL REVENUE ITEMS DURING THE YEAR:	PERCENTAGE	AMOUNT
D PUBLIC SUPPORT, CONTRIBUTIONS AND PROGRAM SERVICE REVENUE (GROSS AMOUNTS)	99.07 %	D\$ 444,207.
E GOVERNMENT GRANTS AND MEMBERSHIP DUES	%	E\$
F OTHER REVENUES SEE STATEMENT 1	0.93 %	F\$ 4,166.
G TOTAL REVENUE, INCOME AND CONTRIBUTIONS RECEIVED (ADD D, E, AND F)	100 %	G\$ 448,373.

II SUMMARY OF ALL EXPENDITURES DURING THE YEAR:	PERCENTAGE	AMOUNT
H OPERATING CHARITABLE PROGRAM EXPENSE	92.96 %	H\$ 346,905.
I EDUCATION PROGRAM SERVICE EXPENSE	%	I\$
J TOTAL CHARITABLE PROGRAM SERVICE EXPENSE (ADD H AND I)	92.96 %	J\$ 346,905.
J1 JOINT COSTS ALLOCATED TO PROGRAM SERVICES (INCLUDED IN J)		\$
K GRANTS TO OTHER CHARITABLE ORGANIZATIONS	%	K\$
L TOTAL CHARITABLE PROGRAM SERVICE EXPENDITURE (ADD J AND K)	92.96 %	L\$ 346,905.
M MANAGEMENT AND GENERAL EXPENSE	6.33 %	M\$ 23,606.
N FUNDRAISING EXPENSE	0.72 %	N\$ 2,683.
O TOTAL EXPENDITURES THIS PERIOD (ADD L, M, AND N)	100 %	O\$ 373,194.

III SUMMARY OF ALL PAID FUNDRAISER AND CONSULTANT ACTIVITIES:	PERCENTAGE	AMOUNT
(Attach Attorney General Report of Individual Fundraising Campaign — Form IFC. One for each PFR.)		
PROFESSIONAL FUNDRAISERS:		
P TOTAL AMOUNT RAISED BY PAID PROFESSIONAL FUNDRAISERS	100 %	P\$ 0.
Q TOTAL FUNDRAISERS FEES AND EXPENSES	%	Q\$ 0.
R NET RECEIVED BY THE CHARITY (P MINUS Q=R)	%	R\$ 0.
PROFESSIONAL FUNDRAISING CONSULTANTS:		
S TOTAL AMOUNT PAID TO PROFESSIONAL FUNDRAISING CONSULTANTS		S\$ 0.

IV COMPENSATION TO THE (3) HIGHEST PAID PERSONS DURING THE YEAR:	AMOUNT
T NAME, TITLE: _____	T\$
U NAME, TITLE: _____	U\$
V NAME, TITLE: _____	V\$

V CHARITABLE PROGRAM DESCRIPTION: CHARITABLE PROGRAM (3 HIGHEST BY \$ EXPENDED) CODE CATEGORIES	See instructions for list CODE
W DESCRIPTION: <u>RESEARCH</u>	W# 053
X DESCRIPTION: <u>EDUCATION & AWARENESS</u>	X# 011
Y DESCRIPTION: <u>FAMILY SUPPORT</u>	Y# 111

IF THE ANSWER TO ANY OF THE FOLLOWING IS YES, ATTACH A DETAILED EXPLANATION:

	YES	NO
1 WAS THE ORGANIZATION THE SUBJECT OF ANY COURT ACTION, FINE, PENALTY OR JUDGMENT?		X
2 HAS THE ORGANIZATION OR A CURRENT DIRECTOR, TRUSTEE, OFFICER OR EMPLOYEE THEREOF, EVER BEEN CONVICTED BY ANY COURT OF ANY MISDEMEANOR INVOLVING THE MISUSE OR MISAPPROPRIATION OF FUNDS OR ANY FELONY?		X
3 DID THE ORGANIZATION MAKE A GRANT AWARD OR CONTRIBUTION TO ANY ORGANIZATION IN WHICH ANY OF ITS OFFICERS, DIRECTORS OR TRUSTEES OWNS AN INTEREST; OR WAS IT A PARTY TO ANY TRANSACTION IN WHICH ANY OF ITS OFFICERS, DIRECTORS OR TRUSTEES HAS A MATERIAL FINANCIAL INTEREST; OR DID ANY OFFICER, DIRECTOR OR TRUSTEE RECEIVE ANYTHING OF VALUE NOT REPORTED AS COMPENSATION?		X
4 HAS THE ORGANIZATION INVESTED IN ANY CORPORATE STOCK IN WHICH ANY OFFICER, DIRECTOR OR TRUSTEE OWNS MORE THAN 10% OF THE OUTSTANDING SHARES?		X
5 IS ANY PROPERTY OF THE ORGANIZATION HELD IN THE NAME OF OR COMMINGLED WITH THE PROPERTY OF ANY OTHER PERSON OR ORGANIZATION?		X
6 DID THE ORGANIZATION USE THE SERVICES OF A PROFESSIONAL FUNDRAISER? (ATTACH FORM IFC)		X
7a DID THE ORGANIZATION ALLOCATE THE COST OF ANY SOLICITATION, MAILING, ADVERTISEMENT OR LITERATURE COSTS BETWEEN PROGRAM SERVICE AND FUNDRAISING EXPENSES?		X
7b IF 'YES', ENTER (i) THE AGGREGATE AMOUNT OF THESE JOINT COSTS \$ _____; (ii) THE AMOUNT ALLOCATED TO PROGRAM SERVICES \$ _____; (iii) THE AMOUNT ALLOCATED TO MANAGEMENT AND GENERAL \$ _____; AND (iv) THE AMOUNT ALLOCATED TO FUNDRAISING \$ _____		
8 DID THE ORGANIZATION EXPEND ITS RESTRICTED FUNDS FOR PURPOSES OTHER THAN RESTRICTED PURPOSES?		X
9 HAS THE ORGANIZATION EVER BEEN REFUSED REGISTRATION OR HAD ITS REGISTRATION OR TAX EXEMPTION SUSPENDED OR REVOKED BY ANY GOVERNMENTAL AGENCY?		X
10 WAS THERE OR DO YOU HAVE ANY KNOWLEDGE OF ANY KICKBACK, BRIBE, OR ANY THEFT, DEFALCATION MISAPPROPRIATION, COMMINGLING OR MISUSE OF ORGANIZATIONAL FUNDS?		X
11 LIST THE NAME AND ADDRESS OF THE FINANCIAL INSTITUTIONS WHERE THE ORGANIZATION MAINTAINS ITS THREE LARGEST ACCOUNTS: <u>SEE STATEMENT 2</u>		
12 NAME AND TELEPHONE NUMBER OF CONTACT PERSON: <u>DIANE CAROBUS 630 548-9600</u>		

ALL ATTACHMENTS MUST ACCOMPANY THIS REPORT – SEE INSTRUCTIONS

UNDER PENALTY OF PERJURY, I (WE) THE UNDERSIGNED DECLARE AND CERTIFY THAT I (WE) HAVE EXAMINED THIS ANNUAL REPORT AND THE ATTACHED DOCUMENTS, INCLUDING ALL THE SCHEDULES AND STATEMENTS AND THE FACTS THEREIN STATED ARE TRUE AND COMPLETE AND FILED WITH THE ILLINOIS ATTORNEY GENERAL FOR THE PURPOSE OF HAVING THE PEOPLE OF THE STATE OF ILLINOIS RELY THEREUPON. I HEREBY FURTHER AUTHORIZE AND AGREE TO SUBMIT MYSELF AND THE REGISTRANT HEREBY TO THE JURISDICTION OF THE STATE OF ILLINOIS.

BE SURE TO INCLUDE ALL FEES DUE:	<u>CHRISTY GREELEY</u>		
1 REPORTS ARE DUE WITHIN SIX MONTHS OF YOUR FISCAL YEAR END.	PRESIDENT or TRUSTEE (PRINT NAME)	SIGNATURE	DATE
2 FOR FEES DUE SEE INSTRUCTIONS.	<u>BRITTNEY LEBEAU</u>		
	TREASURER or TRUSTEE (PRINT NAME)	SIGNATURE	DATE
3 REPORTS THAT ARE LATE OR INCOMPLETE ARE SUBJECT TO A \$100.00 PENALTY.	<u>SUSAN S. LEWIS</u>		
	PREPARER (PRINT NAME)	SIGNATURE	DATE
	<u>SUSAN S. LEWIS, LTD.</u>		
	<u>1064 104TH STREET</u>		
	<u>NAPERVILLE, IL 60564</u>		

2009

ILLINOIS STATEMENTS

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CYSTINOSIS RESEARCH NETWORK, INC.

04-3323789

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STATEMENT 1
FORM AG990-IL, PAGE 1, LINE F
OTHER REVENUES

INTEREST INCOME.....	\$	3,666.
MISCELLANEOUS INCOME.....		500.
TOTAL	\$	<u>4,166.</u>

STATEMENT 2
FORM AG990-IL, PAGE 2, QUESTION 11
NAME AND ACCOUNT NUMBER OF INSTITUTIONS HOLDING THREE LARGEST ACCOUNTS

FIRST UNITED BANK - #30119768 AND #30771711
700 W. EXCHANGE ST. CRETE, IL

WEST SUBURBAN BANK - #5900001598 AND #5900001806
1004 4TH STREET NAPERVILLE, IL 60564