

Short Form
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)

2008

Department of the Treasury
Internal Revenue Service

▶ 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 \$1,000,000 and total assets less than \$2,500,000 at the end of the year may use this form.

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

Open to Public Inspection

A For the 2008 calendar year, or tax year beginning _____, **2008, and ending** _____,

<p>B Check if applicable:</p> <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Termination <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	<p>C Please use IRS label or print or type. See Specific Instructions.</p> CYSTINOSIS RESEARCH NETWORK, INC. 302 WHYTEGATE COURT LAKE FOREST, IL 60045	<p>D Employer identification number 04-3323789</p> <p>E Telephone number 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 Organization type (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 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 \$1,000,000 or more, file Form 990 instead of Form 990-EZ. ▶ \$ 418,492.

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

	1 Contributions, gifts, grants, and similar amounts received	1	357,784.
	2 Program service revenue including government fees and contracts	2	
	3 Membership dues and assessments	3	
	4 Investment income	4	9,365.
REVENUE	5a Gross amount from sale of assets other than inventory	5a	
	b Less: cost or other basis and sales expenses	5b	
	c Gain or (loss) from sale of assets other than inventory (Subtract line 5b from line 5a) (att sch.)	5c	
	6 Special events and activities (complete applicable parts of Schedule G). If any amount is from gaming, check here <input type="checkbox"/>		
	a Gross revenue (not including \$ 157,217. of contributions reported on line 1)	6a	51,343.
	b Less: direct expenses other than fundraising expenses	6b	6,922.
	c Net income or (loss) from special events and activities (Subtract line 6b from line 6a)	6c	44,421.
	7a Gross sales of inventory, less returns and allowances	7a	
	b Less: cost of goods sold	7b	
	c Gross profit or (loss) from sales of inventory (Subtract line 7b from line 7a)	7c	
	8 Other revenue (describe ▶)	8	
	9 Total revenue (add lines 1, 2, 3, 4, 5c, 6c, 7c, and 8)	9	411,570.
EXPENSES	10 Grants and similar amounts paid (attach schedule)	10	285,154.
	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	5,820.
	14 Occupancy, rent, utilities, and maintenance	14	
	15 Printing, publications, postage, and shipping	15	11,504.
	16 Other expenses (describe ▶ SEE STATEMENT 2)	16	103,144.
	17 Total expenses (add lines 10 through 16)	17	405,622.
ASSETS	18 Excess or (deficit) for the year (Subtract line 17 from line 9)	18	5,948.
	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	387,960.
	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	393,908.

Part II Balance Sheets. If Total assets on line 25, column (B) are \$2,500,000 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	393,007.	319,876.
23 Land and buildings		
24 Other assets (describe ▶ SEE STATEMENT 3)	1,896.	81,258.
25 Total assets	394,903.	401,134.
26 Total liabilities (describe ▶ SEE STATEMENT 4)	6,943.	7,226.
27 Net assets or fund balances (line 27 of column (B) must agree with line 21)	387,960.	393,908.

BAA For Privacy Act and Paperwork Reduction Act Notice, see the instructions for Form 990.

Form **990-EZ** (2008)

Part V Other Information (Note the statement requirement in General Instruction V.)

		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 but not reported to the IRS? 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 your reason for not reporting the income on Form 990-T.		
a	Did the organization have unrelated business gross income of \$1,000 or more or 6033(e) notice, reporting, and proxy tax requirements?		X
b	If 'Yes,' has it filed a tax return on Form 990-T for this year?		
36	Was there a liquidation, dissolution, termination, or substantial contraction 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.		
b	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 unpaid at the start of the period covered by this return?		X
b	If 'Yes,' complete Schedule L, Part II and enter the total amount involved. 38b N/A		
39	501(c)(7) organizations. Enter:		
a	Initiation fees and capital contributions included on line 9. 39a N/A		
b	Gross receipts, included on line 9, for public use of club facilities. 39b N/A		
40a	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.		
b	501(c)(3) and (4) organizations. Did the organization engage in any section 4958 excess benefit transaction during the year or did it become aware of an excess benefit transaction from a prior year? If 'Yes,' complete Schedule L, Part I.		X
c	Enter amount of tax imposed on organization managers or disqualified persons during the year under sections 4912, 4955, and 4958. ▶ 0.		
d	Enter amount of tax on line 40c reimbursed by the organization. ▶ 0.		
e	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 ▶ IL		

42a The books are in care of ▶ BRITTNEY LE EAU Telephone no. ▶ 630 548-9600
 Located at ▶ 1064 104TH STREET NAPERVILLE IL ZIP + 4 ▶ 60564

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

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 only. All section 501(c)(3) organizations must answer questions 46-49 and complete the tables for lines 50 and 51. SEE STATEMENT 7

	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 operating 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(s) a section 527 organization?.....	<input type="checkbox"/>	<input type="checkbox"/>

50 Complete this table for the 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				
Total number of other employees paid over \$100,000..... ▶				

51 Complete this table for the 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		
Total number of other independent contractors receiving over \$100,000..... ▶		

Sign Here 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.

▶ 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 ▶ <input type="checkbox"/>	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)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

To be completed by all section 501 (c)(3) organizations and section 4947(a)(1) nonexempt charitable trusts.

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

OMB No. 1545-0047

2008

Open to Public Inspection

Name of the organization CYSTINOSIS RESEARCH NETWORK, INC.	Employer identification number 04-3323789
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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: (Please check only **one** organization.)

- 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).** (Attach Schedule H.)
- 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).** (see instructions)
- 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?

	Yes	No
(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?	11 g (i)	
(ii) a family member of a person described in (i) above?	11 g (ii)	
(iii) a 35% controlled entity of a person described in (i) or (ii) above?	11 g (iii)	

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

Part II Support Schedule for Organizations Described in 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) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(f) Total
1 Gifts, grants, contributions and membership fees received. (Do not include 'unusual grants'.)	126,402.	253,281.	198,456.	313,363.	357,784.	1,249,286.
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 1-3.	126,402.	253,281.	198,456.	313,363.	357,784.	1,249,286.
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.						1,249,286.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(f) Total
7 Amounts from line 4.	126,402.	253,281.	198,456.	313,363.	357,784.	1,249,286.
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.	16,527.
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.)						0.
11 Total support. Add lines 7 through 10.						1,265,813.
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 2008 (line 6, column (f) divided by line 11, column (f)).	14	98.7 %
15 Public support percentage for 2007 Schedule A, Part IV-A, line 26f.	15	99.4 %
16a 33-1/3 support test – 2008. 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 – 2007. 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 – 2008. 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 – 2007. 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) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(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 1-5						
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 total of lines 9, 10c, 11, and 12 for the year or \$5,000						
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) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(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 2008 (line 8, column (f) divided by line 13, column (f)).	15	%
16 Public support percentage from 2007 Schedule A, Part IV-A, line 27g	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2008 (line 10c, column (f) divided by line 13, column (f))	17	%
18 Investment income percentage from 2007 Schedule A, Part IV-A, line 27h	18	%

19a 33-1/3 support tests – 2008. 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 – 2007. 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. ▶

Schedule B
(Form 990, 990-EZ,
or 990-PF)

Department of the Treasury
Internal Revenue Service

Schedule of Contributors

▶ **Attach to Form 990, 990-EZ and 990-PF**
▶ **See separate instructions.**

OMB No. 1545-0047

2008

Name of the organization

CYSTINOSIS RESEARCH NETWORK, INC.

Employer identification number

04-3323789

Organization type (check one):

Filers of:

Form 990 or 990-EZ

Section:

- 501(c)(3) (enter number) organization
- 4947(a)(1) nonexempt charitable trust **not** treated as a private foundation
- 527 political organization

Form 990-PF

- 501(c)(3) exempt private foundation
- 4947(a)(1) nonexempt charitable trust treated as a private foundation
- 501(c)(3) taxable private foundation

Check if your organization is covered by the **General Rule** or a **Special Rule**. (**Note:** Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.)

General Rule –

For organizations filing Form 990, 990-EZ, or 990-PF that received, during the year, \$5,000 or more (in money or property) from any one contributor. (Complete Parts I and II.)

Special Rules –

For a section 501(c)(3) organization filing Form 990, or Form 990-EZ, that met the 33-1/3% support test of the regulations under sections 509(a)(1)/170(b)(1)(A)(vi) and received from any one contributor, during the year, a contribution of the greater of (1) \$5,000 or (2) 2% of the amount on Form 990, Part VIII, line 1h or 2% of the amount on Form 990-EZ, line 1. Complete Parts I and II.

For a section 501(c)(7), (8), or (10) organization filing Form 990, or Form 990-EZ, that received from any one contributor, during the year, aggregate contributions or bequests of more than \$1,000 for use *exclusively* for religious, charitable, scientific, literary, or educational purposes, or the prevention of cruelty to children or animals. Complete Parts I, II, and III.

For a section 501(c)(7), (8), or (10) organization filing Form 990, or Form 990-EZ, that received from any one contributor, during the year, some contributions for use *exclusively* for religious, charitable, etc. purposes, but these contributions did not aggregate to more than \$1,000. (If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc. purpose. Do not complete any of the Parts unless the **General Rule** applies to this organization because it received nonexclusively religious, charitable, etc. contributions of \$5,000 or more during the year.) ▶ \$ _____

Caution: Organizations that are not covered by the General Rule and/or the Special Rules do not file Schedule B (Form 990, 990-EZ, or 990-PF) but they **must** answer 'No' on Part IV, line 2 of their Form 990, or check the box in the heading of their Form 990-EZ, or on line 2 of their Form 990-PF, to certify that they do not meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

BAA For Privacy Act and Paperwork Reduction Act Notice, see the Instructions for Form 990. These instructions will be issued separately.

Schedule B (Form 990, 990-EZ, or 990-PF) (2008)

Name of organization

Employer identification number

CYSTINOSIS RESEARCH NETWORK, INC.

04-3323789

Part I Contributors (see instructions.)

(a) Number	(b) Name, address, and ZIP + 4	(c) Aggregate contributions	(d) Type of contribution
1	THE TOWSLEY FOUNDATION ----- 1410 ASHMAN, P.O. BOX 349 ----- MIDLAND, MI 48640 -----	\$ 50,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution.)
2	ESCHBACH FAMILY FUND ----- 25101 GROESBECK HIGHWAY ----- WARREN, MI 48089 -----	\$ 10,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution.)
3	SIGMA TAU PHARMACEUTICALS ----- 800 S. FREDERICK AVENUE ----- GAITHERSBURG, MD 20877 -----	\$ 16,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution.)
4	TOM & TRACI GENDRON ----- 733 LANGDALE DRIVE ----- FT. COLLINS, CO 80526 -----	\$ 25,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution.)
---	----- ----- ----- -----	\$	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution.)
---	----- ----- ----- -----	\$	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II if there is a noncash contribution.)

Name of organization

Employer identification number

CYSTINOSIS RESEARCH NETWORK, INC.

04-3323789

Part III Exclusively religious, charitable, etc., individual contributions to section 501(c)(7), (8), or (10) organizations aggregating more than \$1,000 for the year. (Complete cols (a) through (e) and the following line entry.)

For organizations completing Part III, enter total of *exclusively* religious, charitable, etc., contributions of **\$1,000 or less** for the year. (Enter this information once – see instructions.) \$ N/A

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	N/A		

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee

CLIENT 07102

CYSTINOSIS RESEARCH NETWORK, INC.

04-3323789

8/18/09

10:01AM

STATEMENT 1
FORM 990-EZ, PART I, LINE 10
GRANTS AND SIMILAR AMOUNTS PAID

DONEE'S NAME:	CORINNE ANTIGNAC, M.D.		
DONEE'S ADDRESS:	149 RUE DE SEVRES		
CASH AMOUNT GIVEN:		\$	12,500.
DONEE'S NAME:	DONALD CAIRNS, PHD		
DONEE'S ADDRESS:	ROBERT GORDON UNIVERSITY		
CASH AMOUNT GIVEN:		\$	32,624.
DONEE'S NAME:	CATHERINE TULEU, PHD		
DONEE'S ADDRESS:	UNIVERSITY OF LONDON		
CASH AMOUNT GIVEN:		\$	25,230.
DONEE'S NAME:	VIVI KALATZOS, PHD		
DONEE'S ADDRESS:	INSTITUT GENETIQUE MOLECULAIRE		
CASH AMOUNT GIVEN:		\$	53,171.
DONEE'S NAME:	LETICIA BELMONT-MARTINEZ, M.D.		
DONEE'S ADDRESS:	COL. BARROS SIERRA		
CASH AMOUNT GIVEN:		\$	15,986.
DONEE'S NAME:	NIH FELLOWSHIP		
DONEE'S ADDRESS:	5625 FISHERS LANE		
	BETHESDA, MD		
CASH AMOUNT GIVEN:		\$	100,000.
DONEE'S NAME:	FRANCESCO EMMA, M.D.		
DONEE'S ADDRESS:	PIAZZA S. ONOFRIO 4		
CASH AMOUNT GIVEN:		\$	28,620.
DONEE'S NAME:	ELENA LEVTCHENKO, M.D.		
DONEE'S ADDRESS:	HERESTRAAT 49, 3000 LEUVEN		
CASH AMOUNT GIVEN:		\$	17,023.

STATEMENT 2
FORM 990-EZ, PART I, LINE 16
OTHER EXPENSES

ADVERTISING AND PROMOTION.....	\$	2,375.
BAD DEBT.....		815.
BANK FEES.....		93.
BUSINESS REGISTRATION FEES.....		260.
CONFERENCES, CONVENTIONS, AND MEETINGS.....		4,536.
HOTELS.....		3,899.
IN-KIND EXPENSES.....		18,214.
INSURANCE.....		2,206.
MEALS.....		262.
MEETINGS.....		1,733.
MISCELLANEOUS.....		715.
OPERATIONS.....		62.
OUTSIDE SERVICES.....		556.
REGISTRATION FEES.....		1,640.
SCHOLARSHIPS.....		1,000.
SPECIAL EVENTS.....		40,051.
SUPPLIES.....		731.
TELEPHONE.....		22,611.

CLIENT 07102

CYSTINOSIS RESEARCH NETWORK, INC.

04-3323789

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STATEMENT 2 (CONTINUED)
FORM 990-EZ, PART I, LINE 16
OTHER EXPENSES

TRAVEL	\$	1,385.
TOTAL	\$	<u>103,144.</u>

STATEMENT 3
FORM 990-EZ, PART II, LINE 24
OTHER ASSETS

	<u>BEGINNING</u>	<u>ENDING</u>
PLEDGES AND GRANTS RECEIVABLE	\$ 0.	\$ 50,361.
PREPAID EXPENSES AND DEFERRED CHARGES	1,896.	30,897.
TOTAL	\$ <u>1,896.</u>	\$ <u>81,258.</u>

STATEMENT 4
FORM 990-EZ, PART II, LINE 26
TOTAL LIABILITIES

	<u>BEGINNING</u>	<u>ENDING</u>
ACCOUNTS PAYABLE AND ACCRUED EXPENSES	\$ 6,943.	\$ 7,226.
TOTAL	\$ <u>6,943.</u>	\$ <u>7,226.</u>

STATEMENT 5
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.

STATEMENT 6
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>
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.

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STATEMENT 6 (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>
JILL MORRILL 974 PRINCETON BLVD, SE GRAND RAPIDS, MI 49506	VP-DEVELOPMENT 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.
PAM WOODWARD 1368 W 2600 N PLEASANT GROVE, UT 84062	VP-FAM. SUPPORT 0	0.	0.	0.
PAULA SHAL 911 COUNTRYSIDE CROSSING WAUNAHEE, WI 53597	VP-EDUC & AWARE 0	0.	0.	0.
CHERI FRIEND 4-27 WYNDHAM HILL DRIVE SUWANEE, GA 30024	DIRECTOR 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	DIRECTOR 0	0.	0.	0.
DAN JULIAN 24010 BURR OAK LANE ATHENS, IL 62613	DIRECTOR 0	0.	0.	0.
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.

**STATEMENT 6 (CONTINUED)
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
JOHN SHEPPARD 2129 LAMONT SAN ANTONIO, TX 78209	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.
TOTAL		<u>\$ 0.</u>	<u>\$ 0.</u>	<u>\$ 0.</u>

**STATEMENT 7
FORM 990-EZ, PART VI
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: 2BN

CO# 01050724

Report for the Fiscal Period:
 Beginning 1/01/08
 & Ending 12/31/08
MO DAY YR

Check all items attached:

- Copy of IRS Return
- Audited Financial Statements
- Copy of Form IFC
- \$15.00 Annual Report Filing Fee
- \$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 \$ 401,134.
CITY, STATE LAKE FOREST, IL 60045	B LIABILITIES	B \$ 7,226.
	C NET ASSETS	C \$ 393,908.
I SUMMARY OF ALL REVENUE ITEMS DURING THE YEAR:	PERCENTAGE	AMOUNT
D PUBLIC SUPPORT, CONTRIBUTIONS AND PROGRAM SERVICE REVENUE (GROSS AMOUNTS)	97.72 %	D \$ 402,205.
E GOVERNMENT GRANTS AND MEMBERSHIP DUES	%	E \$
F OTHER REVENUES.....SEE STATEMENT 1	2.28 %	F \$ 9,365.
G TOTAL REVENUE, INCOME AND CONTRIBUTIONS RECEIVED (ADD D, E, AND F)	100 %	G \$ 411,570.
II SUMMARY OF ALL EXPENDITURES DURING THE YEAR:		
H OPERATING CHARITABLE PROGRAM EXPENSE	76.59 %	H \$ 310,647.
I EDUCATION PROGRAM SERVICE EXPENSE.....	%	I \$
J TOTAL CHARITABLE PROGRAM SERVICE EXPENSE (ADD H AND I)	76.59 %	J \$ 310,647.
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)	76.59 %	L \$ 310,647.
M MANAGEMENT AND GENERAL EXPENSE.....	9.05 %	M \$ 36,710.
N FUNDRAISING EXPENSE.....	14.36 %	N \$ 58,265.
O TOTAL EXPENDITURES THIS PERIOD (ADD L, M, AND N)	100 %	O \$ 405,622.
III SUMMARY OF ALL PAID FUNDRAISER AND CONSULTANT ACTIVITIES:		
(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:		
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: _____		

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

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

INTEREST INCOME.....	\$	9,365.
	TOTAL	<u>\$ 9,365.</u>

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

BANK OF AMERICA, N.A. - # 000044842254
PO BOX 25118 - TAMPA, FL 33622

BANK OF AMERICA, N.A. - # 009419975756
PO BOX 25118 - TAMPA, FL 33622

BANK OF AMERICA, N.A. - CD #91000077304366
PO BOX 25118 - TAMPA, FL 33622