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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)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

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

B Check if applicable: <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		C CYSTINOSIS RESEARCH FOUNDATION 18802 BARDEEN AVE. IRVINE, CA 92612		D Employer Identification Number 32-0067668	
		E Telephone number 949-223-7610		G Gross receipts \$ 3,648,243.	
F Name and address of principal officer SAME AS C ABOVE				H(a) Is this a group return for affiliates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all affiliates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If 'No,' attach a list (see instructions)	
I Tax-exempt status <input checked="" type="checkbox"/> 501(c) (3) (insert no) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527				H(c) Group exemption number	
J Website: WWW.CYSTINOSISRESEARCH.ORG					
K Form of organization <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other				L Year of Formation 2003 M State of legal domicile CA	

Part I Summary

Activities & Governance	1 Briefly describe the organization's mission or most significant activities CYSTINOSIS RESEARCH FOUNDATION'S MISSION IS TWO-FOLD AND FOCUSED: TO SUPPORT BENCH AND CLINICAL CYSTINOSIS RESEARCH FOR BETTER TREATMENTS AND TO FIND A CURE FOR CYSTINOSIS.			
	2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its assets			
	3	Number of voting members of the governing body (Part VI, line 1a)	13	
	4	Number of independent voting members of the governing body (Part VI, line 1b)	13	
	5	Total number of employees (Part V, line 2a)	0	
	6	Total number of volunteers (estimate if necessary)	35	
	7a	Total gross unrelated business revenue from Part VIII, column (C), line 12	0.	
7b	Net unrelated business taxable income from Form 990-T, line 34	0.		
Revenue	8	Contributions and grants (Part VIII, line 1h)	Prior Year 2,752,925.	Current Year 3,223,627.
	9	Program service revenue (Part VIII, line 2g)		
	10	Investment income (Part VIII, column (A), lines 3, 4, and 10c)	48,418.	-33,050.
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		
	12	Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	2,801,343.	3,190,577.
	13	Grants and similar amounts paid (Part IX, column (A), line 13)	2,289,342.	2,079,853.
	14	Benefits paid to or for members (Part IX, column (A), line 14)		
	15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)		
	16a	Professional fundraising fees (Part IX, column (A), line 11e)		
	16b	Total fundraising expenses (Part IX, column (D), line 25)	320,984.	
Expenses	17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24f)	627,095.	510,030.
	18	Total expenses Add lines 13-17 (must equal Part IX, column (A), line 25)	2,916,437.	2,589,883.
	19	Revenue less expenses Subtract line 18 from line 12	-115,094.	600,694.
	20	Total assets (Part X, line 16)	Beginning of Year 3,041,733.	End of Year 4,010,391.
Net Assets or Fund Balances	21	Total liabilities (Part X, line 26)	1,961,670.	2,107,675.
	22	Net assets or fund balances Subtract line 21 from line 20	1,080,063.	1,902,716.

Part II Signature Block

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 <i>Geoffrey Stack</i> GEOFFREY STACK Type or print name and title	Date <i>9/30/2010</i> TRUSTEE
Paid Preparer's Use Only	Preparer's signature <i>MONMOUTH</i> Firm's name (or yours if self-employed) address, and ZIP + 4 MONTGOMERY, QUICK & COMPANY 5951 VARIEL AVENUE WOODLAND HILLS, CA 91367	Date <i>9/29/10</i> Check if self-employed <input type="checkbox"/> Preparer's identifying number (see instructions) 553-08-6528 EIN 95-4489850 Phone no (818) 999-6967

May the IRS discuss this return with the preparer shown above? (see instructions)

☒ Yes ☐ No

Part III Statement of Program Service Accomplishments**1** Briefly describe the organization's mission

CYSTINOSIS RESEARCH FOUNDATION'S MISSION IS TWO-FOLD AND FOCUSED: TO SUPPORT BENCH AND CLINICAL CYSTINOSIS RESEARCH FOR BETTER TREATMENTS AND TO FIND A CURE FOR CYSTINOSIS.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?
☐ Yes ☒ No

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

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

If 'Yes,' describe these changes on Schedule O

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

4a (Code XXXXXX) (Expenses \$ 2,079,853. including grants of \$ 2,079,853.) (Revenue \$)

WHEN THE CYSTINOSIS RESEARCH FOUNDATION WAS ESTABLISHED, ONE OF OUR GOALS WAS TO IMPROVE THE QUALITY OF LIFE FOR CHILDREN WITH CYSTINOSIS. FINDING MORE EFFECTIVE TREATMENTS FOR CYSTINOSIS WAS THE KEY TO THAT GOAL. WE HAVE AGGRESSIVELY PURSUED NEW AND CUTTING-EDGE RESEARCH BY PURSUING THE BEST AND THE BRIGHTEST SCIENTISTS. THE CRF APPROACH TO RESEARCH IS INTERDISCIPLINARY AND MULTI-FACETED. WE PRIORITIZE COLLABORATIONS AND CYSTINOSIS RESEARCH STUDIES THAT RESULT IN HUMAN CLINICAL TRIALS. WE ARE INCREASINGLY FOCUSED ON THE CLINICAL AND TRANSLATIONAL RESEARCH CRUCIAL TO MAKING THE NECESSARY STRIDES TOWARD A CURE FOR CYSTINOSIS.

4b (Code XXXXXX) (Expenses \$ 46,310. including grants of \$) (Revenue \$)

FUNDING QUALITY CYSTINOSIS RESEARCH STUDIES REMAINS A PRIORITY AND IS AN ONGOING PROCESS. TO DATE, THE CRF HAS FUNDED AND COMMITTED OVER \$10.8 MILLION TO CYSTINOSIS RESEARCH AND HAS FUNDED MORE THAN 70 RESEARCH STUDIES AND FELLOWSHIPS. TODAY, WITH THE SUPPORT OF OUR FRIENDS AND COMMUNITY WE HAVE SIGNIFICANTLY CHANGED THE COURSE OF CYSTINOSIS RESEARCH. OUR FUNDING EFFORTS HAVE ALLOWED TALENTED DOCTORS AND RESEARCHERS IN THE AREA OF CYSTINOSIS TO INITIATE NOVEL RESEARCH STUDIES AND TO ADVANCE THEIR RESEARCH EFFORTS. THE VIDEO CAMPAIGN HAS BEEN INSTRUMENTAL IN CONVEYING THIS MESSAGE TO THE PUBLIC AND THE RESEARCH COMMUNITY THROUGH OUR WEB SITE, YOUTUBE AND VARIOUS INTERNET SITES.

4c (Code XXXXXX) (Expenses \$ 12,616. including grants of \$) (Revenue \$)

PRINTING AND POSTAGE COSTS FOR PROGRAM SERVICES

4d Other program services (Describe in Schedule O) SEE SCHEDULE O

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

4e Total program service expenses ▶ 2,138,779.

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)? If 'Yes,' complete Schedule A	X	
2 Is the organization required to complete Schedule B, Schedule of Contributors?	X	
3 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		X
4 Section 501(c)(3) organizations Did the organization engage in lobbying activities? If 'Yes,' complete Schedule C, Part II		X
5 Section 501(c)(4), 501(c)(5), and 501(c)(6) organizations. Is the organization subject to the section 6033(e) notice and reporting requirement and proxy tax? If 'Yes,' complete Schedule C, Part III		
6 Did the organization maintain any donor advised funds or any similar funds or accounts where donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If 'Yes,' complete Schedule D, Part 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? If 'Yes,' complete Schedule D, Part II		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If 'Yes,' complete Schedule D, Part III		X
9 Did the organization report an amount in Part X, line 21, serve as a custodian for amounts not listed in Part X, or provide credit counseling, debt management, credit repair, or debt negotiation services? If 'Yes,' complete Schedule D, Part IV		X
10 Did the organization, directly or through a related organization, hold assets in term, permanent, or quasi-endowments? If 'Yes,' complete Schedule D, Part V		X
11 Is the organization's answer to any of the following questions 'Yes'? If so, complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable	X	
• Did the organization report an amount for land, buildings and equipment in Part X, line 10? If 'Yes,' complete Schedule D, Part VI		
• 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? If 'Yes,' complete Schedule D, Part VII		
• 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? If 'Yes,' complete Schedule D, Part VIII		
• 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? If 'Yes,' complete Schedule D, Part IX		
• Did the organization report an amount for other liabilities in Part X, line 25? If 'Yes,' complete Schedule D, Part X		
• 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? If 'Yes,' complete Schedule D, Part X		
12 Did the organization obtain separate, independent audited financial statement for the tax year? If 'Yes,' complete Schedule D, Parts XI, XII, and XIII	X	
12A Was the organization included in consolidated, independent audited financial statement for the tax year? If 'Yes,' completing Schedule D, Parts XI, XII, and XIII is optional	X	
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If 'Yes,' complete Schedule E		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, and program service activities outside the United States? If 'Yes,' complete Schedule F, Part 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? If 'Yes,' complete Schedule F, Part II	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? If 'Yes,' complete Schedule F, Part III		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? If 'Yes,' complete Schedule G, Part 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? If 'Yes,' complete Schedule G, Part II	X	
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If 'Yes,' complete Schedule G, Part III		X
20 Did the organization operate one or more hospitals? If 'Yes,' complete Schedule H		X

Part IV Checklist of Required Schedules (continued)

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

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Part V Statements Regarding Other IRS Filings and Tax Compliance

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

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Form 990 (2009)

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

Section A. Governing Body and Management

	Yes	No
1a Enter the number of voting members of the governing body	13	
1b Enter the number of voting members that are independent	13	
2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee or key employee? SEE SCHEDULE O	X	
3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?		X
4 Did the organization make any significant changes to its organizational documents since the prior Form 990 was filed?		X
5 Did the organization become aware during the year of a material diversion of the organization's assets?		X
6 Does the organization have members or stockholders?		X
7a Does the organization have members, stockholders, or other persons who may elect one or more members of the governing body?		X
7b Are any decisions of the governing body subject to approval by members, stockholders, or other persons?		X
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a The governing body?	X	
b Each committee with authority to act on behalf of the governing body?	X	
9 Is there any officer, director or 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
10a Does the organization have local chapters, branches, or affiliates?		X
b If 'Yes,' does the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with those of the organization?		
11 Has the organization provided a copy of this Form 990 to all members of its governing body before filing the form?	X	
11A Describe in Schedule O the process, if any, used by the organization to review this Form 990 SEE SCHEDULE O		
12a Does the organization have a written conflict of interest policy? If 'No,' go to line 13	X	
b Are officers, directors or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	X	
c Does the organization regularly and consistently monitor and enforce compliance with the policy? If 'Yes,' describe in Schedule O how this is done SEE SCHEDULE O	X	
13 Does the organization have a written whistleblower policy?	X	
14 Does the organization have a written document retention and destruction policy?	X	
15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?		
a The organization's CEO, Executive Director, or top management official		X
b Other officers of key employees of the organization		X
If 'Yes' to line 15a or 15b, describe the process in Schedule O (See instructions)		
16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?		X
b If 'Yes,' has the organization adopted a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and taken steps to safeguard the organization's exempt status with respect to such arrangements?		

Section C. Disclosures

17 List the states with which a copy of this Form 990 is required to be filed ► NONE

18 Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you make these available. Check all that apply.
☐ Own website ☒ Another's website ☒ Upon request

19 Describe in Schedule O whether (and if so, how) the organization makes its governing documents, conflict of interest policy, and financial statements available to the public SEE SCHEDULE O

20 State the name, physical address, and telephone number of the person who possesses the books and records of the organization
 ► GEOFFREY STACK 18802 BARDEEN AVE IRVINE CA 92612 949 756-5959

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees**

1 a 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. Use Schedule J-2 if additional space is needed.

- 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. See instructions for definition of "key employees."
- 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 the organization did not compensate any current officer, director, or trustee

(A) Name and Title	(B) Average hours per week	(C) Position (check all that apply)						(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			
GEOFFREY STACK TRUSTEE	0	X						0.	0.	0.
NANCY STACK TRUSTEE	30	X						0.	0.	0.
DONALD L. SOLSBY TREASURER	0	X						0.	0.	0.
RENEE CARTER DIRECTOR	0	X						0.	0.	0.
DAVID CHRISTENSEN DIRECTOR	0	X						0.	0.	0.
JASON GRIER DIRECTOR	0	X						0.	0.	0.
JOHN S. HAGESTAD DIRECTOR	0	X						0.	0.	0.
LYNETTE HAYDE DIRECTOR	0	X						0.	0.	0.
MICHAEL K. HAYDE DIRECTOR	0	X						0.	0.	0.
KRIS K. ELFTMANN DIRECTOR	0	X						0.	0.	0.
KEVIN PARTINGTON DIRECTOR	0	X						0.	0.	0.
TERESA PARTINGTON DIRECTOR	0	X						0.	0.	0.
JERRY SCHNEIDER, M.D. DIRECTOR	0	X						0.	0.	0.

[illegible]

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

- | | Yes | No |
|---|-----|----|
| 3 | | X |
| 4 | | X |
| 5 | | X |

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization		
(A) Name and business address	(B) Description of Services	(C) Compensation
2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 in compensation from the organization ▶ 0		

Part VIII Statement of Revenue

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514
CONTRIBUTIONS, GIFTS, GRANTS AND OTHER SIMILAR AMOUNTS	1 a Federated campaigns	1 a				
	b Membership dues	1 b				
	c Fundraising events	1 c 1,175,129.				
	d Related organizations	1 d				
	e Government grants (contributions)	1 e				
	f All other contributions, gifts, grants, and similar amounts not included above	1 f 2,048,498.				
	g Noncash contribns included in lns 1a-1f	\$ 83,852.				
	h Total. Add lines 1a-1f		3,223,627.			
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)		38,527.	38,527.		
	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)		-71,577.	-71,577.		
	8 a Gross income from fundraising events (not including \$ 1,175,129. 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		3,190,577.	-33,050.	0.	0.	

Part IX Statement of Functional Expenses

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

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

<i>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</i>	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to governments and organizations in the U S See Part IV, line 21	1,357,903.	1,357,903.		
2 Grants and other assistance to individuals in the U S See Part IV, line 22				
3 Grants and other assistance to governments, organizations, and individuals outside the U S See Part IV, lines 15 and 16	721,950.	721,950.		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	0.	0.	0.	0.
6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1) and persons described in section 4958(c)(3)(B)	0.	0.	0.	0.
7 Other salaries and wages				
8 Pension plan contributions (include section 401(k) and section 403(b) employer contributions)				
9 Other employee benefits				
10 Payroll taxes				
11 Fees for services (non-employees)				
a Management				
b Legal				
c Accounting	25,965.		20,494.	5,471.
d Lobbying				
e Prof fundraising svcs See Part IV, ln 17				
f Investment management fees				
g Other				
12 Advertising and promotion	19,750.			19,750.
13 Office expenses				
14 Information technology				
15 Royalties				
16 Occupancy				
17 Travel				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings				
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	8,249.		8,249.	
23 Insurance				
24 Other expenses Itemize expenses not covered above (Expenses grouped together and labeled miscellaneous may not exceed 5% of total expenses shown on line 25 below)				
a OUTSIDE SERVICES	74,689.		31,625.	43,064.
b PRINTING AND PUBLICATIONS	70,901.	12,616.	11,032.	47,253.
c HOTEL FEES - FUNDRAISER	68,769.			68,769.
d PROFESSIONAL SERVICES	40,569.		40,569.	
e SPEAKER FEES	40,000.			40,000.
f All other expenses	161,138.	46,310.	18,151.	96,677.
25 Total functional expenses Add lines 1 through 24f	2,589,883.	2,138,779.	130,120.	320,984.
26 Joint costs. Check here <input type="checkbox"/> if following SOP 98-2 Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation				

BAA

Form 990 (2009)

Part X Balance Sheet

		(A) Beginning of year		(B) End of year
ASSETS	1 Cash – non-interest-bearing		1	
	2 Savings and temporary cash investments	2,341,646.	2	2,103,655.
	3 Pledges and grants receivable, net	110,720.	3	1,202,423.
	4 Accounts receivable, net		4	
	5 Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L		5	
	6 Receivables from other disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B). Complete Part II of Schedule L		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	57,023.	9	29,691.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 47,188.		
	b Less: accumulated depreciation.	10b 11,203.	36,359.	10c 35,985.
	11 Investments – publicly-traded securities	495,985.	11	638,637.
	12 Investments – other securities. See Part IV, line 11		12	
	13 Investments – program-related. See Part IV, line 11		13	
	14 Intangible assets		14	
	15 Other assets. See Part IV, line 11		15	
16 Total assets. Add lines 1 through 15 (must equal line 34).	3,041,733.	16	4,010,391.	
LIABILITIES	17 Accounts payable and accrued expenses	20,430.	17	15,304.
	18 Grants payable	1,941,240.	18	2,092,371.
	19 Deferred revenue		19	
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22 Payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	
	25 Other liabilities. Complete Part X of Schedule D		25	
	26 Total liabilities. Add lines 17 through 25	1,961,670.	26	2,107,675.
	NET ASSETS OR FUND BALANCES	Organizations that follow SFAS 117, check here <input checked="" type="checkbox"/> and complete lines 27 through 29 and lines 33 and 34.		
27 Unrestricted net assets		1,080,063.	27	1,902,716.
28 Temporarily restricted net assets			28	
29 Permanently restricted net assets			29	
Organizations that do not follow SFAS 117, check here <input type="checkbox"/> and complete lines 30 through 34.				
30 Capital stock or trust principal, or current funds			30	
31 Paid-in or capital surplus, or land, building, and equipment fund			31	
32 Retained earnings, endowment, accumulated income, or other funds			32	
33 Total net assets or fund balances		1,080,063.	33	1,902,716.
34 Total liabilities and net assets/fund balances.		3,041,733.	34	4,010,391.

BAA

Form 990 (2009)

Part XI Financial Statements and Reporting

- 1 Accounting method used to prepare the Form 990 ☐ Cash ☒ Accrual ☐ Other

If the organization changed its method of accounting from a prior year or checked 'Other,' explain in Schedule O

- 2a Were the organization's financial statements compiled or reviewed by an independent accountant?

- b Were the organization's financial statements audited by an independent accountant?

- c 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

- d If 'Yes' to line 2a or 2b, check a box below to indicate whether the financial statements for the year were issued on a consolidated basis, separate basis, or both

☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis

- 3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?

- b If 'Yes,' did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits

	Yes	No
2a		X
2b	X	
2c	X	
3a		X
3b		

BAA

Form 990 (2009)

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'.)	1,148,690.	1,668,193.	2,562,050.	2,752,925.	3,223,627.	11,355,485.
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	1,148,690.	1,668,193.	2,562,050.	2,752,925.	3,223,627.	11,355,485.
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)						4,077,188.
6 Public support. Subtract line 5 from line 4						7,278,297.

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	1,148,690.	1,668,193.	2,562,050.	2,752,925.	3,223,627.	11,355,485.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	11,993.	48,939.	106,545.	48,418.	38,527.	254,422.
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						11,609,907.
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 ▶ ☐**Section C. Computation of Public Support Percentage**

14 Public support percentage for 2009 (line 6, column (f) divided by line 11, column (f))	14	62.7 %
15 Public support percentage from 2008 Schedule A, Part II, line 14	15	69.7 %

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. ▶ ☒**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. ▶ ☐**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. ▶ ☐**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. ▶ ☐**18 Private foundation.** If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions. ▶ ☐

Part 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 on line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						
14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here. ▶ <input type="checkbox"/>						

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. ▶ <input type="checkbox"/>		
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. ▶ <input type="checkbox"/>		
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions. ▶ <input type="checkbox"/>		

Part IV **Supplemental Information.** Complete this part to provide the explanations required by Part II, line 10; Part II, line 17a or 17b; and Part III, line 12. Provide any other additional information. See instructions.

Supplemental Information. Complete this part to provide the explanations required by Part II, line 10; Part II, line 17a or 17b; and Part III, line 12. Provide any other additional information. See instructions.

[illegible]

**SCHEDULE D
(Form 990)**Department of the Treasury
Internal Revenue Service

Name of the organization

Supplemental Financial Statements

- **Complete if the organization answered 'Yes,' to Form 990, Part IV, lines 6, 7, 8, 9, 10, 11, or 12.**
► **Attach to Form 990. ► See separate instructions**

OMB No 1545-0047

2009**Open to Public Inspection**

Employer identification number

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

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 may be used only for charitable purposes and not for the benefit of the donor or donor advisor or for any other purpose conferring impermissible private benefit?	<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)

<input type="checkbox"/> Preservation of land for public use (e.g., recreation or pleasure)	<input type="checkbox"/> Preservation of an historically important land area
<input type="checkbox"/> Protection of natural habitat	<input type="checkbox"/> Preservation of certified historic structure
<input type="checkbox"/> 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 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	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 easement it holds? ☐ Yes ☐ No

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

7 Amount of expenses incurred in monitoring, inspecting, and enforcing conservation easements during the year ► \$ _____

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and 170(h)(4)(B)(ii)? ☐ Yes ☐ No

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

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets

Complete if the organization answered 'Yes' to Form 990, Part IV, line 8

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

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

(i) Revenues included in Form 990, Part VIII, line 1 ► \$ _____

(ii) Assets included in Form 990, Part X ► \$ _____

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

a Revenues included in Form 990, Part VIII, line 1 ► \$ _____

b Assets included in Form 990, Part X ► \$ _____

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

3 Using the organization's 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 XIV

5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? ☐ Yes ☐ No

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

1a Is the organization an agent, trustee, custodian, or other intermediary for contributions or other assets not included on Form 990, Part X? ☐ Yes ☐ No

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

- c Beginning balance
 d Additions during the year
 e Distributions during the year
 f Ending balance

	Amount
1 c	
1 d	
1 e	
1 f	

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

b If 'Yes,' explain the arrangement in Part XIV

Part V Endowment Funds Complete if 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 year end balance held as

- a Board designated or quasi-endowment ▶ _____ %
 b Permanent endowment ▶ _____ %
 c Term endowment ▶ _____ %

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

- (i) unrelated organizations
 (ii) related organizations

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

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

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

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

Description of investment	(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		47,188.	11,203.	35,985.
e Other				

Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c)) ▶ 35,985.

BAA

Schedule D (Form 990) 2009

Part VII Investments—Other Securities See Form 990, Part X, line 12 N/A

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation Cost or end-of-year market value
Financial derivatives		
Closely-held equity interests		
Other		
Total. (Column (b) must equal Form 990 Part X, col. (B) line 12) ▶		

Part VIII Investments—Program Related (See Form 990, Part X, line 13) N/A

(a) Description of investment type	(b) Book value	(c) Method of valuation Cost or end-of-year market value
Total. (Column (b) must equal Form 990, Part X, Col. (B) line 13) ▶		

Part IX Other Assets (See Form 990, Part X, line 15) N/A

(a) Description	(b) Book value
Total. (Column (b) must equal Form 990, Part X, col. (B), line 15) ▶	

Part X Other Liabilities (See Form 990, Part X, line 25)

(a) Description of Liability	(b) Amount
Federal Income Taxes	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 25) ▶	

2. FIN 48 Footnote In Part XIV, 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

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

1	Total revenue (Form 990, Part VIII, column (A), line 12)	3,190,577.
2	Total expenses (Form 990, Part IX, column (A), line 25)	2,589,883.
3	Excess or (deficit) for the year Subtract line 2 from line 1	600,694.
4	Net unrealized gains (losses) on investments	
5	Donated services and use of facilities	
6	Investment expenses	
7	Prior period adjustments	
8	Other (Describe in Part XIV)	
9	Total adjustments (net) Add lines 4 through 8	
10	Excess or (deficit) for the year per audited financial statements Combine lines 3 and 9	600,694.

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

1	Total revenue, gains, and other support per audited financial statements	1	3,412,536.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12		
a	Net unrealized gains on investments	2a	221,959.
b	Donated services and use of facilities	2b	
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIV)	2d	
e	Add lines 2a through 2d	2e	221,959.
3	Subtract line 2e from line 1	3	3,190,577.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1		
a	Investments expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIV)	4b	
c	Add lines 4a and 4b	4c	
5	Total revenue Add lines 3 and 4c. (This must equal Form 990, Part I, line 12)	5	3,190,577.

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

1	Total expenses and losses per audited financial statements	1	2,589,883.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25		
a	Donated services and use of facilities	2a	
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIV)	2d	
e	Add lines 2a through 2d	2e	
3	Subtract line 2e from line 1	3	2,589,883.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
a	Investments expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIV)	4b	
c	Add lines 4a and 4b	4c	
5	Total expenses Add lines 3 and 4c. (This must equal Form 990, Part I, line 18)	5	2,589,883.

Part XIV Supplemental Information

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

[illegible]

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

2009

Open to Public Inspection

Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

Employer identification number	
--------------------------------	--

32-0067668

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

- 1 **For grantmakers.** Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? ☒ Yes ☐ No
- 2 **For grantmakers.** Describe in Part IV the organization's procedures for monitoring the use of grant funds outside the United States
- 3 Activities per Region (Use Schedule F-1 (Form 990) if additional space is needed)

[illegible]

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

Schedule F (Form 990) (2009)

Part IV Supplemental Information

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

ADDITIONAL SUPPLEMENTAL INFORMATION

SUMMARY OF GRANTEES:

- 1) HOPITAL NECKER, 149 RUE DE SEVRES, PARIS, FRANCE
- 2) ACS DU CNRS, 16 RUE PIERRE ET MARIE CURIE, PARIS, FRANCE
- 3) AGS INSERM PARIS V SAINTE ANNE, 149 75743 PARIS RUE DE SEVRES, PARIS, FRANCE
- 4) BAMBINO GESU CHILDRENS HOSP. & RESEARCH, PIAZZA S. ONOFRIO, ROME, ITALY
- 5) UNIVERSITY HOSPITAL LEUVEN HERESM, 49 3000 LEUVEN, LEUVEN, BELIGUM
- 6) L'AGENT COMPTABLE SECONDAIRE DU, 5534 1919 ROUTE DE MENDE, MONTPELLIER, FRANCE

Department of the Treasury
Internal Revenue Service

Complete if the organization answered 'Yes' to Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.
▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

OMB No. 1545-0047

2009

Open to Public Inspection

Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

Employer identification number

32-0067668

Part I	Fundraising Activities. Complete if the organization answered 'Yes' to Form 990, Part IV, line 17 Form 990EZ filers are not required to complete this part
---------------	--

- 1 Indicate whether the organization raised funds through any of the following activities. Check all that apply.

- | | | | |
|--------------------------|----------------------------------|-------------------------------------|---------------------------------------|
| <input type="checkbox"/> | Mail solicitations | <input type="checkbox"/> | Solicitation of non-government grants |
| <input type="checkbox"/> | Internet and email solicitations | <input type="checkbox"/> | Solicitation of government grants |
| <input type="checkbox"/> | Phone solicitations | <input checked="" type="checkbox"/> | Special fundraising events |
| <input type="checkbox"/> | In-person solicitations | | |

- 2a** Did the organization have written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?

☐ Yes ☒ No

- b** If 'Yes,' list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization

(i) Name of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
Total						0

- 3 List all states in which the organization is registered or licensed to solicit funds or has been notified it is exempt from registration or licensing

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
		ANNUAL FUNDRAI (event type)	(event type)	(total number)	(Add col (a) through col (c))
	1 Gross receipts	1,175,129.			1,175,129.
	2 Less Charitable contributions	1,175,129.			1,175,129.
	3 Gross income (line 1 minus line 2)				
DIRECT EXPENSES	4 Cash prizes				
	5 Noncash prizes				
	6 Rent/facility costs				
	7 Food and beverages				
	8 Entertainment				
	9 Other direct expenses				
	10 Direct expense summary Add lines 4- through 9 in column (d)				
	11 Net income summary Combine lines 3, column (d) and line 10				

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))
	1 Gross revenue				
	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				

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?

b If 'No,' explain _____

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year?

b If 'Yes,' explain _____

11 Does the organization operate gaming activities with nonmembers?

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?

	YES	NO
9a		
10a		
11		
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 ▶ \$ _____			

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, lines 21 or 22.
▶ Attach to Form 990.

OMB No 1545-0047

2009

**Open to Public
Inspection**

Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

Employer identification number

32-0067668

Part I General Information on Grants and Assistance

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

☒ **Yes** ☐ **No**

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

Part II Grants and Other Assistance to Governments and Organizations in the United States. Complete if the organization answered 'Yes' to Form 990, Part IV, line 21 for any recipient that received more than \$5,000. Check this box if no one recipient received more than \$5,000. Use ▶ ☐

Part IV and Schedule I-1 (Form 990) if additional space is needed

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
BOARD OF TRUSTEES, LELAND STANFORD JUNIOR UNIVERSITY, 700 WELCH RD #301N, PALO ALTO, CA 94304	94-1156365	501 (C) (3)	164,483	0			MEDICAL RESEARCH
MASSACHUSETTS GENERAL HOSPITAL, 101 HUNTINGTON AVENUE, SUITE 300 BOSTON, MA 02199	04-1564655	501 (C) (3)	37,500	0			MEDICAL RESEARCH
REGENTS OF THE UC-UCSF, 1855 FOLSOM STREET MCB-425 BOX 0, SAN FRANCISCO, CA 94143	94-6036493	501 (C) (3)	135,976	0			MEDICAL RESEARCH
REGENTS OF UNIVERSITY OF CALIFORNIA, 1111 FRANKLIN ST, 12TH FLOOR, OAKLAND, CA 94607	94-6060626	501 (C) (3)	21,133	0			MEDICAL RESEARCH
SANFORD MEDICAL RESEARCH, USD, 1100 E 21ST STREET #700, SIOUX FALLS, SD 57105	46-0418678	501 (C) (3)	57,824	0			MEDICAL RESEARCH
SEATTLE CHILDREN'S HOSPITAL, 1100 OLIVE WAY #500, SEATTLE, WA 98101	91-0564748	501 (C) (3)	89,069	0			MEDICAL RESEARCH
SOUTHWEST FOUNDATION FOR BIOMEDICAL RESEARCH, P.O. BOX 760549, SAN ANTONIO, TX 78245	74-1109630	501 (C) (3)	128,870	0			MEDICAL RESEARCH
THE SCRIPPS RESEARCH INSTITUTE, 10550 N. TORREY PINES ROAD, LA JOLLA, CA 92037	33-0435954	501 (C) (3)	312,236	0			MEDICAL RESEARCH

2 Enter total number of section 501(c)(3) and government organizations **12**

3 Enter total number of other organizations **0**

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

TEEA3901L 02/10/10

Schedule I (Form 990) 2009

Continuation Sheet for Schedule I (Form 990)

► Attach to Form 990 to list additional information for Schedule I (Form 990), Part II and Part III.

Department of the Treasury
Internal Revenue Service

Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

Employer identification number

32-0067668

Part I	Continuation of Grants and Other Assistance to Governments and Organizations in the United States (Schedule I (Form 990), Part I.)
Part II	Continuation of Grants and Other Assistance to Governments and Organizations in the United States (Schedule I (Form 990), Part II.)

[illegible]

SCHEDULE L
(Form 990 or 990-EZ)Department of the Treasury
Internal Revenue Service**Transactions with Interested Persons**

- Complete if the organization answered
'Yes' on Form 990, Part IV, line 25a, 25b, 26, 27, 28a, 28b, or 28c,
or Form 990-EZ, Part V, line 38a or 40b.
► Attach to Form 990 or Form 990-EZ. ► See separate instructions.

OMB No 1545-0047

2009**Open to Public
Inspection**

Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

Employer identification number

32-0067668

Part I Excess Benefit Transactions (section 501(c)(3) and section 501(c)(4) organizations only).
Complete if the organization answered 'Yes' on Form 990, Part IV, line 25a or 25b, or Form 990-EZ, Part V, line 40b

1	(a) Name of disqualified person	(b) Description of transaction	(c) Corrected?	
			Yes	No

2 Enter the amount of tax imposed on the organization managers or disqualified persons during the year under section 4958 ► \$

3 Enter the amount of tax, if any, on line 2, above, reimbursed by the organization ► \$

Part II Loans to and/or From Interested Persons.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 26 or Form 990-EZ, Part V, line 38a.

(a) Name of interested person and purpose	(b) Loan to or from the organization?		(c) Original principal amount	(d) Balance due	(e) In default?		(f) Approved by board or committee?		(g) Written agreement?	
	To	From			Yes	No	Yes	No	Yes	No
Total				► \$						

Part III Grants or Assistance Benefitting Interested Persons.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 27

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount and type of assistance

Part IV Business Transactions Involving Interested Persons.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 28a, 28b, or 28c

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of transaction \$	(d) Description of transaction	(e) Sharing of organization's revenues?	
				Yes	No
KRIS K ELFTMANN	DIRECTOR	60,838.	SEE NOTE (1)		X
DONALD L SOLSBY	DIRECTOR	35,000.	SEE NOTE (2)		X

BAA For Privacy Act and Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule L (Form 990 or 990-EZ) 2009

SCHEDULE M
(Form 990)

Department of the Treasury
Internal Revenue Service

Noncash Contributions

► **Complete if the organizations answered 'Yes'**
on Form 990, Part IV, lines 29 or 30.
► **Attach to Form 990.**

OMB No 1545-0047

2009

**Open To Public
Inspection**

Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

Employer identification number

32-0067668

Part I Types of Property

	(a) Check if applicable	(b) Number of Contributions	(c) Revenues reported on Form 990, Part VIII, line 1g	(d) Method of determining revenues
1 Art—Works of art				
2 Art—Historical treasures				
3 Art—Fractional interests				
4 Books and publications				
5 Clothing and household goods				
6 Cars and other vehicles				
7 Boats and planes				
8 Intellectual property				
9 Securities—Publicly traded				
10 Securities—Closely held stock				
11 Securities—Partnership, LLC, or trust interests				
12 Securities—Miscellaneous				
13 Qualified conservation contribution— Historic structures				
14 Qualified conservation contribution—Other				
15 Real estate—Residential				
16 Real estate—Commercial				
17 Real estate—Other				
18 Collectibles				
19 Food inventory				
20 Drugs and medical supplies				
21 Taxidermy				
22 Historical artifacts				
23 Scientific specimens				
24 Archeological artifacts				
25 Other ► (<u>OTHER MISC</u>)		50	83,852.	COMPARABLES
26 Other ► ()				
27 Other ► ()				
28 Other ► ()				

29 Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part IV, Donee Acknowledgement

29

30a During the year, did the organization receive by contribution any property reported in Part I, lines 1-28 that it must hold for at least three years from the date of the initial contribution, and which is not required to be used for exempt purposes for the entire holding period?

b If 'Yes,' describe the arrangement in Part II

31 Does the organization have a gift acceptance policy that requires the review of any non-standard contributions?

32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?

b If 'Yes,' describe in Part II

33 If the organization did not report revenues in column (c) for a type of property for which column (a) is checked, describe in Part II

	Yes	No
30a		X
31		X
32a		X
33		

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

Schedule M (Form 990) 2009

Part II

Supplemental Information. Complete this part to provide the information required by Part I, lines 30b, 32b, and 33. Also complete this part for any additional information.

SCHEDULE O
(Form 990)

Supplemental Information to Form 990

OMB No 1545 0047

2009

**Open to Public
Inspection**

Department of the Treasury
Internal Revenue Service

Complete to provide information for responses to specific questions on
Form 990 or to provide any additional information.
▶ Attach to Form 990.

Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

Employer identification number

32-0067668

FORM 990, PART III, LINE 4D - OTHER PROGRAM SERVICES DESCRIPTION

CRF ANNOUNCES TWO GLOBAL CALLS FOR RESEARCH PROPOSALS EACH YEAR. AFTER EVALUATION BY OUR SCIENTIFIC REVIEW BOARD, RESEARCH GRANTS ARE ISSUED. THE SCIENTIFIC REVIEW BOARD IS COMPOSED OF LEADING CYSTINOSIS SCIENTISTS, RESEARCHERS AND DOCTORS FROM AROUND THE WORLD. THE MEMBERS ARE ACTIVELY INVOLVED IN THE GRANT REVIEW PROCESS AND ADVISE THE CYSTINOSIS RESEARCH FOUNDATION ON THE MERIT OF EACH PROPOSAL, SUBMIT FUNDING RECOMMENDATIONS AND OFFER GENERAL RESEARCH GUIDELINES. IN 2006, THE FOUNDATION ESTABLISHED THE FIRST CYSTINOSIS RESEARCH FELLOWSHIP PROGRAM DESIGNED TO SUPPORT SCIENTISTS AND NEW RESEARCHERS WHO HAVE AN INTEREST IN CYSTINOSIS.

TO DATE, THE CRF HAS FUNDED AND COMMITTED OVER \$10.8 MILLION FOR CYSTINOSIS RESEARCH AND HAS FUNDED MORE THAN 70 RESEARCH STUDIES AND FELLOWSHIPS IN SIX COUNTRIES. TODAY, WITH THE SUPPORT OF OUR NETWORK OF FAMILIES AND FRIENDS WE HAVE MADE A SIGNIFICANT AND DRAMATIC DIFFERENCE IN THE COURSE OF CYSTINOSIS RESEARCH.

THE CYSTINOSIS RESEARCH FOUNDATION'S PRIMARY FOCUS IS TO FIND A CURE FOR CYSTINOSIS. A GROUP OF LEADING RESEARCHERS IN STEM CELL AND GENE THERAPIES, MOLECULAR BIOLOGY AND CLINICAL PATHOPHYSIOLOGY HAVE FORMED THE CYSTINOSIS RESEARCH FOUNDATION (CRF) GENE THERAPY CONSORTIUM, WITH THE GOAL TO ADVANCE PROGRESS ON THE MOST PROMISING CURRENT FINDINGS, INCLUDING MOVING NOVEL THERAPEUTIC MODALITIES INTO HUMAN PATIENTS AS QUICKLY AS POSSIBLE. THE CRF GENE THERAPY CONSORTIUM HOLDS THE FIRST REAL PROMISE THAT A CURE FOR CYSTINOSIS IS A POSSIBILITY.

THE SECOND CRF INTERNATIONAL CYSTINOSIS RESEARCH SYMPOSIUM IS PLANNED FOR APRIL 2010 AT THE PRESTIGIOUS ARNOLD AND MABEL BECKMAN CENTER OF THE NATIONAL ACADEMIES OF ENGINEERING AND SCIENCE ON THE UCI CAMPUS. THE EVENT WILL BE ATTENDED BY MORE THAN

Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

Employer identification number

32-0067668

FORM 990, PART III, LINE 4D - OTHER PROGRAM SERVICES DESCRIPTION (CONTINUED)

60 RESEARCHERS AND SCIENTISTS REPRESENTING SEVEN COUNTRIES WHO HAVE BEEN WORKING TO
ACHIEVE BETTER TREATMENTS AND A CURE FOR CYSTINOSIS.

FORM 990, PART VI, LINE 2 - BUSINESS OR FAMILY RELATIONSHIP OF OFFICERS, DIRECT

TRUSTEES, GEOFFREY AND NANCY STACK, ARE HUSBAND AND WIFE.

DIRECTORS, MICHAEL AND LYNETTE HAYDE, ARE HUSBAND AND WIFE.

DIRECTORS, KEVIN AND TERESA PARTINGTON, ARE HUSBAND AND WIFE.

FORM 990, PART VI, LINE 11 - FORM 990 REVIEW PROCESS

FORM 990 IS REVIEWED BY BOARD OF DIRECTORS PRIOR TO FILING. AUDITORS FOR THE
FOUNDATION HAVE REVIEWED THE RETURN AND PROVIDED COMMENTS TO THE TAX PREPARER.

FORM 990, PART VI, LINE 12C - EXPLANATION OF MONITORING AND ENFORCEMENT OF CONFLICTS

BOARD REVIEWS POSSIBLE CONFLICTS ON A REGULAR BASIS AND DISCLOSES REVIEW AT BOARD
MEETINGS

FORM 990, PART VI, LINE 19 - OTHER ORGANIZATION DOCUMENTS PUBLICLY AVAILABLE

CRF MAINTAINS THE GOVERNING DOCUMENTS, POLICIES AND PROCEDURES AND FINANCIAL
STATEMENTS AT ITS OFFICES IN IRVINE, CALIFORNIA. COPIES OF THESE DOCUMENTS ARE
AVAILABLE TO THE PUBLIC UPON REQUEST. OUR FORM 990 IS POSTED ON GUIDESTAR ON THE
INTERNET.

Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

Employer identification number

32-0067668

Area with horizontal dashed lines for supplemental information.

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

SCHEDULE L - PART IV

NOTE (1)

DIRECTOR KRIS ELFTMANN IS THE OWNER OF NOELLE MARKETING GROUP WHICH PROVIDES MARKETING SERVICES FOR THE FOUNDATION. TOTAL FEES PAID TO NOELLE MARKETING GROUP IN 2009 WERE \$60,838.

NOTE (2)

DIRECTOR DONALD SOLSBY'S WIFE, ZOE SOLSBY, IS A CONSULTANT TO THE FOUNDATION. MRS. SOLSBY RECEIVED COMPENSATION OF \$35,000 IN 2009.

SCHEDULE B - PART I, ITEM 2 AND PART II, ITEM 1 - NON-CASH GIFTS

NOTE (3)

THE BALANCE CONSISTS OF APPROXIMATELY 50 NON-CASH GIFTS NONE OF WHICH EXCEEDED 2% OF FORM 990, PART VIII, LINE 1(H)

SCHEDULE G - PART II

NOTE (4) - FUNDRAISERS

THE FOUNDATION HOLDS ANNUAL FUNDRAISING EVENTS. HOWEVER THE INCOME IS RECEIVED IN THE FORM OF CHARITABLE CONTRIBUTIONS AND SO NO SEPARATE ACCOUNTING HAS BEEN SHOWN ON SCHEDULE G. DIRECT COSTS OF THE FUNDRAISERS ARE SHOWN ON FORM 990, PART IX. CONTROL OF FUNDS IS MAINTAINED BY THE FOUNDATION AND NOT THIRD PARTY PROFESSIONAL FUNDRAISERS.

Form **8868**

(Rev April 2009)

Department of the Treasury
Internal Revenue Service**Application for Extension of Time To File an
Exempt Organization Return**

OMB No 1545-1709

► **File a separate application for each return.**

- If you are filing for an **Automatic 3-Month Extension**, complete only **Part I** and check this box ☒
- If you are filing for an **Additional (Not Automatic) 3-Month Extension**, complete only **Part II** (on page 2 of this form)

Do not complete Part II unless you have already been granted an automatic 3-month extension on a previously filed Form 8868**Part I Automatic 3-Month Extension of Time.** Only submit original (no copies needed)A corporation required to file Form 990-T and requesting an automatic 6-month extension – check this box and complete Part I only ☐*All other corporations (including 1120-C filers), partnerships, REMICS, and trusts must use Form 7004 to request an extension of time to file income tax returns*

Electronic Filing (e-file). Generally, you can electronically file Form 8868 if you want a 3-month automatic extension of time to file one of the returns noted below (6 months for a corporation required to file Form 990-T). However, you cannot file Form 8868 electronically if (1) you want the additional (not automatic) 3-month extension or (2) you file Forms 990-BL, 6069, or 8870, group returns, or a composite or consolidated Form 990-T. Instead, you must submit the fully completed and signed page 2 (Part II) of Form 8868. For more details on the electronic filing of this form, visit www.irs.gov/efile and click on *e-file for Charities & Nonprofits*

Type or print File by the due date for filing your return. See instructions.	Name of Exempt Organization	Employer identification number
	CYSTINOSIS RESEARCH FOUNDATION	32-0067668
	Number, street and room or suite number. If a P.O. box, see instructions.	
	18802 BARDEEN AVE.	
	City, town or post office, state, and ZIP code. For a foreign address, see instructions.	
	IRVINE, CA 92612	

Check type of return to be filed (file a separate application for each return)

<input checked="" type="checkbox"/> Form 990	<input type="checkbox"/> Form 990-T (corporation)	<input type="checkbox"/> Form 4720
<input type="checkbox"/> Form 990-BL	<input type="checkbox"/> Form 990-T (section 401(a) or 408(a) trust)	<input type="checkbox"/> Form 5227
<input type="checkbox"/> Form 990-EZ	<input type="checkbox"/> Form 990-T (trust other than above)	<input type="checkbox"/> Form 6069
<input type="checkbox"/> Form 990-PF	<input type="checkbox"/> Form 1041-A	<input type="checkbox"/> Form 8870

- The books are in the care of ► GEOFFREY STACK

Telephone No ► 949 756-5959

FAX No. ► _____

- If the organization does not have an office or place of business in the United States, check this box ☐
- If this is for a Group Return, enter the organization's four digit Group Exemption Number (GEN) _____ If this is for the whole group, check this box ☐ If it is for part of the group, check this box ☐ and attach a list with the names and EINs of all members the extension will cover

1 I request an automatic 3-month (6 months for a corporation required to file Form 990-T) extension of time until 8/15, 20 10, to file the exempt organization return for the organization named above. The extension is for the organization's return for

- ☒ calendar year 20 09 or
- ☐ tax year beginning _____, 20 _____, and ending _____, 20 _____

2 If this tax year is for less than 12 months, check reason ☐ Initial return ☐ Final return ☐ Change in accounting period

3a If this application is for Form 990-BL, 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less any nonrefundable credits. See instructions.

3a \$ 0.

b If this application is for Form 990-PF or 990-T, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit.

3b \$ 0.

c **Balance Due.** Subtract line 3b from line 3a. Include your payment with this form, or, if required, deposit with FTD coupon or, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions.

3c \$ 0.

Caution. If you are going to make an electronic fund withdrawal with this Form 8868, see Form 8453-EO and Form 8879-EO for payment instructions.

BAA For Privacy Act and Paperwork Reduction Act Notice, see instructions.Form **8868** (Rev 4-2009)

- If you are filing for an **Additional (Not Automatic) 3-Month Extension**, complete only **Part II** and check this box ☒

Note. Only complete Part II if you have already been granted an automatic 3-month extension on a previously filed Form 8868

- If you are filing for an **Automatic 3-Month Extension**, complete only **Part I** (on page 1)

Part II Additional (Not Automatic) 3-Month Extension of Time. Only file the original (no copies needed)	Name of Exempt Organization			Employer identification number
	CYSTINOSIS RESEARCH FOUNDATION			32-0067668
	Number street and room or suite number. If a P.O. box, see instructions			For IRS use only
	MONTGOMERY, GLICK & COMPANY 5951 VARIEL AVENUE			
Type or print	City, town or post office, state and ZIP code. For a foreign address, see instructions			
	WOODLAND HILLS, CA 91367			

Check type of return to be filed (File a separate application for each return)

- | | | | |
|--|--|--------------------------------------|------------------------------------|
| <input checked="" type="checkbox"/> Form 990 | <input type="checkbox"/> Form 990-PF | <input type="checkbox"/> Form 1041-A | <input type="checkbox"/> Form 6069 |
| <input type="checkbox"/> Form 990-BL | <input type="checkbox"/> Form 990-T (section 401(a) or 408(a) trust) | <input type="checkbox"/> Form 4720 | <input type="checkbox"/> Form 8870 |
| <input type="checkbox"/> Form 990-EZ | <input type="checkbox"/> Form 990-T (trust other than above) | <input type="checkbox"/> Form 5227 | |

STOP! Do not complete Part II if you were not already granted an automatic 3-month extension on a previously filed Form 8868.

- The books are in care of **▶ GEOFFREY STACK**
Telephone No **▶ 949 756-5959** FAX No **▶**
- If the organization does not have an office or place of business in the United States, check this box ☐
- If this is for a Group Return, enter the organization's four digit Group Exemption Number (GEN) _____ If this is for the whole group, check this box ☐ If it is for part of the group, check this box ☐ and attach a list with the names and EINs of all members the extension is for

- 4 I request an additional 3 month extension of time until 11/15 20 10
- 5 For calendar year 2009, or other tax year beginning _____, 20____, and ending _____, 20____
- 6 If this tax year is for less than 12 months, check reason ☐ Initial return ☐ Final return ☐ Change in accounting period
- 7 State in detail why you need the extension TAX PREPARER HAS JUST RECEIVED COPY OF AUDITED FINANCIAL STATEMENTS AND NEEDS ADDITIONAL TIME TO PREPARE THE RETURNS

8a If this application is for Form 990-BL, 990-PF, 990-T, 4720 or 6069, enter the tentative tax, less any nonrefundable credits. See instructions	8a \$
8b If this application is for Form 990-PF, 990-T, 4720, or 6069, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit and any amount paid previously with Form 8868	8b \$
8c Balance Due. Subtract line 8b from line 8a. Include your payment with this form, or, if required, deposit with FTD coupon or, if required, by using EFTPS (Electronic Federal Tax Payment System). See instrs	8c \$

Signature and Verification

Under penalties of perjury, I declare that I have examined this form, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true correct, and complete, and that I am authorized to prepare this form

Signature **▶** Title **▶** CMA Date **▶** 8/6/10