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Form 990  Department of the Treasury Internal Revenue Service	Return of Organization Exempt From Income Tax Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except black lung benefit trust or private foundation)	OMB No 1545-0047 2012 Open to Public Inspection
	The organization may have to use a copy of this return to satisfy state reporting requirements	

A For the 2012 calendar year, or tax year beginning 01-01-2012 , 2012, and ending 12-31-2012

B Check if applicable ☐ Address change ☐ Name change ☐ Initial return ☐ Terminated ☐ Amended return ☐ Application pending	C Name of organization CYSTINOSIS RESEARCH FOUNDATION		D Employer identification number 32-0067668	
	Doing Business As			
	Number and street (or P O box if mail is not delivered to street address) 18802 BARDEEN AVE	Room/suite	E Telephone number (949) 223-7610	
	City or town, state or country, and ZIP + 4 IRVINE, CA 92612			
			G Gross receipts \$ 3,134,175	
F Name and address of principal officer		H(a) Is this a group return for affiliates? ☐ Yes ☒ No		
		H(b) Are all affiliates included? ☐ Yes ☒ No If "No," attach a list (see instructions)		
I Tax-exempt status ☒ 501(c)(3) ☐ 501(c) () ◀ (insert no) ☐ 4947(a)(1) or ☐ 527		H(c) Group exemption number ▶		
J Website: ▶ www.cystinosisresearch.org				
K Form of organization ☒ Corporation ☐ Trust ☐ Association ☐ Other ▶		L Year of formation 2003	M State of legal domicile CA	

Part I	Summary
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Activities & Governance	1 Briefly describe the organization's mission or most significant activities THE CYSTINOSIS RESEARCH FOUNDATION'S MISSION IS TO SUPPORT BENCH,CLINICAL AND TRANSLATIONAL CYSTINOSIS RESEARCH FOR BETTER TREATMENTS AND A CURE CRF HAS BEEN INSTRUMENTAL IN ESTABLISHING A GLOBAL PATIENT REGISTRY TO HELP ACCELERATE CYSTINOSIS RESEARCH PROGRESS			
	2 Check this box ☒ if the organization discontinued its operations or disposed of more than 25% of its net assets			
	3	Number of voting members of the governing body (Part VI, line 1a)	3	13
	4	Number of independent voting members of the governing body (Part VI, line 1b)	4	13
	5	Total number of individuals employed in calendar year 2012 (Part V, line 2a)	5	1
6	Total number of volunteers (estimate if necessary)	6		
7a	Total unrelated business revenue from Part VIII, column (C), line 12	7a	0	
7b	Net unrelated business taxable income from Form 990-T, line 34	7b		
Revenue	8	Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year
	9	Program service revenue (Part VIII, line 2g)	2,310,205	2,572,531
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	23,544	56,547
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		0
	12	Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	2,333,749	2,629,078
	Expenses	13	Grants and similar amounts paid (Part IX, column (A), lines 1–3)	1,367,294
14		Benefits paid to or for members (Part IX, column (A), line 4)		0
15		Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)		33,456
16a		Professional fundraising fees (Part IX, column (A), line 11e)		0
b		Total fundraising expenses (Part IX, column (D), line 25) <u>512,533</u>		
17		Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)	575,735	780,962
18		Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25)	1,943,029	3,206,982
19		Revenue less expenses Subtract line 18 from line 12	390,720	-577,904
Net Assets or Fund Balances			Beginning of Current Year	End of Year
	20	Total assets (Part X, line 16)	3,179,445	3,287,069
	21	Total liabilities (Part X, line 26)	1,675,242	2,285,060
	22	Net assets or fund balances Subtract line 21 from line 20	1,504,203	1,002,009

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

Sign Here	*****			2013-09-16	
	Signature of officer			Date	
Paid Preparer Use Only	GEOFFREY STACK Trustee				
	Type or print name and title				
Paid Preparer Use Only	Print/Type preparer's name PETER MONTGOMERY		Preparer's signature		Date
	Check ☐ if self-employed		PTIN P01209820		
	Firm's name ► Montgomery Glick & Company			Firm's EIN ►	
	Firm's address ► 23801 Calabasas Rd Ste 103 Calabasas, CA 91302			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

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

☐

1	Briefly describe the organization's mission			
THE CYSTINOSIS RESEARCH FOUNDATION'S MISSION IS TO SUPPORT BENCH,CLINICAL AND TRANSLATIONAL CYSTINOSIS RESEARCH FOR BETTER TREATMENTS AND A CURE CRF HAS BEEN INSTRUMENTAL IN ESTABLISHING A GLOBAL PATIENT REGISTRY TO HELP ACCELERATE CYSTINOSIS RESEARCH PROGRESS				
2	Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? ☐ Yes ☒ No			
If "Yes," describe these new services on Schedule O				
3	Did the organization cease conducting, or make significant changes in how it conducts, any program services? ☐ Yes ☒ No			
If "Yes," describe these changes on Schedule O				
4	Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported			
4a	(Code)	(Expenses \$ 2,392,564	including grants of \$ 2,392,564)	(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 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 IN 33 COUNTRIES WHO HAVE AN INTEREST IN CYSTINOSIS TO DATE, THE CRF HAS FUNDED AND COMMITTED OVER \$20 MILLION FOR CYSTINOSIS RESEARCH AND HAS FUNDED MORE THAN 103 RESEARCH STUDIES AND FELLOWSHIPS IN ELEVEN 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				
4b	(Code)	(Expenses \$ 159,496	including grants of \$)	(Revenue \$)
THE CYSTINOSIS RESEARCH FOUNDATION'S INTERNATIONAL CYSTINOSIS RESEARCH SYMPOSIUM WAS ESTABLISHED IN 2008, IS HELD EVERY TWO YEARS AND IS ONLY OPEN TO INVITED RESEARCHERS AND CLINICIANS THE APPROXIMATELY 65 INVITEES ARE EXPERTS IN THEIR FIELDS, AND ON SOME ASPECTS OF THE CARE AND TREATMENT OF CYSTINOSIS THEY ARE FROM LEADING INTERNATIONAL UNIVERSITIES AND RESEARCH INSTITUTIONS THE SYMPOSIUM HAS BECOME KNOWN FOR THE OPENNESS OF THE ATTENDEES, AND FOR THEIR WILLINGNESS TO SHARE IDEAS AND COLLABORATE PAST ATTENDEES HAVE COMMENTED THAT THE CONFERENCE FOSTERS SYNERGY, RARE IN THE SCIENTIFIC COMMUNITY, WHICH HAS PLAYED A KEY ROLE IN THEIR INDIVIDUAL AND GROUP SUCCESS CRF SPONSORS AND ORGANIZES THE ANNUAL CRF DAY OF HOPE FAMILY CONFERENCE THAT IS DESIGNED TO UNITE FAMILIES AND THE RESEARCH COMMUNITY IN AN EFFORT TO LEARN ABOUT RESEARCH PROGRESS AND ENCOURAGE DIALOG BETWEEN THE MEDICAL AND SCIENTIFIC COMMUNITIES AND THE CYSTINOSIS FAMILY COMMUNITY THE CONFERENCE PROVIDES CYSTINOSIS FAMILIES THE OPPORTUNITY TO SHARE STORIES AND FORM FRIENDSHIPS CREATING A BOND OF SUPPORT FOR THE DAY-TO-DAY CHALLENGES OF LIVING WITH CYSTINOSIS IN AUGUST 2010, IN COLLABORATION AND PARTNERSHIP WITH 12 OTHER CYSTINOSIS FAMILY FOUNDATIONS, THE CRF ESTABLISHED THE FIRST PATIENT REGISTRY FOR CYSTINOSIS AND THE CURE CYSTINOSIS INTERNATIONAL REGISTRY (CCIR) WAS LAUNCHED IT IS THE FIRST AND ONLY COMPREHENSIVE, GLOBAL CYSTINOSIS PATIENT REGISTRY THE CCIR HAS A COMMITTED LEADERSHIP TEAM OF DEDICATED CLINICIANS, RESEARCHERS AND COMMUNITY LEADERS WHOSE MISSION IS TO REGISTER EVERY PERSON WITH CYSTINOSIS AND CONNECT THEM WITH THE RESEARCH COMMUNITY THE CCIR IS AN ESSENTIAL TOOL FOR THE GLOBAL CYSTINOSIS RESEARCH COMMUNITY AND THE DATA IT PROVIDES IS CRITICAL TO THE DESIGN OF NEW RESEARCH STUDIES AND THE DEVELOPMENT OF NOVEL THERAPEUTIC TREATMENTS TO DATE, PATIENTS AND RESEARCHERS IN 33 COUNTRIES HAVE REGISTERED WITH CCIR				
4c	(Code)	(Expenses \$ 21,340	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 \$20 MILLION TO CYSTINOSIS RESEARCH AND HAS FUNDED MORE THAN 103 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, YOU TUBE AND VARIOUS SOCIAL MEDIA OUTLETS				
4d	Other program services (Describe in Schedule O)			
	(Expenses \$	including grants of \$	(Revenue \$)	
4e	Total program service expenses ▶		2,573,400	

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

Part IV

Checklist of Required Schedules (continued)

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

Part V

Statements Regarding Other IRS Filings and Tax Compliance

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

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable.		
1b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable.		
1c			No
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.		
2b		Yes	
3a			No
3b			No
4a			No
b			
5a			No
5b			No
5c			
6a			No
6b			
7 Organizations that may receive deductible contributions under section 170(c).			
7a			No
7b			
7c			No
7d			0
7e			No
7f			No
7g			No
7h			No
8			No
9 Sponsoring organizations maintaining donor advised funds.			
9a			No
9b			No
10 Section 501(c)(7) organizations. Enter			
10a			
10b			
11 Section 501(c)(12) organizations. Enter			
11a			
11b			
12a			No
12b			
13a			No
13b			
13c			
14a			No
14b			

Part VI

Governance, Management, and Disclosure

For each "Yes" response to lines 2 through 7b below, and for a "No" response to lines 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O. See instructions.

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

Section A. Governing Body and Management

		Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year	13	
If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O			
1b	Enter the number of voting members included in line 1a, above, who 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?	2	Yes
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?	3	No
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4	No
5	Did the organization become aware during the year of a significant diversion of the organization's assets?	5	No
6	Did the organization have members or stockholders?	6	No
7a	Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?	7a	No
7b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?	7b	No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following		
8a	The governing body?	8a	Yes
8b	Each committee with authority to act on behalf of the governing body?	8b	Yes
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O	9	No

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

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

Section C. Disclosure

17	List the States with which a copy of this Form 990 is required to be filed
18	Section 6104 requires an organization to make its Form 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply. ☐ Own website ☒ Another's website ☒ Upon request ☐ Other (explain in Schedule O)
19	Describe in Schedule O whether (and if so, how), the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year
20	State the name, physical address, and telephone number of the person who possesses the books and records of the organization GEOFFREY STACK 18802 BARDEEN AVE IRVINE, CA (949) 756-5959

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

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

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

- 1a Complete this table for all persons required to be listed Report compensation for the calendar year ending with or within the organization's tax year
- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation Enter -0- in columns (D), (E), and (F) if no compensation was paid

List all of the organization's **current** key employees, if any See instructions for definition of "key employee "

List the organization's five **current** highest compensated employees (other than an officer, director, trustee or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations

List all of the organization's **former** officers, key employees, or highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations

List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations

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

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

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(1) JODY STRAUSS	0 00							0	0	0
Trustee	0 00									
(2) JOHN C MANLY	0 00							0	0	0
Trustee	0 00									
(3) DENICE FLERCHINGER	0 00							0	0	0
Trustee	0 00									
(4) STEPHANIE CHERQUI	0 00							0	0	0
Trustee	0 00									
(5) WHITNEY GLAIZE	0 00	X						0	0	0
Trustee	0 00									
(6) TRICIA STURGIS	0 00	X						0	0	0
Trustee	0 00									
(7) TERESA PARTINGTON	0 00	X						0	0	0
Trustee	0 00									
(8) KEVIN PARTINGTON	0 00	X						0	0	0
Trustee	0 00									
(9) KRIS K ELFTMANN	0 00	X						0	0	0
Trustee	0 00									
(10) MICHAEL K HAYDE	0 00	X						0	0	0
Trustee	0 00									
(11) JOHN S HAGESTAD	0 00	X						0	0	0
Trustee	0 00									
(12) JASON GRIER	0 00	X						0	0	0
Trustee	0 00									
(13) DAVID CHRISTENSEN	0 00	X						0	0	0
Trustee	0 00									
(14) BRUCE CRAIR	0 00	X						0	0	0
Trustee	0 00									
(15) DONALD L SOLSBY	0 00	X						0	0	0
Trustee	0 00									
(16) NANCY STACK	40 00	X						0	0	0
Chair -TRUSTEE	0 00									
(17) GEOFFREY STACK	0 00	X						0	0	0
Trustee	0 00									

Part VII

[illegible]

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

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

Section B. Independent Contractors

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

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

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

Part VIII

Statement of Revenue

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

			(A)	(B)	(C)	(D)
			Total revenue	Related or exempt function revenue	Unrelated business revenue	Revenue excluded from tax under sections 512, 513, or 514
Contributions, Gifts, Grants and Other Similar Amounts	1a	Federated campaigns . . .	1a			
	b	Membership dues	1b			
	c	Fundraising events	1c	1,098,283		
	d	Related organizations	1d			
	e	Government grants (contributions)	1e			
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	1,474,248		
	g	Noncash contributions included in lines 1a-1f \$		71,560		
	h	Total. Add lines 1a-1f		2,572,531		
Program Service Revenue	2a		Business Code			
	b					
	c					
	d					
	e					
	f	All other program service revenue				
	g	Total. Add lines 2a-2f		0		
	Other Revenue	3	Investment income (including dividends, interest, and other similar amounts)	25,848	25,848	
4		Income from investment of tax-exempt bond proceeds . .	0			
5		Royalties	0			
6a		Gross rents	(i) Real	(ii) Personal		
b		Less rental expenses				
c		Rental income or (loss)				
d		Net rental income or (loss)			0	
7a		Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other		
b		Less cost or other basis and sales expenses	535,796			
c		Gain or (loss)	505,097			
d		Net gain or (loss)	30,699		30,699	
8a		Gross income from fundraising events (not including \$ 1,098,283 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 . .			0	
9a		Gross income from gaming activities See Part IV, line 19	a			
b		Less direct expenses	b			
c		Net income or (loss) from gaming activities . .			0	
10a		Gross sales of inventory, less returns and allowances .	a			
b		Less cost of goods sold	b			
c		Net income or (loss) from sales of inventory . .			0	
Miscellaneous Revenue		Business Code				
11a						
b						
c						
d	All other revenue					
e	Total. Add lines 11a-11d		0			
12	Total revenue. See Instructions		2,629,078	56,547		

Part IX

Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.		(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to governments and organizations in the United States. See Part IV, line 21.	851,981	851,981		
2	Grants and other assistance to individuals in the United States. See Part IV, line 22.	0			
3	Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16.	1,540,583	1,540,583		
4	Benefits paid to or for members.	0			
5	Compensation of current officers, directors, trustees, and key employees.	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			
7	Other salaries and wages.	30,510		30,510	
8	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions).	0			
9	Other employee benefits.	0			
10	Payroll taxes.	2,946		2,946	
11	Fees for services (non-employees):				
a	Management.	0			
b	Legal.	0			
c	Accounting.	31,060		10,962	20,098
d	Lobbying.	0			
e	Professional fundraising services. See Part IV, line 17.	0			
f	Investment management fees.	0			
g	Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O).	0			
12	Advertising and promotion.	111,732			111,732
13	Office expenses.	0			
14	Information technology.	0			
15	Royalties.	0			
16	Occupancy.	0			
17	Travel.	16,881		12,977	3,904
18	Payments of travel or entertainment expenses for any federal, state, or local public officials.	0			
19	Conferences, conventions, and meetings.	0			
20	Interest.	0			
21	Payments to affiliates.	0			
22	Depreciation, depletion, and amortization.	10,680		10,680	
23	Insurance.	2,790		2,790	
24	Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O).				
a	OTHER EXPENSES	49,741	7,402	4,132	38,207
b	OUTSIDE SERVICES	81,724	8,200		73,524
c	EDUCATION	112,985	112,985		
d	Printing and Publications	151,527	10,071	838	140,618
e	All other expenses	211,842	42,178	45,214	124,450
25	Total functional expenses. Add lines 1 through 24e.	3,206,982	2,573,400	121,049	512,533
26	Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ☐ if following SOP 98-2 (ASC 958-720).				

Part X

Balance Sheet

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

					(A)		(B)
					Beginning of year		End of year
Assets	1	Cash—non-interest-bearing				1	0
	2	Savings and temporary cash investments			2,282,476	2	2,340,039
	3	Pledges and grants receivable, net			84,900	3	50,948
	4	Accounts receivable, net				4	0
	5	Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L				5	0
	6	Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions) Complete Part II of Schedule L				6	0
	7	Notes and loans receivable, net				7	0
	8	Inventories for sale or use			4,631	8	0
	9	Prepaid expenses and deferred charges			57,251	9	66,452
	10a	Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	10a	56,838	25,723	10c	15,044
	b	Less accumulated depreciation	10b	41,794			
	11	Investments—publicly traded securities			724,464	11	814,586
	12	Investments—other securities See Part IV, line 11				12	0
	13	Investments—program-related See Part IV, line 11				13	0
	14	Intangible assets				14	0
	15	Other assets See Part IV, line 11				15	0
	16	Total assets. Add lines 1 through 15 (must equal line 34)			3,179,445	16	3,287,069
Liabilities	17	Accounts payable and accrued expenses			27,883	17	27,335
	18	Grants payable			1,647,359	18	2,257,725
	19	Deferred revenue				19	
	20	Tax-exempt bond liabilities				20	
	21	Escrow or custodial account liability Complete Part IV of Schedule D				21	
	22	Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons Complete Part II of Schedule L				22	
	23	Secured mortgages and notes payable to unrelated third parties				23	
	24	Unsecured notes and loans payable to unrelated third parties				24	
	25	Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24) Complete Part X of Schedule D				25	
	26	Total liabilities. Add lines 17 through 25			1,675,242	26	2,285,060
Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here ☒ and complete lines 27 through 29, and lines 33 and 34.						
	27	Unrestricted net assets			1,504,203	27	1,002,009
	28	Temporarily restricted net assets				28	
	29	Permanently restricted net assets				29	
	Organizations that do not follow SFAS 117 (ASC 958), check here ☐ and complete lines 30 through 34.						
	30	Capital stock or trust principal, or current funds				30	
	31	Paid-in or capital surplus, or land, building or equipment fund				31	
	32	Retained earnings, endowment, accumulated income, or other funds				32	
	33	Total net assets or fund balances			1,504,203	33	1,002,009
	34	Total liabilities and net assets/fund balances			3,179,445	34	3,287,069

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	2,629,078
2	Total expenses (must equal Part IX, column (A), line 25)	2	3,206,982
3	Revenue less expenses Subtract line 2 from line 1	3	-577,904
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	1,504,203
5	Net unrealized gains (losses) on investments	5	75,710
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	1,002,009

Part XII Financial Statements and Reporting

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

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

SCHEDULE A

(Form 990 or 990EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

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

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

OMB No 1545-0047

2012

Open to Public
Inspection

Name of the organization CYSTINOSIS RESEARCH FOUNDATION	Employer identification number 32-0067668
--	--

Part I

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

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

- 1

☐

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

☐

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

☐

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

☐

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

☐

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

☐

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

☒

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 33¹/₃% 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 33¹/₃% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975 See **section 509(a)(2).** (Complete Part III)
- 10

☐

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

☐

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

a

☐

Type I

b

☐

Type II

c

☐

Type III - Functionally integrated

d

☐

Type III - Non-functionally integrated
- e

☐

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

☐

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

☐

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

(i)

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

(ii)

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

(iii)

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

h

☐

Provide the following information about the supported organization(s)
- | | Yes | No |
|----------|-----|----|
| 11g(i) | | |
| 11g(ii) | | |
| 11g(iii) | | |
- | (i) Name of supported organization | (ii) EIN | (iii) Type of organization (described on lines 1- 9 above or IRC section (see instructions)) | (iv) Is the organization in col (i) listed in your governing document? | | (v) Did you notify the organization in col (i) of your support? | | (vi) Is the organization in col (i) organized in the U S ? | | (vii) Amount of monetary support |
|------------------------------------|----------|--|--|----|---|----|--|----|----------------------------------|
| | | | Yes | No | Yes | No | Yes | No | |
| | | | | | | | | | |
| | | | | | | | | | |
| Total | | | | | | | | | |
- For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990EZ.

Cat No 11285F

Schedule A (Form 990 or 990-EZ) 2012

Part II

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

Section A. Public Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants ")	2,752,925	3,223,627	2,220,084	2,310,205	2,572,531	13,079,372
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						0
3 The value of services or facilities furnished by a governmental unit to the organization without charge						0
4 Total. Add lines 1 through 3	2,752,925	3,223,627	2,220,084	2,310,205	2,572,531	13,079,372
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)						4,950,848
6 Public support. Subtract line 5 from line 4						8,128,524

Section B. Total Support							
Calendar year (or fiscal year beginning in) ▶		(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
7	Amounts from line 4	2,752,925	3,223,627	2,220,084	2,310,205	2,572,531	13,079,372
8	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	48,418	38,527	20,489	16,407	25,848	149,689
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)						13,229,061
12	Gross receipts from related activities, etc (see instructions)					12	
13	First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here ▶						

Section C. Computation of Public Support Percentage			
14	Public support percentage for 2012 (line 6, column (f) divided by line 11, column (f))	14	61 440 %
15	Public support percentage for 2011 Schedule A, Part II, line 14	15	64 360 %
16a	33 1/3% support test—2012. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization		
b	33 1/3% support test—2011. 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—2012. 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—2011. 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 IIISupport Schedule for Organizations Described in Section 509(a)(2)
(Complete only if you checked the box on line 9 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support (Subtract line 7c from line 6.)						

Section B. Total Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						
14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here ▶						

Section C. Computation of Public Support Percentage		
15 Public support percentage for 2012 (line 8, column (f) divided by line 13, column (f))	15	
16 Public support percentage from 2011 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage		
17 Investment income percentage for 2012 (line 10c, column (f) divided by line 13, column (f))	17	
18 Investment income percentage from 2011 Schedule A, Part III, line 17	18	
19a 33 1/3% support tests—2012. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization ▶		
b 33 1/3% support tests—2011. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization ▶		
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions ▶		

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. Also complete this part for any additional information. (See instructions).

Facts And Circumstances Test

Explanation

SCHEDULE D
(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

OMB No 1545-0047

2012

Open to Public Inspection

Name of the organization CYSTINOSIS RESEARCH FOUNDATION	Employer identification number 32-0067668
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Part I

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

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

Part II

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

1

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

☐ Preservation of land for public use (e g , recreation or education)☐ Preservation of an historically important land area☐ Protection of natural habitat☐ Preservation of a certified historic structure☐ Preservation of open space

2

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

	Held at the End of the Year
a	Total number of conservation easements
b	Total acreage restricted by conservation easements
c	Number of conservation easements on a certified historic structure included in (a)
d	Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register

3

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

4

Number of states where property subject to conservation easement is located ▶_____

5

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

☐ Yes☐ No

6

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

7

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

8

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

☐ Yes☐ No

9

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

Part III

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

1a

If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items

b

If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items

(i) Revenues included in Form 990, Part VIII, line 1

▶\$ _____

(ii) Assets included in Form 990, Part X

▶\$ _____

2

If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items

a

Revenues included in Form 990, Part VIII, line 1

▶\$ _____

b

Assets included in Form 990, Part X

▶\$ _____

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

Cat No 52283D

Schedule D (Form 990) 2012

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

3

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

a

☐ Public exhibition

b

☐ Scholarly research

c

☐ Preservation for future generations

d

☐ Loan or exchange programs

e

☐ Other

4

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

5

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

☐ Yes

☐ No

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

1a

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

☐ Yes

☐ No

b

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

c

Beginning balance

d

Additions during the year

e

Distributions during the year

f

Ending balance

	Amount
1c	
1d	
1e	
1f	

2a

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

☐ Yes

☐ No

b

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

☐

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

	(a)Current year	(b)Prior year	b (c)Two years back	(d)Three years back	(e)Four years back
1a Beginning of year balance					
b Contributions					
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					

2

Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as

a

Board designated or quasi-endowment

b

Permanent endowment

c

Temporarily restricted endowment

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

3a

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

(i) unrelated organizations

(ii) related organizations

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

b

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

4

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

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment		56,838	41,794	15,044
e Other				
Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				15,044

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

1	Total revenue, gains, and other support per audited financial statements	1	2,704,788
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12		
a	Net unrealized gains on investments	2a	75,710
b	Donated services and use of facilities	2b	
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII)	2d	
e	Add lines 2a through 2d	2e	75,710
3	Subtract line 2e from line 1	3	2,629,078
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII)	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	2,629,078

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

1	Total expenses and losses per audited financial statements	1	3,206,982
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 XIII)	2d	
e	Add lines 2a through 2d	2e	
3	Subtract line 2e from line 1	3	3,206,982
4	Amounts included on Form 990, Part IX, line 25, but not on line 1 :		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII)	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	3,206,982

Part XIII Supplemental Information

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

Identifier	Return Reference	Explanation
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32-0067668

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

Schedule F (Form 990) 2012

Part II

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

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			SWITZERLAND	RESEARCH	212,500	CHECK			
			NEW ZEALAND	RESEARCH	46,449	CHECK			
			ITALY	RESEARCH	372,650	CHECK			
			FRANCE	RESEARCH	489,984	CHECK			
			BELGIUM	RESEARCH	419,000	CHECK			

2

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

8

3

Enter total number of other organizations or entities ▶

Part III

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of non-cash assistance	(g) Description of non-cash assistance	(h) Method of valuation (book, FMV, appraisal, other)
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Part IV Foreign Forms

- 1

Was the organization a U S transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)*

☐ Yes

☒ No
- 2

Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A)*

☐ Yes

☒ No
- 3

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

☐ Yes

☒ No
- 4

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

☐ Yes

☒ No
- 5

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

☐ Yes

☒ No
- 6

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

☐ Yes

☒ No

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

[illegible]

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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. Form 990-EZ filers are not required to complete this part.

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

32-0067668

Part II Fundraising Events. Complete if the organization answered "Yes" to Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
		ANNUAL FUNDRAISER - SEE NOTE (4) (event type)	(event type)	(total number)	(add col (a) through col (c))
Revenue	1	Gross receipts	1,098,283		1,098,283
	2	Less Contributions . . .	1,098,283		1,098,283
	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 line 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.

		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col (a) through col (c))
Revenue	1	Gross revenue			
Direct Expenses	2	Cash prizes			
	3	Non-cash prizes			
	4	Rent/facility costs			
	5	Other direct expenses . . .			
	6	Yes No	Yes No	Yes No	
	7	Direct expense summary Add lines 2 through 5 in column (d) ►			
	8	Net gaming income summary Combine lines 1 and 7 in column (d) ►			

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?

Yes No

b If "No," explain _____

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

Yes No

b If "Yes," explain _____

Does the organization operate gaming activities with nonmembers? ☐ Yes ☐ No

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

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 contract with a third party from whom the organization receives gaming revenue? ☐ Yes ☐ No

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 

☐ Director/officer ☐ Employee ☐ 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? ☐ Yes ☐ No

b Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year  \$ _____

Part IV Supplemental Information. Complete this part to provide the explanations required by Part I, line 2b, columns (iii) and (v), and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also complete this part to provide any additional information (see instructions).

Identifier	Return Reference	Explanation
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Part I General Information on Grants and Assistance

- 1

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

☒ Yes ☐ No
- 2

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

Part II Grants and Other Assistance to Governments and Organizations in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

(a) Name and address of organization or government	(b) EIN	(c) IRC Code section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
(1) UNIVERSITY OF VIRGINIA PO BOX 400195 CHARLOTTESVILLE,VA 22904	54-6001796		219,099	0			MEDICAL RESEARCH
(2) UNIVERSITY OF CALIFORNIA SD 9500 GILMAN DRIVE DEPT 0935 LA JOLLA,CA 92093	95-6006144		288,255	0			MEDICAL RESEARCH
(3) UNIVERSITY OF CA AT IRVINE 300 UNIVERSITY TOWER IRVINE,CA 92697	95-2226406		199,749	0			MEDICAL RESEARCH
(4) THE SCRIPPS RESEARCH INSTITUTE 10550 N TORREY PINES ROAD LA JOLLA,CA 92037	33-0435954		144,878	0			MEDICAL RESEARCH

Part III

Grants and Other Assistance to Individuals in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 22.
Part III can be duplicated if additional space is needed.

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

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

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, lines 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

2012

Open to Public Inspection

Name of the organization CYSTINOSIS RESEARCH FOUNDATION	Employer identification number 32-0067668
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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) Relationship between disqualified person and organization	(c) Description of transaction	(d) Corrected?	
				Yes	No

2 Enter the amount of tax incurred by 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-EZ, Part V, line 38a, or Form 990, Part IV, line 26, or if the organization reported an amount on Form 990, Part X, line 5, 6, or 22

(a) Name of interested person	(b) Relationship with organization	(c) Purpose of loan	(d) Loan to or from the organization?		(e) Original principal amount	(f) Balance due	(g) In default?		(h) Approved by board or committee?	(i) Written agreement?	
			To	From			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 of assistance	(d) Type of assistance	(e) Purpose 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
(1) KRIS ELFTMANN	DIRECTOR	267,129	SEE NOTE (2)		No
(2) DONALD L SOLSBY	DIRECTOR	39,000	SEE NOTE (1)		No

Part V**Supplemental Information**

Complete this part to provide additional information for responses to questions on Schedule L (see instructions)

Identifier	Return Reference	Explanation
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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

2012

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 or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
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 ► (MISC)		200	71,560	SALES
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

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?

30a

Yes

No

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?

31

Yes

No

32a

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

32a

Yes

No

b

If "Yes," describe in Part II

33

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

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

Cat No 51227J

Schedule M (Form 990) (2012)

Part II

Supplemental Information. Complete this part to provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also complete this part for any additional information.

Identifier	Return Reference	Explanation
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SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

**Complete to provide information for responses to specific questions on
Form 990 or to provide any additional information.**
► Attach to Form 990 or 990-EZ.

OMB No 1545-0047

2012

**Open to Public
Inspection**

Name of the organization
CYSTINOSIS RESEARCH FOUNDATION

Employer identification number

32-0067668

Identifier	Return Reference	Explanation
Form 990, Part VI, Line 19	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
Form 990, Part VI, Line 12c	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 11b	Form 990, Part VI, Line 11b 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 2	Form 990, Part VI, Line 2 Description of Business or Family Relationship of Officers, Directors, Et	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
		Client Note 2 - SCHEDULE G - PART II NOTE (2) - FUNDRAISERSTHE 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
		Client Note 1 - SCHEDULE L - PART IVNOTE (1)DIRECTOR DONALD SOLSBY'S WIFE, ZOE SOLSBY, IS A CONSULTANT TO THE FOUNDATION MRS SOLSBY RECEIVED COMPENSATION OF \$39,000 IN 2012 NOTE (2)DIRECTOR KRIS ELFTMANN IS AN OWNER OF NOELLE CORPORATE COMMUNICATIONS WHICH PROVIDES MARKETING SERVICES AND PRODUCTS, SUCH AS MAGAZINE PUBLICATIONS TO THE FOUNDATION TOTAL PAYMENTS OF \$267,129 WERE MADE TO NOELLE CORPORATE COMMUNICATIONS IN 2012