

Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

- ▶ Do not enter social security numbers on this form as it may be made public.
- ▶ Information about Form 990 and its instructions is at www.irs.gov/form990.

2016

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

A For the 2016 calendar year, or tax year beginning , 2016, **and ending** ,

B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Final return/terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C CYSTINOSIS RESEARCH FOUNDATION 18802 BARDEEN AVE. IRVINE, CA 92612 F Name and address of principal officer: SAME AS C ABOVE	D Employer identification number 32-0067668 E Telephone number 949-223-7610 G Gross receipts \$ 5,112,834.
I Tax-exempt status <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527		H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If 'No,' attach a list. (see instructions)
J Website: ▶ WWW.CYSTINOSISRESEARCH.ORG		H(c) Group exemption number ▶
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

1	Briefly describe the organization's mission or most significant activities: <u>CRF'S MISSION IS TO SUPPORT BENCH, CLINICAL AND TRANSLATIONAL RESEARCH TO FIND BETTER TREATMENTS AND A CURE FOR CYSTINOSIS</u>		
2	Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
3	Number of voting members of the governing body (Part VI, line 1a)	3	21
4	Number of independent voting members of the governing body (Part VI, line 1b)	4	21
5	Total number of individuals employed in calendar year 2016 (Part V, line 2a)	5	1
6	Total number of volunteers (estimate if necessary)	6	0
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	0.
8	Contributions and grants (Part VIII, line 1h)	8	4,818,959.
9	Program service revenue (Part VIII, line 2g)	9	3,213,127.
10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	10	69,576.
11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	11	3,282,703.
12	Total revenue – add lines 8 through 11 (must equal Part VIII, column (A), line 12)	12	4,857,558.
13	Grants and similar amounts paid (Part IX, column (A), lines 1-3)	13	1,895,803.
14	Benefits paid to or for members (Part IX, column (A), line 4)	14	1,580,936.
15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	15	60,146.
16a	Professional fundraising fees (Part IX, column (A), line 11e)	16a	62,729.
b	Total fundraising expenses (Part IX, column (D), line 25) ▶ 600,799.	b	600,799.
17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	17	842,413.
18	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	18	2,798,362.
19	Revenue less expenses. Subtract line 18 from line 12	19	484,341.
20	Total assets (Part X, line 16)	20	4,779,733.
21	Total liabilities (Part X, line 26)	21	2,195,760.
22	Net assets or fund balances. Subtract line 21 from line 20	22	2,583,973.

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	Signature of officer GEOFFREY STACK Type or print name and title	Date TRUSTEE
Paid Preparer Use Only	Print/Type preparer's name PETER MONTGOMERY	Preparer's signature Date Check <input type="checkbox"/> if self-employed PTIN P01209820
	Firm's name ▶ MONTGOMERY, GLICK & COMPANY Firm's address ▶ 23801 CALABASAS RD STE 103 CALABASAS, CA 91302	Firm's EIN ▶ 954489850 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 or note to any line in this Part III

1 Briefly describe the organization's mission:

CRF'S MISSION IS TO SUPPORT BENCH, CLINICAL AND TRANSLATIONAL RESEARCH TO FIND BETTER TREATMENTS AND 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 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 \$ 1,580,936. including grants of \$ 1,580,936.) (Revenue \$)

SEE SCHEDULE O

4b (Code:) (Expenses \$ 494,908. including grants of \$) (Revenue \$)

4c (Code:) (Expenses \$ 208,493. including grants of \$) (Revenue \$)

4d Other program services (Describe in Schedule O.)

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

4e Total program service expenses **▶ 2,284,337.**

Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If 'Yes,' complete Schedule A.</i>	X	
2 Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> (see instructions)?		X
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If 'Yes,' complete Schedule C, Part I.</i>		X
4 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? <i>If 'Yes,' complete Schedule C, Part II.</i>		X
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? <i>If 'Yes,' complete Schedule C, Part III.</i>		X
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If 'Yes,' complete Schedule D, Part I.</i>		X
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If 'Yes,' complete Schedule D, Part II.</i>		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If 'Yes,' complete Schedule D, Part III.</i>		X
9 Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If 'Yes,' complete Schedule D, Part IV.</i>		X
10 Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? <i>If 'Yes,' complete Schedule D, Part V.</i>		X
11 If the organization's answer to any of the following questions is 'Yes,' then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If 'Yes,' complete Schedule D, Part VI.</i>	X	
b Did the organization report an amount for investments – other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? <i>If 'Yes,' complete Schedule D, Part VII.</i>		X
c Did the organization report an amount for investments – program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? <i>If 'Yes,' complete Schedule D, Part VIII.</i>		X
d Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? <i>If 'Yes,' complete Schedule D, Part IX.</i>		X
e Did the organization report an amount for other liabilities in Part X, line 25? <i>If 'Yes,' complete Schedule D, Part X.</i>		X
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If 'Yes,' complete Schedule D, Part X.</i>		X
12a Did the organization obtain separate, independent audited financial statements for the tax year? <i>If 'Yes,' complete Schedule D, Parts XI and XII.</i>	X	
b Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If 'Yes,' and if the organization answered 'No' to line 12a, then completing Schedule D, Parts XI and XII is optional.</i>	X	
13 Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If 'Yes,' complete Schedule E.</i>		X
14a Did the organization maintain an office, employees, or agents outside of the United States?		X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If 'Yes,' complete Schedule F, Parts I and IV.</i>	X	
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If 'Yes,' complete Schedule F, Parts II and IV.</i>	X	
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If 'Yes,' complete Schedule F, Parts III and IV.</i>		X
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If 'Yes,' complete Schedule G, Part I</i> (see instructions).		X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If 'Yes,' complete Schedule G, Part II.</i>	X	
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If 'Yes,' complete Schedule G, Part III.</i>		X

Part IV Checklist of Required Schedules (continued)

	Yes	No
20a Did the organization operate one or more hospital facilities? <i>If 'Yes,' complete Schedule H.</i>		X
b If 'Yes' to line 20a, did the organization attach a copy of its audited financial statements to this return?		
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If 'Yes,' complete Schedule I, Parts I and II.</i>	X	
22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If 'Yes,' complete Schedule I, Parts I and III.</i>		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? <i>If 'Yes,' complete Schedule J.</i>		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, that was issued after December 31, 2002? <i>If 'Yes,' answer lines 24b through 24d and complete Schedule K. If 'No,' go to line 25a.</i>		X
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
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?		
d Did the organization act as an 'on behalf of' issuer for bonds outstanding at any time during the year?		
25a Section 501(c)(3), 501(c)(4), and 501(c)(29) 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>		X
b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If 'Yes,' complete Schedule L, Part I.</i>		X
26 Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? <i>If 'Yes,' complete Schedule L, Part II.</i>		X
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>		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):		
a A current or former officer, director, trustee, or key employee? <i>If 'Yes,' complete Schedule L, Part IV.</i>		X
b A family member of a current or former officer, director, trustee, or key employee? <i>If 'Yes,' complete Schedule L, Part IV.</i>		X
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>		X
29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If 'Yes,' complete Schedule M.</i>		X
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>		X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If 'Yes,' complete Schedule N, Part I.</i>		X
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>		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? <i>If 'Yes,' complete Schedule R, Part I.</i>		X
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>		X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
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>		
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>		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? <i>If 'Yes,' complete Schedule R, Part VI.</i>		X
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.	X	

BAA

Form **990** (2016)

Part V Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response or note to any line in this Part V

		Yes	No
1 a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable. <input type="text" value="0"/>		
1 b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable. <input type="text" value="0"/>		
1 c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? <input type="checkbox"/>		
2 a	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. <input type="text" value="1"/>		
2 b	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 (see instructions)	X	
3 a	Did the organization have unrelated business gross income of \$1,000 or more during the year?		X
3 b	If 'Yes,' has it filed a Form 990-T for this year? If 'No' to line 3b, provide an explanation in Schedule O.		
4 a	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
4 b	If 'Yes,' enter the name of the foreign country: See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).		
5 a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		X
5 b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		X
5 c	If 'Yes,' to line 5a or 5b, did the organization file Form 8886-T?		
6 a	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 as charitable contributions?		X
6 b	If 'Yes,' did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
7	Organizations that may receive deductible contributions under section 170(c).		
7 a	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	
7 b	If 'Yes,' did the organization notify the donor of the value of the goods or services provided?	X	
7 c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		X
7 d	If 'Yes,' indicate the number of Forms 8282 filed during the year. <input type="text"/>		
7 e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		X
7 f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		X
7 g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		
7 h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?		
9	Sponsoring organizations maintaining donor advised funds.		
9 a	Did the sponsoring organization make any taxable distributions under section 4966?		
9 b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?		
10	Section 501(c)(7) organizations. Enter:		
10 a	Initiation fees and capital contributions included on Part VIII, line 12. <input type="text"/>		
10 b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities. <input type="text"/>		
11	Section 501(c)(12) organizations. Enter:		
11 a	Gross income from members or shareholders. <input type="text"/>		
11 b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.) <input type="text"/>		
12 a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?		
12 b	If 'Yes,' enter the amount of tax-exempt interest received or accrued during the year. <input type="text"/>		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
13 a	Is the organization licensed to issue qualified health plans in more than one state? Note. See the instructions for additional information the organization must report on Schedule O.		
13 b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans. <input type="text"/>		
13 c	Enter the amount of reserves on hand <input type="text"/>		
14 a	Did the organization receive any payments for indoor tanning services during the tax year?		X
14 b	If 'Yes,' has it filed a Form 720 to report these payments? If 'No,' provide an explanation in Schedule O.		

Part VI Governance, Management, and Disclosure For each 'Yes' response to lines 2 through 7b below, and for a 'No' response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O. See instructions.

Check if Schedule O contains a response or note to any line in this Part VI.

Section A. Governing Body and Management

		Yes	No
1 a	Enter the number of voting members of the governing body at the end of the tax year. 1 a 21 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.		
1 b	Enter the number of voting members included in line 1a, above, who are independent. 1 b 21		
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 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? 3		X
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? 4		X
5	Did the organization become aware during the year of a significant diversion of the organization's assets? 5		X
6	Did the organization have members or stockholders? 6		X
7 a	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? 7 a		X
7 b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? 7 b		X
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
8 a	a The governing body? 8 a	X	
8 b	b Each committee with authority to act on behalf of the governing body? 8 b	X	
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		X

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

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

Section C. Disclosure

- 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 (Section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
 Own website Another's website Upon request Other (explain in Schedule O)
- 19** Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year. SEE SCHEDULE O
- 20** State the name, address, and telephone number of the person who possesses the organization's books and records: ▶
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

Check if Schedule O contains a response or note to any line in this Part VII.

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.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See instructions for definition of 'key employee.'
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

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

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

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below 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) NANCY STACK CHAIR - TRUSTEE	40 0	X						0.	0.	0.
(2) GEOFFREY STACK VICE CHAIR	0 0	X						0.	0.	0.
(3) DONALD L. SOLSBY TRUSTEE	2 0	X						0.	0.	0.
(4) BRUCE CRAIR TRUSTEE	0 0	X						0.	0.	0.
(5) STEPHANIE CHERQUI TRUSTEE	0 0	X						0.	0.	0.
(6) MARCU ALEXANDER TRUSTEE	0 0	X						0.	0.	0.
(7) DAVID W. MOSSMAN TRUSTEE	0 0	X						0.	0.	0.
(8) JOHN S. HAGESTAD TRUSTEE	0 0	X						0.	0.	0.
(9) ERIN LITTLE TRUSTEE	0 0	X						0.	0.	0.
(10) MICHAEL K. HAYDE TRUSTEE	0 0	X						0.	0.	0.
(11) KRIS K. ELFTMANN TRUSTEE	0 0	X						0.	0.	0.
(12) KEVIN PARTINGTON TRUSTEE	0 0	X						0.	0.	0.
(13) TERESA PARTINGTON TRUSTEE	0 0	X						0.	0.	0.
(14) BRIAN STURGIS TRUSTEE	0 0	X						0.	0.	0.

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

(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			
(15) ROBERT D. OLSON TRUSTEE	0	X					0.	0.	0.	
(16) DENICE FLERCHINGER TRUSTEE	0	X					0.	0.	0.	
(17) JOHN C. MANLY TRUSTEE	0	X					0.	0.	0.	
(18) JODY STRAUSS TRUSTEE	0	X					0.	0.	0.	
(19) THOMAS A. GENDRON TRUSTEE	0	X					0.	0.	0.	
(20) TRACI GENDRON TRUSTEE	0	X					0.	0.	0.	
(21) STEPHEN L. JENKINS, MD TRUSTEE	0	X					0.	0.	0.	
(22)										
(23)										
(24)										
(25)										
1 b Sub-total							0.	0.	0.	
c Total from continuation sheets to Part VII, Section A							0.	0.	0.	
d Total (add lines 1b and 1c)							0.	0.	0.	
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	X
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	X
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	X

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) 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 of compensation from the organization **0**

Part VIII Statement of Revenue

Check if Schedule O contains a response or note to any line in this Part VIII

		(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514	
Contributions, Gifts, Grants and Other Similar Amounts	1 a Federated campaigns	1 a				
	b Membership dues	1 b				
	c Fundraising events	1 c 2,602,043.				
	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 2,216,916.				
	g Noncash contributions included in lines 1a-1f: \$					
	h Total. Add lines 1a-1f	▶ 4,818,959.				
Program Service Revenue	2 a Business Code					
	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)	▶ 26,853.	26,853.			
	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	267,022.			
		(ii) Other				
		b Less: cost or other basis and sales expenses	255,276.			
		c Gain or (loss)	11,746.			
	d Net gain or (loss)	▶ 11,746.	11,746.			
	8 a Gross income from fundraising events (not including.. \$ 2,602,043. 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	▶ 4,857,558.	38,599.	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).

Check if Schedule O contains a response or note to any line in this Part IX. X

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 domestic organizations and domestic governments. See Part IV, line 21	1,003,284.	1,003,284.		
2 Grants and other assistance to domestic individuals. See Part IV, line 22				
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	577,652.	577,652.		
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	57,875.			57,875.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits				
10 Payroll taxes	4,854.			4,854.
11 Fees for services (non-employees):				
a Management				
b Legal				
c Accounting	50,140.	2,948.	30,444.	16,748.
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees				
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O.)				
12 Advertising and promotion	135,057.	28,258.		106,799.
13 Office expenses				
14 Information technology				
15 Royalties				
16 Occupancy				
17 Travel	24,286.	1,031.	8,505.	14,750.
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				
23 Insurance	8,036.		8,036.	
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 CORNEAL CYSTINOSIS-NANOWAFER	270,623.	270,623.		
b EDUCATION	189,047.	189,047.		
c PRINTING AND PUBLICATIONS	181,080.	69,823.	3,696.	107,561.
d OUTSIDE SERVICES	162,932.	29,250.	46,377.	87,305.
e All other expenses. SEE SCH. O.	372,682.	112,421.	55,354.	204,907.
25 Total functional expenses. Add lines 1 through 24e.	3,037,548.	2,284,337.	152,412.	600,799.
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 <input type="checkbox"/> if following SOP 98-2 (ASC 958-720).				

Part X Balance Sheet

Check if Schedule O contains a response or note to any line in this Part X.

		(A) Beginning of year		(B) End of year
Assets	1 Cash – non-interest-bearing.....		1	
	2 Savings and temporary cash investments.....	3,565,590.	2	4,672,285.
	3 Pledges and grants receivable, net.....	112,500.	3	63,746.
	4 Accounts receivable, net.....		4	
	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	
	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	
	7 Notes and loans receivable, net.....		7	
	8 Inventories for sale or use.....		8	
	9 Prepaid expenses and deferred charges.....	123,678.	9	122,507.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D.....	10a 56,838.		
	b Less: accumulated depreciation.....	10b 56,838.	10c	
	11 Investments – publicly traded securities.....	977,965.	11	1,466,645.
	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).....	4,779,733.	16	6,325,183.	
Liabilities	17 Accounts payable and accrued expenses.....	75,547.	17	63,761.
	18 Grants payable.....	2,120,213.	18	1,739,002.
	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.....	2,195,760.	26	1,802,763.
Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.			
	27 Unrestricted net assets.....	2,583,973.	27	4,522,420.
	28 Temporarily restricted net assets.....		28	
	29 Permanently restricted net assets.....		29	
	Organizations that do not follow SFAS 117 (ASC 958), 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, or equipment fund.....		31	
	32 Retained earnings, endowment, accumulated income, or other funds.....		32	
	33 Total net assets or fund balances.....	2,583,973.	33	4,522,420.
34 Total liabilities and net assets/fund balances.....	4,779,733.	34	6,325,183.	

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Form 990 (2016)

Part XI Reconciliation of Net Assets

Check if Schedule O contains a response or note to any line in this Part XI.

1	Total revenue (must equal Part VIII, column (A), line 12)	1	4,857,558.
2	Total expenses (must equal Part IX, column (A), line 25)	2	3,037,548.
3	Revenue less expenses. Subtract line 2 from line 1	3	1,820,010.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	2,583,973.
5	Net unrealized gains (losses) on investments	5	118,437.
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	4,522,420.

Part XII Financial Statements and Reporting

Check if Schedule O contains a response or note to any line in this Part XII.

		Yes	No
1	Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____		
If the organization changed its method of accounting from a prior year or checked 'Other,' explain in Schedule O.			
2 a	Were the organization's financial statements compiled or reviewed by an independent accountant?		X
If 'Yes,' check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both:			
<input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis			
2 b	Were the organization's financial statements audited by an independent accountant?	X	
If 'Yes,' check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both:			
<input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis			
2 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?	X	
If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.			
3 a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		X
3 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.		

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Form **990** (2016)

SCHEDULE A
(Form 990 or 990-EZ)

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.

▶ Information about Schedule A (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2016

Open to Public Inspection

Name of the organization CYSTINOSIS RESEARCH FOUNDATION	Employer identification number 32-0067668
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Part I Reason for Public Charity Status (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, 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 (Form 990 or 990-EZ).)
- 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 agricultural research organization described in **section 170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university: _____
- 10 An organization that normally receives: (1) more than 33-1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33-1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2)**. (Complete Part III.)
- 11 An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 12 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 in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
 - a **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
 - b **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
 - c **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
 - d **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
 - e Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
 - f Enter the number of supported organizations
 - g Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
(A)						
(B)						
(C)						
(D)						
(E)						
Total						

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I 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) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any 'unusual grants'.)	2,572,531.	3,130,529.	3,324,548.	3,213,127.	4,818,959.	17,059,694.
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.	2,572,531.	3,130,529.	3,324,548.	3,213,127.	4,818,959.	17,059,694.
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f).						0.
6 Public support. Subtract line 5 from line 4.						17,059,694.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
7 Amounts from line 4.	2,572,531.	3,130,529.	3,324,548.	3,213,127.	4,818,959.	17,059,694.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources.	25,848.	19,064.	9,190.			54,102.
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 VI.)						0.
11 Total support. Add lines 7 through 10.						17,113,796.
12 Gross receipts from related activities, etc. (see instructions)					12	0.
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here ▶ <input type="checkbox"/>						

Section C. Computation of Public Support Percentage

14 Public support percentage for 2016 (line 6, column (f) divided by line 11, column (f)).	14	99.68 %
15 Public support percentage from 2015 Schedule A, Part II, line 14.	15	93.02 %

16a **33-1/3% support test—2016.** 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—2015.** 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—2016.** 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 VI how the organization meets the 'facts-and-circumstances' test. The organization qualifies as a publicly supported organization. ▶

b **10%-facts-and-circumstances test—2015.** 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 VI 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 10 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) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(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) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(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 VI.)						
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**. ▶

Section C. Computation of Public Support Percentage

15 Public support percentage for 2016 (line 8, column (f) divided by line 13, column (f)).	15	%
16 Public support percentage from 2015 Schedule A, Part III, line 15.	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2016 (line 10c, column (f) divided by line 13, column (f)).	17	%
18 Investment income percentage from 2015 Schedule A, Part III, line 17.	18	%

19a 33-1/3% support tests—2016. 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—2015. 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 Supporting Organizations

(Complete only if you checked a box in line 12 on Part I. If you checked 12a of Part I, complete Sections A and B. If you checked 12b of Part I, complete Sections A and C. If you checked 12c of Part I, complete Sections A, D, and E. If you checked 12d of Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

	Yes	No
1 Are all of the organization's supported organizations listed by name in the organization's governing documents? <i>If 'No,' describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.</i>		
2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If 'Yes,' explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>		
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If 'Yes,' answer (b) and (c) below.</i>		
b Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? <i>If 'Yes,' describe in Part VI when and how the organization made the determination.</i>		
c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If 'Yes,' explain in Part VI what controls the organization put in place to ensure such use.</i>		
4a Was any supported organization not organized in the United States ('foreign supported organization')? <i>If 'Yes' and if you checked 12a or 12b in Part I, answer (b) and (c) below.</i>		
b Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>If 'Yes,' describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.</i>		
c Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? <i>If 'Yes,' explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.</i>		
5a Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If 'Yes,' answer (b) and (c) below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).</i>		
b Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
c Substitutions only. Was the substitution the result of an event beyond the organization's control?		
6 Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? <i>If 'Yes,' provide detail in Part VI.</i>		
7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? <i>If 'Yes,' complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? <i>If 'Yes,' complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
9a Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? <i>If 'Yes,' provide detail in Part VI.</i>		
b Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? <i>If 'Yes,' provide detail in Part VI.</i>		
c Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? <i>If 'Yes,' provide detail in Part VI.</i>		
10a Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? <i>If 'Yes,' answer 10b below.</i>		
b Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i>		

Part IV Supporting Organizations (continued)

	Yes	No
11 Has the organization accepted a gift or contribution from any of the following persons?		
a A person who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the governing body of a supported organization?		
b A family member of a person described in (a) above?		
c A 35% controlled entity of a person described in (a) or (b) above? <i>If 'Yes' to a, b, or c, provide detail in Part VI.</i>		

Section B. Type I Supporting Organizations

	Yes	No
1 Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>If 'No,' describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>		
2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? <i>If 'Yes,' explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.</i>		

Section C. Type II Supporting Organizations

	Yes	No
1 Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <i>If 'No,' describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).</i>		

Section D. All Type III Supporting Organizations

	Yes	No
1 Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?		
2 Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? <i>If 'No,' explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
3 By reason of the relationship described in (2), did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? <i>If 'Yes,' describe in Part VI the role the organization's supported organizations played in this regard.</i>		

Section E. Type III Functionally Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).			
a <input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.			
b <input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.			
c <input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).			
2 Activities Test. Answer (a) and (b) below.			
a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>If 'Yes,' then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>			
b Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If 'Yes,' explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>			
3 Parent of Supported Organizations. Answer (a) and (b) below.			
a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>Provide details in Part VI.</i>			
b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? <i>If 'Yes,' describe in Part VI the role played by the organization in this regard.</i>			

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

1 Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in Part VI). **See instructions.** All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

Section A – Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
1	Net short-term capital gain	1	
2	Recoveries of prior-year distributions	2	
3	Other gross income (see instructions)	3	
4	Add lines 1 through 3.	4	
5	Depreciation and depletion	5	
6	Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6	
7	Other expenses (see instructions)	7	
8	Adjusted Net Income (subtract lines 5, 6, and 7 from line 4).	8	

Section B – Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):		
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	Total (add lines 1a, 1b, and 1c)	1d	
e	Discount claimed for blockage or other factors (explain in detail in Part VI):		
2	Acquisition indebtedness applicable to non-exempt-use assets	2	
3	Subtract line 2 from line 1d.	3	
4	Cash deemed held for exempt use. Enter 1-1/2% of line 3 (for greater amount, see instructions).	4	
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5	
6	Multiply line 5 by .035.	6	
7	Recoveries of prior-year distributions	7	
8	Minimum Asset Amount (add line 7 to line 6)	8	

Section C – Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	1	
2	Enter 85% of line 1.	2	
3	Minimum asset amount for prior year (from Section B, line 8, Column A)	3	
4	Enter greater of line 2 or line 3.	4	
5	Income tax imposed in prior year	5	
6	Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6	

7 Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).

BAA

Schedule A (Form 990 or 990-EZ) 2016

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)

Section D – Distributions	Current Year
1 Amounts paid to supported organizations to accomplish exempt purposes	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	
4 Amounts paid to acquire exempt-use assets	
5 Qualified set-aside amounts (prior IRS approval required)	
6 Other distributions (describe in Part VI). See instructions.	
7 Total annual distributions. Add lines 1 through 6.	
8 Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions.	
9 Distributable amount for 2016 from Section C, line 6	
10 Line 8 amount divided by Line 9 amount	

Section E – Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2016	(iii) Distributable Amount for 2016
1 Distributable amount for 2016 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2016 (reasonable cause required – explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2016:			
a			
b			
c From 2013			
d From 2014			
e From 2015			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2016 distributable amount			
i Carryover from 2011 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
4 Distributions for 2016 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2016 distributable amount			
c Remainder. Subtract lines 4a and 4b from 4.			
5 Remaining underdistributions for years prior to 2016, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI. See instructions.			
6 Remaining underdistributions for 2016. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.			
7 Excess distributions carryover to 2017. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a			
b Excess from 2013			
c Excess from 2014			
d Excess from 2015			
e Excess from 2016			

BAA

Schedule A (Form 990 or 990-EZ) 2016

Part VI **Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a, and 3b; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information.
(See instructions.)

SCHEDULE D (Form 990)

Supplemental Financial Statements

OMB No. 1545-0047

2016

Department of the Treasury Internal Revenue Service

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

Information about Schedule D (Form 990) and its instructions is at www.irs.gov/form990.

Open to Public Inspection

Name of the organization

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' on Form 990, Part IV, line 6.

Table with 3 columns: Line number, (a) Donor advised funds, (b) Funds and other accounts. Rows 1-4 for total number, aggregate value of contributions, aggregate value of grants, and 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?
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?

Part II Conservation Easements.

Complete if the organization answered 'Yes' on 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)
Protection of a 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.

Table with 2 columns: Description, Held at the End of the Tax Year. Rows 2a, 2b, 2c, 2d for total number, total acreage, number of easements on certified historic structure, and number of easements included in (c) acquired after 8/17/06.

- 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?
6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year
7 Amount of expenses incurred in monitoring, inspecting, handling of violations, 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)?
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' on Form 990, Part IV, line 8.

- 1 a 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) Revenue included on 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 Revenue included on Form 990, Part VIII, line 1
b Assets included in Form 990, Part X

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

- 3 Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply):
- a Public exhibition
 - b Scholarly research
 - c Preservation for future generations
 - d Loan or exchange programs
 - e Other _____
- 4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? Yes No

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

- 1 a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? Yes No
- b If 'Yes,' explain the arrangement in Part XIII and complete the following table:
- | | Amount |
|---------------------------------|--------|
| c Beginning balance | 1 c |
| d Additions during the year | 1 d |
| e Distributions during the year | 1 e |
| f Ending balance | 1 f |
- 2 a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? Yes No
- b If 'Yes,' explain the arrangement in Part XIII. Check here if the explanation has been provided on Part XIII. Yes No

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1 a 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 on lines 2a, 2b, and 2c should equal 100%.
- 3 a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- | | Yes | No |
|--|--------|----|
| (i) unrelated organizations | 3a(i) | |
| (ii) related organizations | 3a(ii) | |
| b If 'Yes' on line 3a(ii), are the related organizations listed as required on Schedule R? | 3b | |

Part VI Land, Buildings, and Equipment.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11a. 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
1 a Land				
b Buildings				
c Leasehold improvements				
d Equipment		56,838.	56,838.	0.
e Other				

Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.) 0.

Part VII Investments – Other Securities.

N/A

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives		
(2) Closely-held equity interests		
(3) Other		
(A) -----		
(B) -----		
(C) -----		
(D) -----		
(E) -----		
(F) -----		
(G) -----		
(H) -----		
(I) -----		
Total. (Column (b) must equal Form 990, Part X, column (B) line 12.)		

Part VIII Investments – Program Related.

N/A

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
(10)		
Total. (Column (b) must equal Form 990, Part X, column (B) line 13.)		

Part IX Other Assets.

N/A

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
Total. (Column (b) must equal Form 990, Part X, column (B) line 15.)	

Part X Other Liabilities.

Complete if the organization answered 'Yes' on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25

(a) Description of liability	(b) Book value
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
(11)	
Total. (Column (b) must equal Form 990, Part X, column (B) line 25.)	

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

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

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements	1	4,857,558.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
	a Net unrealized gains (losses) on investments	2 a	
	b Donated services and use of facilities	2 b	
	c Recoveries of prior year grants	2 c	
	d Other (Describe in Part XIII.)	2 d	
	e Add lines 2 a through 2 d	2 e	
3	Subtract line 2 e from line 1	3	4,857,558.
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	4 a	
	b Other (Describe in Part XIII.)	4 b	
	c Add lines 4 a and 4 b	4 c	
5	Total revenue. Add lines 3 and 4 c . (This must equal Form 990, Part I, line 12.)	5	4,857,558.

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

Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements	1	3,037,548.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:		
	a Donated services and use of facilities	2 a	
	b Prior year adjustments	2 b	
	c Other losses	2 c	
	d Other (Describe in Part XIII.)	2 d	
	e Add lines 2 a through 2 d	2 e	
3	Subtract line 2 e from line 1	3	3,037,548.
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	4 a	
	b Other (Describe in Part XIII.)	4 b	
	c Add lines 4 a and 4 b	4 c	
5	Total expenses. Add lines 3 and 4 c . (This must equal Form 990, Part I, line 18.)	5	3,037,548.

Part XIII Supplemental Information.

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.

**SCHEDULE F
(Form 990)**

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

- ▶ Complete if the organization answered 'Yes' on Form 990, Part IV, line 14b, 15, or 16.
 - ▶ Attach to Form 990.
 - ▶ Information about Schedule F (Form 990) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2016

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' on Form 990, Part IV, line 14b.

- 1 For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? . . . **Yes** **No**
- 2 For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.
- 3 Activities per Region.** (The following Part I, line 3 table can be duplicated if additional space is needed.) **PART V**

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
(1) BELGIUM			GRANTS	MEDICAL RESEARCH	0.
(2) FRANCE			GRANTS	MEDICAL RESEARCH	26,400.
(3) INDIA			GRANTS	MEDICAL RESEARCH	0.
(4) ITALY			GRANTS	MEDICAL RESEARCH	180,400.
(5) NEW ZEALAND			GRANTS	MEDICAL RESEARCH	145,852.
(6) SWITZERLAND			GRANTS	MEDICAL RESEARCH	0.
(7) FRANCE			GRANTS	MEDICAL RESEARCH	225,000.
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
3 a Sub-total					577,652.
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b) . . .	0	0			577,652.

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

Schedule F (Form 990) 2016

Part II Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered 'Yes' on 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 noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
(1)				MEDICAL RESEARCH		CHECK			
(2)				MEDICAL RESEARCH		CHECK			
(3)				MEDICAL RESEARCH		CHECK			
(4)				MEDICAL RESEARCH		CHECK			
(5)				MEDICAL RESEARCH		CHECK			
(6)				MEDICAL RESEARCH		CHECK			
(7)				MEDICAL RESEARCH		CHECK			
(8)									
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									

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. ▶ 7

3 Enter total number of other organizations or entities ▶ 0

Part III Grants and Other Assistance to Individuals Outside the United States. Complete if the organization answered 'Yes' on Form 990, Part IV, line 16. Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of noncash assistance	(g) Description of noncash assistance	(h) Method of valuation (book, FMV, appraisal, other)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

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 separately 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; do not file with Form 990).* Yes No

- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If 'Yes,' the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect To Certain Foreign Corporations (see Instructions for Form 5471).* Yes No

- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If 'Yes,' the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621).* Yes No

- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If 'Yes,' the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865).* Yes No

- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If 'Yes,' the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; do not file with Form 990).* Yes No

Part V Supplemental Information

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.

PART I - ADDITIONAL SUPPLEMENTAL INFORMATION

SUMMARY OF GRANTEES:

(2) & (7) UNIVERSITY OF PARIS DESCARTES, 245 RUE DES SAINT-PERES, 75006 PARIS,
FRANCE

(4) BAMBINO GESU HOSPITAL, PIAZZA S. ONOFRIA 4, 00165 ROME, ITALY

(5) THE UNIVERSITY OF AUCKLAND, NEW ZEALAND

**SCHEDULE G
(Form 990 or 990-EZ)**

Department of the Treasury
Internal Revenue Service

Supplemental Information Regarding Fundraising or Gaming Activities

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

▶ Information about Schedule G (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2016

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' on Form 990, Part IV, line 17. Form 990-EZ 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.

- a** Mail solicitations
- b** Internet and email solicitations
- c** Phone solicitations
- d** In-person solicitations
- e** Solicitation of non-government grants
- f** Solicitation of government grants
- g** Special fundraising events

2a Did the organization have a 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 10 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 and address 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 column (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
Total						0.

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

CA _____

Part II Fundraising Events. Complete if the organization answered 'Yes' on 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.

REVENUE	(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
	ANNUAL FUNDRAISE (event type)	(event type)	NONE (total number)	(add column (a) through column (c))
1	Gross receipts	2,602,043.		2,602,043.
2	Less: Contributions	2,602,043.		2,602,043.
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. Subtract line 10 from line 3, column (d)			

Part III Gaming. Complete if the organization answered 'Yes' on 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 column (a) through column (c))
1	Gross revenue			
DIRECT EXPENSES	2	Cash prizes		
	3	Noncash 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
7	Direct expense summary. Add lines 2 through 5 in column (d)			
8	Net gaming income summary. Subtract line 7 from line 1, column (d)			

- 9 Enter the state(s) in which the organization conducts gaming activities: _____
- a Is the organization licensed to conduct gaming activities in each of these states? Yes No
- b If 'No,' explain: _____
- 10 a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? Yes No
- b If 'Yes,' explain: _____

11 Does the organization conduct 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 conducted in:

a The organization's facility	13 a	%
b An outside facility	13 b	%

14 Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name ▶ _____

Address ▶ _____

15 a 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 to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ _____

Part IV Supplemental Information. 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 provide any additional information. See instructions

**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' on Form 990, Part IV, line 21 or 22.
▶ Attach to Form 990.

▶ Information about Schedule I (Form 990) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2016

**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 Domestic Organizations and Domestic Governments. Complete if the organization answered 'Yes' on 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.

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 noncash assistance	(h) Purpose of grant or assistance
(1) UNIVERSITY OF CALIFORNIA, SD 9500 GILMAN DRIVE, DEPT 0935 LA JOLLA, CA 92093	95-6006144		160,589.	0.			MEDICAL RESEARCH
(2) THE SCRIPPS RESEARCH INSTITUT 10550 N. TORREY PINES ROAD LA JOLLA, CA 92037	33-0435954		75,000.	0.			MEDICAL RESEARCH
(3) MASSACHUSETTS GENERAL HOSPITA 101 HUNTINGTON AVENUE, SUITE BOSTON, MA 02199	04-1564655		96,129.	0.			MEDICAL RESEARCH
(4) REGENTS OF UCSD 9500 GILMAN DRIVE MC 0934 LA JOLLA, CA 92093	94-6060626		141,082.	0.			MEDICAL RESEARCH
(5) THE SCRIPPS RESEARCH INSTITUT 10550 N. TORREY PINES RD. LA JOLLA, CA 92307	33-0435954		150,000.	0.			MEDICAL RESEARCH
(6) HARVARD MEDICAL SCHOOL A-111 25 SHATTUCK ST BOSTON, MA 02115	53-0199180		225,000.	0.			MEDICAL RESEARCH
(7) UNIVERSITY OF PITTSBURGH SCHO 3550 TERRACE ST PITTSBURGH, PA 15213	11-3708851		155,484.	0.			MEDICAL RESEARCH
(8)							

2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table ▶ 7

3 Enter total number of other organizations listed in the line 1 table ▶ 0

Part III Grants and Other Assistance to Domestic Individuals. Complete if the organization answered 'Yes' on 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 noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
1					
2					
3					
4					
5					
6					
7					

Part IV Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

SCHEDULE L
(Form 990 or 990-EZ)

Transactions With Interested Persons

OMB No. 1545-0047

2016

Open To Public Inspection

Department of the Treasury
Internal Revenue Service

▶ **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.**
▶ **Information about Schedule L (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.**

Name of the organization

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Part I Excess Benefit Transactions (section 501(c)(3), section 501(c)(4), and 501(c)(29) 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
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					

2 Enter the amount of tax incurred by 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-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	Yes	No
			(1)									
(2)												
(3)												
(4)												
(5)												
(6)												
(7)												
(8)												
(9)												
(10)												
Total						▶ \$ _____						

Part III Grants or Assistance Benefiting 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
(1)				
(2)				
(3)				
(4)				
(5)				
(6)				
(7)				
(8)				
(9)				
(10)				

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

Schedule L (Form 990 or 990-EZ) 2016

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		SEE NOTE (1)		X
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					

Part V Supplemental Information

Provide additional information for responses to questions on Schedule L (see instructions).

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Name of the organization

Supplemental Information to Form 990 or 990-EZ

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

▶ Attach to Form 990 or 990-EZ.

▶ Information about Schedule O (Form 990 or 990-EZ) and its instructions is
at www.irs.gov/form990.

OMB No. 1545-0047

2016

**Open to Public
Inspection**

Employer identification number

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

FORM 990, PART III, LINE 4A - PROGRAM SERVICE ACCOMPLISHMENTS

HISTORY - "NATALIE'S WISH"

NATALIE'S WISH, 'TO HAVE MY DISEASE GO AWAY FOR EVER' - THOSE SEVEN WORDS PROVIDED THE INSPIRATION TO ESTABLISH THE CYSTINOSIS RESEARCH FOUNDATION (CRF) IN 2003. WE KNEW AT THAT MOMENT THAT WE NEEDED TO MAKE EVERY EFFORT TO MAKE NATALIE'S WISH - AND THE WISHES OF OTHERS WITH CYSTINOSIS - A REALITY.

RESEARCH

CYSTINOSIS IS A RARE, METABOLIC AND GENETIC DISEASE THAT AFFLICTS APPROXIMATELY 2,000 CHILDREN AND ADULTS WORLDWIDE. CRF'S FOCUS IS INCREASINGLY ON THE CLINICAL AND TRANSLATIONAL RESEARCH CRUCIAL TO MAKING STRIDES TOWARDS A CURE FOR CYSTINOSIS. CRF IS COMMITTED TO PRIORITIZING AND AGGRESSIVELY SUPPORTING RESEARCH WHICH HAS THE POTENTIAL TO SIGNIFICANTLY IMPROVE THE QUALITY OF LIFE FOR PATIENTS WITH CYSTINOSIS. CRF ANNOUNCES TWO GLOBAL CALLS FOR RESEARCH PROPOSALS EACH YEAR. AFTER CAREFUL EVALUATION OF EVERY APPLICATION BY THE CRF SCIENTIFIC REVIEW BOARD, RESEARCH GRANTS ARE AWARDED. IN 2006, CRF ESTABLISHED THE FIRST CYSTINOSIS RESEARCH FELLOWSHIP PROGRAM DESIGNED TO SUPPORT SCIENTISTS AND NEW RESEARCHERS WHO HAVE AN INTEREST IN CYSTINOSIS.

RESEARCH GIVES US HOPE

WE FIRMLY BELIEVE THAT RESEARCH GIVES US HOPE - AND HOPE ALLOWS US TO LIVE WITH CYSTINOSIS UNTIL THE DAY A CURE IS FOUND.

SINCE 2003, THE CYSTINOSIS RESEARCH FOUNDATION (CRF) HAS BECOME THE LARGEST FUND PROVIDER OF CYSTINOSIS RESEARCH IN THE WORLD - RAISING MORE THAN \$39 MILLION. CRF HAS CHANGED THE COURSE OF CYSTINOSIS BY INVESTING DONORS' GIFTS STRATEGICALLY AND AGGRESSIVELY TO CREATE A THRIVING RESEARCH COMMUNITY. FROM THE BEGINNING, ALL CRF OPERATING COSTS ARE PRIVATELY UNDERWRITTEN SO THAT 100 PERCENT OF THE FUNDS DONATED GOES TO SUPPORT CYSTINOSIS RESEARCH.

Name of the organization

Employer identification number

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

FORM 990, PART III, LINE 4A - PROGRAM SERVICE ACCOMPLISHMENTS

WE ARE PLEASED TO ANNOUNCE THAT IN 2016 CRF ISSUED 10 NEW GRANTS TOTALING MORE THAN \$1.56 MILLION FOR CYSTINOSIS RESEARCH. AN ADDITIONAL SEVEN GRANT AGREEMENTS WERE AWARDED PRIOR TO YEAR-END TOTALING \$1.39 MILLION WITH THE FUNDING FOR THESE GRANTS AVAILABLE IN THE CASH RESERVES. THE NEW GRANTS BRING US THAT MUCH CLOSER TO BETTER TREATMENTS AND A CURE.

CRF HAS ISSUED GRANTS TO THE BEST AND BRIGHTEST RESEARCHERS IN THE WORLD. TO DATE, WE HAVE FUNDED 151 MULTI-YEAR RESEARCH STUDIES AT LEADING RESEARCH INSTITUTIONS IN 12 COUNTRIES. CRF-FUNDED RESEARCHERS HAVE PUBLISHED MORE THAN 67 ARTICLES IN PRESTIGIOUS, TOP-RATED JOURNALS. THOSE ARTICLES, AVAILABLE TO EVERYONE IN THE WORLD, HAVE ADDED TO THE UNDERSTANDING OF THE PATHOGENESIS OF CYSTINOSIS.

FROM THE BEGINNING, WE HAVE UNDERSTOOD THAT FUNDING BASIC AND BENCH RESEARCH WAS IMPORTANT TO UNDERSTANDING CYSTINOSIS. OVER THE YEARS, AS DISCOVERIES WERE MADE IN THE LAB, CRF BEGAN FUNDING CLINICAL RESEARCH, AND NOW WE ARE TRANSLATING THE DATA FROM THE CLINICAL STUDIES TO THE PATIENTS. ONE OF OUR EARLIEST MILESTONES, AND THE ONE OF WHICH WE ARE MOST PROUD, IS THAT CRF FUNDED EVERY BENCH AND CLINICAL TRIAL THAT LED TO THE DISCOVERY OF A DELAYED-RELEASE FORM OF THE LIFE-SAVING MEDICATION CYSTINOSIS PATIENTS MUST TAKE. THE DELAYED-RELEASE MEDICATION, APPROVED BY THE FDA IN 2013, IS CONSIDERED THE MOST SIGNIFICANT ADVANCEMENT IN THE TREATMENT OF CYSTINOSIS IN 30 YEARS. OUR LATEST RESEARCH MILESTONE IS THE CREATION OF THE FIRST DONOR STEM CELL TRANSPLANTATION TRIAL AT UCLA, WHICH BRINGS US TANTALIZINGLY CLOSE TO A CURE. MOVING FORWARD, WE HAVE TARGETED SEVERAL AREAS OF RESEARCH INCLUDING MUSCLE WASTING, NEUROLOGICAL ISSUES, CORNEAL CYSTINOSIS, AND STEM CELL AND GENE THERAPY, ALL WITH THE GOAL OF FINDING BETTER TREATMENTS AND A CURE FOR CYSTINOSIS.

NANOTECHNOLOGY AND CORNEAL CYSTINOSIS

WE ARE DEDICATED TO FINDING BETTER TREATMENTS FOR CORNEAL CYSTINOSIS. CORNEAL CYSTINOSIS IS THE BUILD-UP OF CYSTINE CRYSTALS IN THE EYES THAT CAUSES PHOTOPHOBIA

Name of the organization

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FORM 990, PART III, LINE 4A - PROGRAM SERVICE ACCOMPLISHMENTS

(EXTREME SENSITIVITY TO LIGHT) SEVERE EYE PAIN, AND SOMETIMES, BLINDNESS. THERE IS AN EXISTING TREATMENT BUT IT IS RIGOROUS AND REQUIRES HOURLY DOSING OF MEDICATED EYE DROPS. FOR MANY, COMPLIANCE IS DIFFICULT.

GHANASHYAM ACHARYA, PHD, AND JENNIFER SIMPSON, MD, HAVE COLLABORATED ON A NOVEL TREATMENT FOR CORNEAL CYSTINOSIS. DR. ACHARYA HAS INVENTED A NANOWAFER THAT WE BELIEVE WILL REVOLUTIONIZE THE TREATMENT OF CORNEAL CYSTINOSIS. THE NANOWAFER CAN BE LOADED WITH CYSTEAMINE MEDICATION TO TREAT CORNEAL CYSTINOSIS. THE NANOWAFER IS PLACED IN THE EYE, AND AS IT DISSOLVES, THE MEDICATION SLOWLY RELEASES IN THE EYE OFFERING RELIEF FOR HOURS.

IN 2016, CRF FORMED CORNEAL CYSTINOLYSIS, INC., (CCI) FOR THE PURPOSE OF RESEARCH AND DEVELOPMENT OF A NOVEL TREATMENT FOR CORNEAL CYSTINOSIS. THE TREATMENT PROPOSES TO USE A NANOWAFER LOADED WITH CYSTEAMINE MEDICATION TO TREAT CORNEAL CYSTINOSIS. CRF OWNS THE LICENSE FOR THE CYSTEAMINE NANOWAFER WHICH ENSURES THAT WE REMAIN FOCUSED AND COMMITTED TO BRINGING THE NEW TREATMENT TO THE PATIENTS. THE SCIENTIST WHO DEVELOPED THE NANOWAFER IS DR. GHANSHYAM ACHARYA AT BAYLOR COLLEGE OF MEDICINE. CRF AND DR. ACHARYA ARE COMMITTED TO THIS PROJECT AND HOPE TO FILE A NEW DRUG APPLICATION IN 2018.

STEM CELL AND GENE THERAPY

WE BELIEVE THAT STEM CELLS WILL BE THE CURE FOR CYSTINOSIS. CRF WORKS CLOSELY WITH STÉPHANIE CHERQUI, PHD, WHOSE FOCUS IS STEM CELLS AND GENE THERAPY. DR. CHERQUI HAS WORKED TOGETHER WITH THE FDA FOR SEVERAL YEARS AND IS AWAITING FDA APPROVAL TO COMMENCE THE FIRST AUTOLOGOUS STEM CELL AND GENE THERAPY CLINICAL TRIAL. WE ARE OPTIMISTIC THAT THE FDA WILL APPROVE THIS STUDY IN 2017. ONCE IT IS APPROVED, WE CAN HELP RECRUIT PATIENTS SOON THEREAFTER. DR. CHERQUI'S WORK IS OUR HOPE; NOT ONLY HAS THE TREATMENT REVERSED CYSTINOSIS IN MICE, LAST YEAR SHE SUCCESSFULLY CURED CORNEAL CYSTINOSIS IN THE MOUSE MODEL.

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FORM 990, PART III, LINE 4A - PROGRAM SERVICE ACCOMPLISHMENTS

CYSTINOSIS RESEARCH HELPS OTHERS

MANY OF THE DISCOVERIES MADE BY CRF RESEARCHERS ARE CURRENTLY BEING APPLIED TO OTHER MORE PREVALENT AND WELL-KNOWN DISORDERS AND DISEASES INCLUDING OTHER CORNEAL DISEASES, KIDNEY DISEASES AND GENETIC AND SYSTEMIC DISEASES SIMILAR TO CYSTINOSIS. SUPPORT FOR CYSTINOSIS RESEARCH HAS REACHED FAR BEYOND THE CYSTINOSIS COMMUNITY. A CURE FOR CYSTINOSIS WILL HELP FIND CURES FOR OTHER DISEASES POTENTIALLY HELPING MILLIONS OF PEOPLE.

CRF FAMILIES AND PARTNERS

THE CYSTINOSIS RESEARCH FOUNDATION HAS WITNESSED TREMENDOUS GROWTH AS OTHER CYSTINOSIS FAMILIES HAVE JOINED OUR EFFORTS. THEIR FRIENDS AND FAMILIES HAVE EMBRACED THE CYSTINOSIS CAUSE AND ENTHUSIASTICALLY RAISE FUNDS TO SUPPORT CYSTINOSIS RESEARCH THROUGH CRF. WE HAVE FOUND STRENGTH IN NUMBERS AND OUR JOINT EFFORT GIVES US A RENEWED SENSE OF COMMUNITY AND PURPOSE.

DAY OF HOPE CONFERENCE

EACH YEAR THE CYSTINOSIS RESEARCH FOUNDATION HOSTS THE DAY OF HOPE FAMILY CONFERENCE. IN 2016, 56 FAMILIES FROM AROUND THE WORLD GATHERED ALONG WITH CRF FUNDED RESEARCHERS TO SHARE STORIES, HOPES AND DREAMS AND BUILD LIFE-LONG FRIENDSHIPS. LEADING CYSTINOSIS RESEARCHERS SHARED THEIR PROGRESS ON GENE AND STEM CELL THERAPIES, NOVEL EYE RESEARCH AND NEUROLOGICAL CHALLENGES RELATED TO CYSTINOSIS. THE CONFERENCE ALLOWS FAMILIES TO LEARN MORE ABOUT THE ONGOING CYSTINOSIS RESEARCH AND THE HOPE IT BRINGS TO OUR COMMUNITY.

CURE CYSTINOSIS INTERNATIONAL REGISTRY

THE CURE CYSTINOSIS INTERNATIONAL REGISTRY (CCIR) WAS LAUNCHED IN 2010 AND NOW HAS APPROXIMATELY 576 CYSTINOSIS PATIENTS REGISTERED FROM 44 COUNTRIES. THE CYSTINOSIS RESEARCH FOUNDATION IN PARTNERSHIP AND COLLABORATION WITH THE CYSTINOSIS FOUNDATION AND TWELVE OTHER CYSTINOSIS FAMILY FOUNDATIONS FROM AROUND THE WORLD, ESTABLISHED

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FORM 990, PART III, LINE 4A - PROGRAM SERVICE ACCOMPLISHMENTS

THIS COMPREHENSIVE, GLOBAL PATIENT REGISTRY FOR CYSTINOSIS. THE CCIR QUESTIONNAIRE WAS DEVELOPED BY MEDICAL AND SCIENTIFIC EXPERTS SPECIFICALLY FOR THE CYSTINOSIS COMMUNITY. TO IMPROVE ACCESSIBILITY, THE CCIR HAS BEEN TRANSLATED INTO SPANISH, PORTUGUESE, DUTCH AND FRENCH. IT IS OUR MISSION TO REGISTER EVERY PERSON WITH CYSTINOSIS, THUS CONNECTING THEM TO THE RESEARCH COMMUNITY IN AN EFFORT TO FIND A CURE FOR CYSTINOSIS. THE CCIR IS A CENTRAL HUB OF INFORMATION AND IS AN ESSENTIAL TOOL FOR THE GLOBAL CYSTINOSIS RESEARCH COMMUNITY. WE ARE CERTAIN THAT THE INFORMATION PROVIDED BY THE PATIENTS WILL ACCELERATE THE RESEARCH PROCESS AND UNITE US IN OUR QUEST TO FIND A CURE FOR CYSTINOSIS.

CRF INTERNATIONAL RESEARCH SYMPOSIUM

CRF'S INTERNATIONAL RESEARCH SYMPOSIUM IS HELD EVERY TWO YEARS AND IS ONLY OPEN TO INVITED RESEARCHERS AND SCIENTISTS. APPROXIMATELY 65 CYSTINOSIS EXPERTS FROM LEADING INTERNATIONAL UNIVERSITIES AND RESEARCH INSTITUTIONS GATHER TO SHARE THEIR RESEARCH DATA AND TO DISCUSS CUTTING EDGE RESEARCH IDEAS IN AN EFFORT TO ACCELERATE RESEARCH. THE SYMPOSIUM IS KNOWN FOR THE OPENNESS OF THE ATTENDEES, AND FOR THEIR WILLINGNESS TO WORK TOGETHER AND FORM COLLABORATIONS. THE SYMPOSIUM HAS CREATED A SYNERGISTIC RESEARCH COMMUNITY WORKING IN PARTNERSHIP WITH CRF.

FORM 990, PART VI, LINE 2 - BUSINESS OR FAMILY RELATIONSHIP OF OFFICERS, DIRECTORS, ETC.

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

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

DIRECTORS, TRACI AND THOMAS GENDRON, ARE HUSBAND AND WIFE

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.

Name of the organization

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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 OUR WEBSITE AND ON GUIDESTAR ON THE INTERNET.

**FORM 990, PART IX, LINE 24E
OTHER EXPENSES**

	(A) TOTAL	(B) PROGRAM SERVICES	(C) MANAGEMENT & GENERAL	(D) FUNDRAISING
AUCTION ITEMS	10,073.			10,073.
CCI OTHER	4,095.		4,095.	
CCI PROFESSIONAL FEES	22,845.		22,845.	
CREDIT CARD FEES	27,416.			27,416.
GRANTS DISCOUNTED	924.	924.		
NANOWAFER PROJECT	5,988.	5,988.		
OTHER EXPENSES	64,295.	178.	862.	63,255.
PATIENT REGISTRY	12,135.	12,135.		
PHOTOGRAPHY	44,797.			44,797.
POSTAGE AND SHIPPING	13,824.		3,612.	10,212.
SUPPLIES	35,257.		1,222.	34,035.
SYMPOSIUM	93,196.	93,196.		
TELEPHONE	1,717.		1,717.	
TOURNAMENT SITE	11,363.			11,363.
WEBSITE	24,757.		21,001.	3,756.
TOTAL	\$ 372,682.	\$ 112,421.	\$ 55,354.	\$ 204,907.

CLIENT 3745

MONTGOMERY, GLICK & COMPANY
23801 CALABASAS RD STE 103
CALABASAS, CA 91302
818-999-6967

SEPTEMBER 8, 2017

NANCY STACK
CYSTINOSIS RESEARCH FOUNDATION
18802 BARDEEN AVE.
IRVINE, CA 92612

DEAR GEOFFREY:

YOUR 2016 FEDERAL RETURN OF ORGANIZATION EXEMPT FROM INCOME TAX WILL BE ELECTRONICALLY FILED WITH THE INTERNAL REVENUE SERVICE UPON RECEIPT OF A SIGNED FORM 8879-EO - IRS E-FILE SIGNATURE AUTHORIZATION. NO TAX IS PAYABLE WITH THE FILING OF THIS RETURN.

YOUR 2016 CALIFORNIA EXEMPT ORGANIZATION ANNUAL INFORMATION RETURN WILL BE ELECTRONICALLY FILED WITH THE STATE OF CALIFORNIA UPON RECEIPT OF A SIGNED FORM 8453-EO. THERE IS A BALANCE DUE OF \$10 PAYABLE BY NOVEMBER 15, 2017. MAIL YOUR CALIFORNIA PAYMENT VOUCHER, FORM 3586, ON OR BEFORE NOVEMBER 15, 2017 TO:

FRANCHISE TAX BOARD
P.O. BOX 942857
SACRAMENTO, CA 94257-0531

ENCLOSED IS YOUR CALIFORNIA REGISTRATION/RENEWAL FEE REPORT TO THE ATTORNEY GENERAL. THE ORIGINAL SHOULD BE SIGNED AT THE BOTTOM OF PAGE ONE. THERE IS A FEE DUE OF \$150 PAYABLE BY NOVEMBER 15, 2017. MAKE THE CHECK OR MONEY ORDER PAYABLE TO "ATTORNEY GENERAL'S REGISTRY OF CHARITABLE TRUSTS" AND MAIL YOUR CALIFORNIA REPORT ON OR BEFORE NOVEMBER 15, 2017 TO:

REGISTRY OF CHARITABLE TRUSTS
P.O. BOX 903447
SACRAMENTO, CA 94203-4470

PLEASE CALL US IF YOU HAVE ANY QUESTIONS.

YOURS SINCERELY,

PETER MONTGOMERY

CLIENT 3745

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

NO.	DESCRIPTION	DATE ACQUIRED	DATE SOLD	COST/ BASIS	BUS. PCT.	CUR 179/ SDA	PRIOR 179/ SDA/ DEPR.	METHOD	LIFE	CURRENT DEPR.
FORM 199										
MACHINERY AND EQUIPMENT										
1	SOFTWARE	4/30/08		12,038			12,038	S/L	7	0
2	WEBSITE	9/01/08		27,275			27,275	S/L	5	0
3	WEBSITE	6/30/09		7,875			7,875	S/L	5	0
4	WEBSITE	10/01/10		9,650			9,633	S/L	5	0
TOTAL MACHINERY AND EQUIPME				56,838		0	56,821			0
TOTAL DEPRECIATION				56,838		0	56,821			0
GRAND TOTAL DEPRECIATION				56,838		0	56,821			0

CLIENT 3745

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

NO.	DESCRIPTION	DATE ACQUIRED	DATE SOLD	COST/ BASIS	BUS. PCT.	CUR 179 BONUS	SPECIAL DEPR. ALLOW.	PRIOR 179/ BONUS/ SP. DEPR.	PRIOR DEC. BAL DEPR.	SALVAG /BASIS REDUCT	DEPR. BASIS	PRIOR DEPR.	METHOD	LIFE	RATE	CURRENT DEPR.
FORM 990/990-PF																
MACHINERY AND EQUIPMENT																
1	SOFTWARE	4/30/08		12,038							12,038	12,038	S/L	7		0
2	WEBSITE	9/01/08		27,275							27,275	27,275	S/L	5		0
3	WEBSITE	6/30/09		7,875							7,875	7,875	S/L	5		0
4	WEBSITE	10/01/10		9,650							9,650	9,633	S/L	5		0
TOTAL MACHINERY AND EQUIPME				56,838		0	0	0	0	0	56,838	56,821				0
TOTAL DEPRECIATION				<u>56,838</u>		<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>56,838</u>	<u>56,821</u>				<u>0</u>
GRAND TOTAL DEPRECIATION				<u>56,838</u>		<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>56,838</u>	<u>56,821</u>				<u>0</u>

Form **8879-EO**

IRS e-file Signature Authorization for an Exempt Organization

OMB No. 1545-1878

For calendar year 2016, or fiscal year beginning _____, 2016, and ending _____, 20____

2016

Department of the Treasury
Internal Revenue Service

▶ **Do not send to the IRS. Keep for your records.**

▶ **Information about Form 8879-EO and its instructions is at www.irs.gov/form8879eo.**

Name of exempt organization

Employer identification number

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

Name and title of officer

GEOFFREY STACK

TRUSTEE

Part I Type of Return and Return Information (Whole Dollars Only)

Check the box for the return for which you are using this Form 8879-EO and enter the applicable amount, if any, from the return. If you check the box on line **1a**, **2a**, **3a**, **4a**, or **5a**, below, and the amount on that line for the return being filed with this form was blank, then leave line **1b**, **2b**, **3b**, **4b**, or **5b**, whichever is applicable, blank (do not enter -0-). But, if you entered -0- on the return, then enter -0- on the applicable line below. **Do not** complete more than 1 line in Part I.

1 a Form 990 check here	▶ <input checked="" type="checkbox"/>	b Total revenue , if any (Form 990, Part VIII, column (A), line 12)	1 b <u>4,857,558.</u>
2 a Form 990-EZ check here	▶ <input type="checkbox"/>	b Total revenue , if any (Form 990-EZ, line 9)	2 b _____
3 a Form 1120-POL check here	▶ <input type="checkbox"/>	b Total tax (Form 1120-POL, line 22)	3 b _____
4 a Form 990-PF check here	▶ <input type="checkbox"/>	b Tax based on investment income (Form 990-PF, Part VI, line 5)	4 b _____
5 a Form 8868 check here	▶ <input type="checkbox"/>	b Balance Due (Form 8868, line 3c)	5 b _____

Part II Declaration and Signature Authorization of Officer

Under penalties of perjury, I declare that I am an officer of the above organization and that I have examined a copy of the organization's 2016 electronic return and accompanying schedules and statements and to the best of my knowledge and belief, they are true, correct, and complete. I further declare that the amount in Part I above is the amount shown on the copy of the organization's electronic return. I consent to allow my intermediate service provider, transmitter, or electronic return originator (ERO) to send the organization's return to the IRS and to receive from the IRS (a) an acknowledgement of receipt or reason for rejection of the transmission, (b) the reason for any delay in processing the return or refund, and (c) the date of any refund. If applicable, I authorize the U.S. Treasury and its designated Financial Agent to initiate an electronic funds withdrawal (direct debit) entry to the financial institution account indicated in the tax preparation software for payment of the organization's federal taxes owed on this return, and the financial institution to debit the entry to this account. To revoke a payment, I must contact the U.S. Treasury Financial Agent at 1-888-353-4537 no later than 2 business days prior to the payment (settlement) date. I also authorize the financial institutions involved in the processing of the electronic payment of taxes to receive confidential information necessary to answer inquiries and resolve issues related to the payment. I have selected a personal identification number (PIN) as my signature for the organization's electronic return and, if applicable, the organization's consent to electronic funds withdrawal.

Officer's PIN: check one box only

I authorize MONTGOMERY, GLICK & COMPANY to enter my PIN 03745 as my signature
ERO firm name Enter five numbers, but do not enter all zeros

on the organization's tax year 2016 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I also authorize the aforementioned ERO to enter my PIN on the return's disclosure consent screen.

As an officer of the organization, I will enter my PIN as my signature on the organization's tax year 2016 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I will enter my PIN on the return's disclosure consent screen.

Officer's signature ▶ _____ Date ▶ _____

Part III Certification and Authentication

ERO's EFIN/PIN. Enter your six-digit electronic filing identification number (EFIN) followed by your five-digit self-selected PIN 95285068720
do not enter all zeros

I certify that the above numeric entry is my PIN, which is my signature on the 2016 electronically filed return for the organization indicated above. I confirm that I am submitting this return in accordance with the requirements of **Pub. 4163**, Modernized e-File (MeF) Information for Authorized IRS e-file Providers for Business Returns.

ERO's signature ▶ _____ Date ▶ _____

**ERO Must Retain This Form – See Instructions
Do Not Submit This Form To the IRS Unless Requested To Do So**

BAA For Paperwork Reduction Act Notice, see instructions.

Form **8879-EO** (2016)

CLIENT 3745

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

NOTE (1) - CONSOLIDATED STATEMENTS
FORM 990 PART IV, 12(B)

THE EXEMPT ORGANIZATION CONSOLIDATED FINANCIAL STATEMENTS INCLUDE THE ACCOUNTS OF CORNEAL CYSTINOLYSIS, INC (CCI), A TEXAS CORPORATION, OWNED 100% BY THE CYSTINOSIS RESEARCH FOUNDATION. THE EXEMPT ORGANIZATION RETURN INCLUDES AND IS BASED ON THE CONSOLIDATED ACCOUNTS.

NOTE (2) - SCHEDULE L - PART IV

DIRECTOR KRIS ELFTMANN IS AN OWNER OF NOELLE CORPORATE COMMUNICATIONS WHICH PROVIDES MARKETING SERVICES AND PRODUCTS, SUCH AS MAGAZINE PUBLICATIONS TO THE FOUNDATION. THE COST OS SUCH SERVICES WAS APPROXIMATELY \$30,000 IN 2016.

NOTE (2)

DIRECTOR DONALD SOLSBY'S WIFE, ZOE SOLSBY, IS A CONSULTANT TO THE FOUNDATION. MRS. SOLSBY RECEIVED COMPENSATION OF APPROXIMATELY \$54,000 IN 2016.

NOTE (2) - FUNDRAISERS

SCHEDULE G - PART II

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.

NOTE (4) FORM RRF-1, QUESTION 7

THE FOUNDATION HELD A RAFFLE AT ITS ANNUAL GOLF TOURNAMENT ON OCTOBER 17, 2016. PROCEEDS FROM THE RAFFLE ARE INCLUDED IN THE FUNDRAISING INCOME ON FORM 990, PART VIII, LINE 1(C).

Calendar Year 2016 or fiscal year beginning (mm/dd/yyyy) , and ending (mm/dd/yyyy)
Corporation/Organization name: CYSTINOSIS RESEARCH FOUNDATION
California corporation number: 9801377
FEIN: 32-0067668
Street address (suite or room): 18802 BARDEEN AVE.
City: IRVINE State: CA Zip code: 92612

A First Return
B Amended Return
C IRC Section 4947(a)(1) trust
D Final Information Return?
E Check accounting method: 1 Cash 2 Accrual 3 Other
F Federal return filed?
G Is this a group filing?
H Is this organization in a group exemption?
I Did the organization have any changes to its guidelines not reported to the FTB?
J If exempt under R&TC Section 23701d, has the organization engaged in political activities?
K Is the organization exempt under R&TC Section 23701g?
L If organization is exempt under R&TC Section 23701d and meets the filing fee exception, check box.
M Is the organization a Limited Liability Company?
N Did the organization file Form 100 or Form 109 to report taxable income?
O Is the organization under audit by the IRS or has the IRS audited in a prior year?
P Is federal Form 1023/1024 pending?
Date filed with IRS

Part I Complete Part I unless not required to file this form. See General Instructions B and C.

Table with 3 columns: Description, Line Number, Amount. Rows include Receipts and Revenues (1-8), Expenses (9-10), and Filing Fee (11-17). Total receipts: 293,875. Total expenses: 2,459,896. Balance due: 10.

Sign Here: Signature of officer, Title: TRUSTEE, Date
Paid Preparer's Use Only: Preparer's signature, Firm's name: MONTGOMERY, GLICK & COMPANY, Address: 23801 CALABASAS RD STE 103, CALABASAS, CA 91302, Telephone: 818-999-6967
May the FTB discuss this return with the preparer shown above? See instructions. [X] Yes [] No

Part II Organizations with gross receipts of more than \$50,000 and private foundations regardless of amount of gross receipts – complete Part II or furnish substitute information.

Receipts from Other Sources	1	Gross sales or receipts from all business activities. See instructions.	1	
	2	Interest	2	8,462.
	3	Dividends	3	18,391.
	4	Gross rents	4	
	5	Gross royalties	5	
	6	Gross amount received from sale of assets (See instructions)	6	267,022.
	7	Other income. Attach schedule	7	
	8	Total gross sales or receipts from other sources. Add line 1 through line 7. Enter here and on Side 1, Part I, line 1.	8	293,875.
Expenses and Disbursements	9	Contributions, gifts, grants, and similar amounts paid. Attach schedule. SEE STATEMENT 1	9	1,003,284.
	10	Disbursements to or for members	10	
	11	Compensation of officers, directors, and trustees. Attach schedule. SEE STMT 2	11	0.
	12	Other salaries and wages	12	57,875.
	13	Interest	13	
	14	Taxes	14	4,854.
	15	Rents	15	
	16	Depreciation and depletion (See instructions)	16	
	17	Other Expenses and Disbursements. Attach schedule. SEE STATEMENT 3	17	1,393,883.
	18	Total expenses and disbursements. Add line 9 through line 17. Enter here and on Side 1, Part I, line 9.	18	2,459,896.

Schedule L Balance Sheet		Beginning of taxable year		End of taxable year	
		(a)	(b)	(c)	(d)
Assets					
1	Cash		3,565,590.		4,672,285.
2	Net accounts receivable		112,500.		63,746.
3	Net notes receivable				
4	Inventories				
5	Federal and state government obligations				
6	Investments in other bonds				
7	Investments in stock		977,965.		1,466,645.
8	Mortgage loans				
9	Other investments. Attach schedule				
10a	Depreciable assets	56,838.		56,838.	
b	Less accumulated depreciation	56,838.		56,838.	
11	Land				
12	Other assets. Attach schedule. STM 4		123,678.		122,507.
13	Total assets		4,779,733.		6,325,183.
Liabilities and net worth					
14	Accounts payable		75,547.		63,761.
15	Contributions, gifts, or grants payable		2,120,213.		1,739,002.
16	Bonds and notes payable				
17	Mortgages payable				
18	Other liabilities. Attach schedule				
19	Capital stock or principal fund		2,583,973.		4,522,420.
20	Paid-in or capital surplus. Attach reconciliation				
21	Retained earnings or income fund				
22	Total liabilities and net worth		4,779,733.		6,325,183.

Schedule M-1 Reconciliation of income per books with income per return				
Do not complete this schedule if the amount on Schedule L, line 13, column (d), is less than \$50,000.				
1	Net income per books	2,397,662.	7	Income recorded on books this year not included in this return. Attach schedule
2	Federal income tax		8	Deductions in this return not charged against book income this year. Attach schedule
3	Excess of capital losses over capital gains		9	Total. Add line 7 and line 8
4	Income not recorded on books this year. Attach schedule		10	Net income per return. Subtract line 9 from line 6
5	Expenses recorded on books this year not deducted in this return. Attach schedule			
6	Total. Add line 1 through line 5	2,397,662.		

2016 Corporation Depreciation and Amortization

3885

Attach to Form 100 or Form 100W. **FORM 199**

Corporation name CYSTINOSIS RESEARCH FOUNDATION	California corporation number 9801377
---	---

Part I Election To Expense Certain Property Under IRC Section 179

1 Maximum deduction under IRC Section 179 for California.....	1	\$25,000															
2 Total cost of IRC Section 179 property placed in service.....	2																
3 Threshold cost of IRC Section 179 property before reduction in limitation.....	3	\$200,000															
4 Reduction in limitation. Subtract line 3 from line 2. If zero or less, enter -0-.....	4																
5 Dollar limitation for taxable year. Subtract line 4 from line 1. If zero or less, enter -0-.....	5																
<table border="1" style="width:100%; border-collapse: collapse;"> <tr> <th style="width:45%;">6 (a) Description of property</th> <th style="width:20%;">(b) Cost (business use only)</th> <th style="width:35%;">(c) Elected cost</th> </tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> </table>			6 (a) Description of property	(b) Cost (business use only)	(c) Elected cost												
6 (a) Description of property	(b) Cost (business use only)	(c) Elected cost															
7 Listed property (elected IRC Section 179 cost).....	7																
8 Total elected cost of IRC Section 179 property. Add amounts in column (c), line 6 and line 7.....	8																
9 Tentative deduction. Enter the smaller of line 5 or line 8.....	9																
10 Carryover of disallowed deduction from prior taxable years.....	10																
11 Business income limitation. Enter the smaller of business income (not less than zero) or line 5.....	11																
12 IRC Section 179 expense deduction. Add line 9 and line 10, but do not enter more than line 11.....	12																
13 Carryover of disallowed deduction to 2017. Add line 9 and line 10, less line 12.....	13																

Part II Depreciation and Election of Additional First Year Depreciation Deduction Under R&TC Section 24356

14 (a) Description of property	(b) Date acquired (mm/dd/yyyy)	(c) Cost or other basis	(d) Depreciation allowed or allowable in earlier years	(e) Depreciation method	(f) Life or rate	(g) Depreciation for this year	(h) Additional first year depreciation
SOFTWARE	4/30/2008	12,038.	12,038.	S/L	7		
WEBSITE	9/01/2008	27,275.	27,275.	S/L	5		
WEBSITE	6/30/2009	7,875.	7,875.	S/L	5		
WEBSITE	10/01/2010	9,650.	9,633.	S/L	5		
15 Add the amounts in column (g) and column (h). The total of column (h) may not exceed \$2,000. See instructions for line 14, column (h).....						15	

Part III Summary

16 Total: If the corporation is electing: IRC Section 179 expense, add the amount on line 12 and line 15, column (g) or Additional first year depreciation under R&TC Section 24356, add the amounts on line 15, columns (g) and (h) or Depreciation (if no election is made), enter the amount from line 15, column (g).....	16	
17 Total depreciation claimed for federal purposes from federal Form 4562, line 22.....	17	
18 Depreciation adjustment. If line 17 is greater than line 16, enter the difference here and on Form 100 or Form 100W, Side 1, line 6. If line 17 is less than line 16, enter the difference here and on Form 100 or Form 100W, Side 2, line 12. (If California depreciation amounts are used to determine net income before state adjustments on Form 100 or Form 100W, no adjustment is necessary.).....	18	

Part IV Amortization

19 (a) Description of property	(b) Date acquired (mm/dd/yyyy)	(c) Cost or other basis	(d) Amortization allowed or allowable in earlier years	(e) R&TC section (see instr)	(f) Period or percentage	(g) Amortization for this year
20 Total. Add the amounts in column (g).....						20
21 Total amortization claimed for federal purposes from federal Form 4562, line 44.....						21
22 Amortization adjustment. If line 21 is greater than line 20, enter the difference here and on Form 100 or Form 100W, Side 1, line 6. If line 21 is less than line 20, enter the difference here and on Form 100 or Form 100W, Side 2, line 12.....						22

STATEMENT 1
FORM 199, PART II, LINE 9
CONTRIBUTIONS, GIFTS, GRANTS, AND SIMILAR AMOUNTS PAID

DONEE'S NAME:	UNIVERSITY OF CALIFORNIA, SD	
DONEE'S STREET ADDRESS:	9500 GILMAN DRIVE, DEPT 0935	
DONEE'S CITY, STATE, ZIP:	LA JOLLA, CA 92093	
AMOUNT GIVEN:		160,589.
DONEE'S NAME:	THE SCRIPPS RESEARCH INSTITUT	
DONEE'S STREET ADDRESS:	10550 N. TORREY PINES ROAD	
DONEE'S CITY, STATE, ZIP:	LA JOLLA, CA 92037	
AMOUNT GIVEN:		75,000.
DONEE'S NAME:	MASSACHUSETTS GENERAL HOSPITAL	
DONEE'S STREET ADDRESS:	101 HUNTINGTON AVENUE, SUITE 300	
DONEE'S CITY, STATE, ZIP:	BOSTON, MA 02199	
AMOUNT GIVEN:		96,129.
DONEE'S NAME:	REGENTS OF UCSD	
DONEE'S STREET ADDRESS:	9500 GILMAN DRIVE MC 0934	
DONEE'S CITY, STATE, ZIP:	LA JOLLA, CA 92093	
AMOUNT GIVEN:		141,082.
DONEE'S NAME:	THE SCRIPPS RESEARCH INSTITUT	
DONEE'S STREET ADDRESS:	10550 N. TORREY PINES RD.	
DONEE'S CITY, STATE, ZIP:	LA JOLLA, CA 92307	
AMOUNT GIVEN:		150,000.
DONEE'S NAME:	HARVARD MEDICAL SCHOOL	
DONEE'S STREET ADDRESS:	A-111 25 SHATTUCK ST	
DONEE'S CITY, STATE, ZIP:	BOSTON , MA 02115	
AMOUNT GIVEN:		225,000.
DONEE'S NAME:	UNIVERSITY OF PITTSBURGH SCHO	
DONEE'S STREET ADDRESS:	3550 TERRACE ST	
DONEE'S CITY, STATE, ZIP:	PITTSBURGH , PA 15213	
AMOUNT GIVEN:		155,484.
	TOTAL	<u>\$ 1,003,284.</u>

STATEMENT 2
FORM 199, PART II, LINE 11
COMPENSATION OF OFFICERS, DIRECTORS, TRUSTEES AND KEY EMPLOYEES

CURRENT OFFICERS:

<u>NAME AND ADDRESS</u>	<u>TITLE AND AVERAGE HOURS PER WEEK DEVOTED</u>	<u>TOTAL COMPEN- SATION</u>	<u>CONTRI- BUTION TO EBP & DC</u>	<u>EXPENSE ACCOUNT/ OTHER</u>
NANCY STACK 18802 BARDEEN AVE. IRVINE, CA 92612	CHAIR - TRUSTEE 40.00	\$ 0.	\$ 0.	0.

STATEMENT 2 (CONTINUED)

FORM 199, PART II, LINE 11

COMPENSATION OF OFFICERS, DIRECTORS, TRUSTEES AND KEY EMPLOYEES

CURRENT OFFICERS:

NAME AND ADDRESS	TITLE AND AVERAGE HOURS PER WEEK DEVOTED	TOTAL COMPEN- SATION	CONTRI- BUTION TO EBP & DC	EXPENSE ACCOUNT/ OTHER
GEOFFREY STACK 18802 BARDEEN AVE IRVINE, CA 92612-1521	VICE CHAIR 0	\$ 0.	\$ 0.	\$ 0.
DONALD L. SOLSBY 1045 W. KATELLA AVE, STE 100 ORANGE, CA 92867	TRUSTEE 2.00	0.	0.	0.
BRUCE CRAIR 20634 CIRCULO LOMA YORBA LINDA, CA 92887	TRUSTEE 0	0.	0.	0.
STEPHANIE CHERQUI 10550 N. TORREY PINES ROAD LA JOLLA, CA 92037	TRUSTEE 0	0.	0.	0.
MARCU ALEXANDER 3010 N. ALAMO ROAD BOISE, ID 83704	TRUSTEE 0	0.	0.	0.
DAVID W. MOSSMAN 200 E. BAKER ST, STE 100 COSTA MESA, CA 92626	TRUSTEE 0	0.	0.	0.
JOHN S. HAGESTAD 18802 BARDEEN AVENUE IRVINE, CA 92612	TRUSTEE 0	0.	0.	0.
ERIN LITTLE 5244 BRUCE RD 3 PORT ELGIN, ONTARIO N0H2C6 CANAD	TRUSTEE 0	0.	0.	0.
MICHAEL K. HAYDE 8 EXECUTIVE CIRCLE IRVINE, CA 92614	TRUSTEE 0	0.	0.	0.
KRIS K. ELFTMANN 3395 MICHELSON DR, #2231 IRVINE, CA 92612	TRUSTEE 0	0.	0.	0.
KEVIN PARTINGTON 400 CAPITOL MALL, STE 650 SACRAMENTO, CA 95814	TRUSTEE 0	0.	0.	0.
TERESA PARTINGTON 1315 TENEIGHTH WAY SACRAMENTO, CA 95818	TRUSTEE 0	0.	0.	0.

STATEMENT 2 (CONTINUED)

FORM 199, PART II, LINE 11

COMPENSATION OF OFFICERS, DIRECTORS, TRUSTEES AND KEY EMPLOYEES

CURRENT OFFICERS:

NAME AND ADDRESS	TITLE AND AVERAGE HOURS PER WEEK DEVOTED	TOTAL COMPEN- SATION	CONTRI- BUTION TO EBP & DC	EXPENSE ACCOUNT/ OTHER
BRIAN STURGIS 565 WHISKEY JACK CIRCLE SANDPOINT, ID 83864	TRUSTEE 0	\$ 0.	\$ 0.	\$ 0.
ROBERT D. OLSON 520 NEWPORT CENTER DR, STE 600 NEWPORT BEACH, CA 92660	TRUSTEE 0	0.	0.	0.
DENICE FLERCHINGER PO BOX 754 CLARKSTON, WA 99403	TRUSTEE 0	0.	0.	0.
JOHN C. MANLY 19100 VON KARMAN AVE, STE 800 IRVINE, CA 92612	TRUSTEE 0	0.	0.	0.
JODY STRAUSS 534 LITTLE DOVER CRESCENT WATERLOO, ONTARIO N2K 4E4 CANADA	TRUSTEE 0	0.	0.	0.
THOMAS A. GENDRON 1000 E. DRAKE RD FORT COLLINS, CO 80521	TRUSTEE 0	0.	0.	0.
TRACI GENDRON 3825 HARBOR WALK LANE FORT COLLINS, CO 80525	TRUSTEE 0	0.	0.	0.
STEPHEN L. JENKINS, MD 2122 S. ONEIDA ST SALT LAKE CITY, UT 84109	TRUSTEE 0	0.	0.	0.
	TOTAL	\$ 0.	\$ 0.	\$ 0.

STATEMENT 3

FORM 199, PART II, LINE 17

OTHER EXPENSES

ACCOUNTING FEES.....	\$ 50,140.
ADVERTISING AND PROMOTION.....	135,057.
AUCTION ITEMS.....	10,073.
CCI OTHER.....	4,095.
CCI PROFESSIONAL FEES.....	22,845.
CORNEAL CYSTINOSIS-NANOWAFER.....	270,623.
CREDIT CARD FEES.....	27,416.
EDUCATION.....	189,047.
GRANTS DISCOUNTED.....	924.
INSURANCE.....	8,036.
NANOWAFER PROJECT.....	5,988.

STATEMENT 3 (CONTINUED)
FORM 199, PART II, LINE 17
OTHER EXPENSES

OTHER EXPENSES.....	\$	64,295.
OUTSIDE SERVICES.....		162,932.
PATIENT REGISTRY.....		12,135.
PHOTOGRAPHY.....		44,797.
POSTAGE AND SHIPPING.....		13,824.
PRINTING AND PUBLICATIONS.....		181,080.
SUPPLIES.....		35,257.
SYMPOSIUM.....		93,196.
TELEPHONE.....		1,717.
TOURNAMENT SITE.....		11,363.
TRAVEL.....		24,286.
WEBSITE.....		24,757.
	TOTAL	<u>\$ 1,393,883.</u>

STATEMENT 4
FORM 199, SCHEDULE L, LINE 12
OTHER ASSETS

PREPAID EXPENSES AND DEFERRED CHARGES.....		122,507.
	TOTAL	<u>\$ 122,507.</u>

Voucher at bottom of page.

DO NOT MAIL A PAPER COPY OF THE CORPORATE OR EXEMPT ORGANIZATION TAX RETURN WITH THE PAYMENT VOUCHER. If the amount of payment is zero, do not mail this voucher.

WHERE TO FILE: Using black or blue ink, make check or money order payable to the 'Franchise Tax Board.' Write the corporation number or FEIN and '2016 FTB 3586' on the check or money order. Detach voucher below. Enclose, but do not staple, payment with voucher and mail to:

FRANCHISE TAX BOARD
PO BOX 942857
SACRAMENTO CA 94257-0531

Make all checks or money orders payable in U.S. dollars and drawn against a U.S. financial institution.

WHEN TO FILE: Corporations - File and Pay by the 15th day of the 4th month following the close of the taxable year. S corporations - File and Pay by the 15th day of the 3rd month following the close of the taxable year. Exempt organizations - File and Pay by the 15th day of the 5th month following the close of the taxable year.

When the due date falls on a weekend or holiday, the deadline to file and pay without penalty is extended to the next business day.

Due to the federal Emancipation Day holiday observed on April 17, 2017, tax returns filed and payments mailed or submitted on April 18, 2017, will be considered timely.

ONLINE SERVICES: Corporations can make payments online with Web Pay for Businesses. Corporations can make an immediate payment or schedule payments up to a year in advance. Go to ftb.ca.gov for more information.

--- DETACH HERE --- IF NO PAYMENT IS DUE, DO NOT MAIL THIS VOUCHER --- DETACH HERE ---
CAUTION: You may be required to pay electronically, see instructions.

TAXABLE YEAR
2016

Payment Voucher for Corporations and Exempt Organizations e-filed Returns

CALIFORNIA FORM
3586 (e-file)

9801377 CYST 32-0067668 000000000000 16 FORM 3
TYB 01-01-16 TYE 12-31-16
CYSTINOSIS RESEARCH FOUNDATION
GEOFFREY STACK
18802 BARDEEN AVE
IRVINE CA 92612

949-223-7610

AMOUNT OF PAYMENT 10.

Date Accepted _____

DO NOT MAIL THIS FORM TO THE FTB

TAXABLE YEAR

California e-file Return Authorization for Exempt Organizations

FORM

2016

8453-EO

Exempt Organization name

Identifying number

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

Part I Electronic Return Information (whole dollars only)

1	Total gross receipts (Form 199, line 4)	1	5,112,834.
2	Total gross income (Form 199, line 8)	2	4,857,558.
3	Total expenses and disbursements (Form 199, Line 9)	3	2,459,896.

Part II Settle Your Account Electronically for Taxable Year 2016

4 Electronic funds withdrawal 4a Amount _____ 4b Withdrawal date (mm/dd/yyyy) _____

Part III Banking Information (Have you verified the exempt organization's banking information?)

5 Routing number _____
6 Account number _____ 7 Type of account: Checking Savings

Part IV Declaration of Officer

I authorize the exempt organization's account to be settled as designated in Part II. If I check Part II, Box 4, I authorize an electronic funds withdrawal for the amount listed on line 4a.

Under penalties of perjury, I declare that I am an officer of the above exempt organization and that the information I provided to my electronic return originator (ERO), transmitter, or intermediate service provider and the amounts in Part I above agree with the amounts on the corresponding lines of the exempt organization's 2016 California electronic return. To the best of my knowledge and belief, the exempt organization's return is true, correct, and complete. If the exempt organization is filing a balance due return, I understand that if the Franchise Tax Board (FTB) does not receive full and timely payment of the exempt organization's fee liability, the exempt organization will remain liable for the fee liability and all applicable interest and penalties. I authorize the exempt organization return and accompanying schedules and statements be transmitted to the FTB by the ERO, transmitter, or intermediate service provider. **If the processing of the exempt organization's return or refund is delayed, I authorize the FTB to disclose to the ERO or intermediate service provider, the reason(s) for the delay.**

Sign Here Signature of officer _____ Date _____ Title **TRUSTEE**

Part V Declaration of Electronic Return Originator (ERO) and Paid Preparer. See instructions.

I declare that I have reviewed the above exempt organization's return and that the entries on form FTB 8453-EO are complete and correct to the best of my knowledge. (If I am only an intermediate service provider, I understand that I am not responsible for reviewing the exempt organization's return. I declare, however, that form FTB 8453-EO accurately reflects the data on the return.) I have obtained the organization officer's signature on form FTB 8453-EO before transmitting this return to the FTB; I have provided the organization officer with a copy of all forms and information that I will file with the FTB, and I have followed all other requirements described in FTB Pub. 1345, 2016 e-file Handbook for Authorized e-file Providers. I will keep form FTB 8453-EO on file for **four** years from the due date of the return or **four** years from the date the exempt organization return is filed, whichever is later, and I will make a copy available to the FTB upon request. If I am also the paid preparer, under penalties of perjury, I declare that I have examined the above exempt organization's return and accompanying schedules and statements, and to the best of my knowledge and belief, they are true, correct, and complete. I make this declaration based on all information of which I have knowledge.

ERO Must Sign	ERO's signature	Date	Check if also paid preparer <input checked="" type="checkbox"/>	Check if self-employed <input type="checkbox"/>	ERO's PTIN
	Firm's name (or yours if self-employed) and address	MONTGOMERY, GLICK & COMPANY 23801 CALABASAS RD STE 103 CALABASAS CA			FEIN
					954489850 ZIP Code 91302

Under penalties of perjury, I declare that I have examined the above organization's return and accompanying schedules and statements, and to the best of my knowledge and belief, they are true, correct, and complete. I make this declaration based on all information of which I have knowledge.

Paid Preparer Must Sign	Paid preparer's signature	Date	Check if self-employed <input type="checkbox"/>	Paid preparer's PTIN
	Firm's name (or yours if self-employed) and address	FEIN		
				ZIP code

For Privacy Notice, get FTB 1131 ENG/SP.

FTB 8453-EO 2016

CLIENT 3745

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

NO.	DESCRIPTION	DATE ACQUIRED	DATE SOLD	COST/ BASIS	BUS. PCT.	CUR 179/ SDA	PRIOR 179/ SDA/ DEPR.	METHOD	LIFE	CURRENT DEPR.
FORM 199										
MACHINERY AND EQUIPMENT										
1	SOFTWARE	4/30/08		12,038			12,038	S/L	7	0
2	WEBSITE	9/01/08		27,275			27,275	S/L	5	0
3	WEBSITE	6/30/09		7,875			7,875	S/L	5	0
4	WEBSITE	10/01/10		9,650			9,633	S/L	5	0
TOTAL MACHINERY AND EQUIPME				56,838		0	56,821			0
TOTAL DEPRECIATION				56,838		0	56,821			0
GRAND TOTAL DEPRECIATION				56,838		0	56,821			0

NO.	DESCRIPTION	DATE ACQUIRED	DATE SOLD	COST/ BASIS	BUS. PCT.	CUR 179 BONUS	SPECIAL DEPR. ALLOW.	PRIOR 179/ BONUS/ SP. DEPR.	PRIOR DEC. BAL DEPR.	SALVAG /BASIS REDUCT	DEPR. BASIS	PRIOR DEPR.	METHOD	LIFE	RATE	CURRENT DEPR.
FORM 199																
MACHINERY AND EQUIPMENT																
1	SOFTWARE	4/30/08		12,038							12,038	12,038	S/L	7		0
2	WEBSITE	9/01/08		27,275							27,275	27,275	S/L	5		0
3	WEBSITE	6/30/09		7,875							7,875	7,875	S/L	5		0
4	WEBSITE	10/01/10		9,650							9,650	9,633	S/L	5		0
TOTAL MACHINERY AND EQUIPME				56,838		0	0	0	0	0	56,838	56,821				0
TOTAL DEPRECIATION				<u>56,838</u>		<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>56,838</u>	<u>56,821</u>				<u>0</u>
GRAND TOTAL DEPRECIATION				<u>56,838</u>		<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>56,838</u>	<u>56,821</u>				<u>0</u>

CLIENT 3745

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

NOTE (1) - CONSOLIDATED STATEMENTS
FORM 990 PART IV, 12(B)

THE EXEMPT ORGANIZATION CONSOLIDATED FINANCIAL STATEMENTS INCLUDE THE ACCOUNTS OF CORNEAL CYSTINOLYSIS, INC (CCI), A TEXAS CORPORATION, OWNED 100% BY THE CYSTINOSIS RESEARCH FOUNDATION. THE EXEMPT ORGANIZATION RETURN INCLUDES AND IS BASED ON THE CONSOLIDATED ACCOUNTS.

NOTE (2) - SCHEDULE L - PART IV

DIRECTOR KRIS ELFTMANN IS AN OWNER OF NOELLE CORPORATE COMMUNICATIONS WHICH PROVIDES MARKETING SERVICES AND PRODUCTS, SUCH AS MAGAZINE PUBLICATIONS TO THE FOUNDATION. THE COST OS SUCH SERVICES WAS APPROXIMATELY \$30,000 IN 2016.

NOTE (2)

DIRECTOR DONALD SOLSBY'S WIFE, ZOE SOLSBY, IS A CONSULTANT TO THE FOUNDATION. MRS. SOLSBY RECEIVED COMPENSATION OF APPROXIMATELY \$54,000 IN 2016.

NOTE (2) - FUNDRAISERS

SCHEDULE G - PART II

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.

NOTE (4) FORM RRF-1, QUESTION 7

THE FOUNDATION HELD A RAFFLE AT ITS ANNUAL GOLF TOURNAMENT ON OCTOBER 17, 2016. PROCEEDS FROM THE RAFFLE ARE INCLUDED IN THE FUNDRAISING INCOME ON FORM 990, PART VIII, LINE 1(C).

IN

MAIL TO:
 Registry of Charitable Trusts
 P.O. Box 903447
 Sacramento, CA 94203-4470
 Telephone: (916) 445-2021

WEBSITE ADDRESS:
<http://ag.ca.gov/charities/>

ANNUAL REGISTRATION RENEWAL FEE REPORT TO ATTORNEY GENERAL OF CALIFORNIA

Sections 12586 and 12587, California Government Code
 11 Cal. Code Regs. sections 301-307, 311 and 312

Failure to submit this report annually no later than four months and fifteen days after the end of the organization's accounting period may result in the loss of tax exemption and the assessment of a minimum tax of \$800, plus interest, and/or fines or filing penalties as defined in Government Code Section 12586.1. IRS extensions will be honored.



State Charity Registration Number <u>CT123183</u> <u>CYSTINOSIS RESEARCH FOUNDATION</u> <small>Name of Organization</small> <u>18802 BARDEEN AVE.</u> <small>Address (Number and Street)</small> <u>IRVINE, CA 92612</u> <small>City or Town State ZIP Code</small>	Check if: <input type="checkbox"/> Change of address <input type="checkbox"/> Amended report Corporate or Organization No. <u>9801377</u> Federal Employer I.D. No. <u>32-0067668</u>
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ANNUAL REGISTRATION RENEWAL FEE SCHEDULE (11 Cal. Code Regs. sections 301-307, 311 and 312)
 Make Check Payable to Attorney General's Registry of Charitable Trusts

Gross Annual Revenue	Fee	Gross Annual Revenue	Fee	Gross Annual Revenue	Fee
Less than \$25,000	0	Between \$100,001 and \$250,000	\$50	Between \$1,000,001 and \$10 million	\$150
Between \$25,000 and \$100,000	\$25	Between \$250,001 and \$1 million	\$75	Between \$10,000,001 and \$50 million	\$225
				Greater than \$50 million	\$300

PART A – ACTIVITIES

For your most recent full accounting period (beginning 1/01/16 ending 12/31/16) list:
 Gross annual revenue \$ 4,857,558. Total assets \$ 6,325,183.

PART B – STATEMENTS REGARDING ORGANIZATION DURING THE PERIOD OF THIS REPORT

Note: If you answer 'yes' to any of the questions below, you must attach a separate sheet providing an explanation and details for each 'yes' response. Please review RRF-1 instructions for information required.

	Yes	No
1 During this reporting period, were there any contracts, loans, leases or other financial transactions between the organization and any officer, director or trustee thereof either directly or with an entity in which any such officer, director or trustee had any financial interest?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
2 During this reporting period, was there any theft, embezzlement, diversion or misuse of the organization's charitable property or funds?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
3 During this reporting period, did non-program expenditures exceed 50% of gross revenues?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
4 During this reporting period, were any organization funds used to pay any penalty, fine or judgment? If you filed a Form 4720 with the Internal Revenue Service, attach a copy.	<input type="checkbox"/>	<input checked="" type="checkbox"/>
5 During this reporting period, were the services of a commercial fundraiser or fundraising counsel for charitable purposes used? If 'yes,' provide an attachment listing the name, address, and telephone number of the service provider.	<input type="checkbox"/>	<input checked="" type="checkbox"/>
6 During this reporting period, did the organization receive any governmental funding? If so, provide an attachment listing the name of the agency, mailing address, contact person, and telephone number.	<input type="checkbox"/>	<input checked="" type="checkbox"/>
7 During this reporting period, did the organization hold a raffle for charitable purposes? If 'yes,' provide an attachment indicating the number of raffles and the date(s) they occurred.	<input checked="" type="checkbox"/>	<input type="checkbox"/>
8 Does the organization conduct a vehicle donation program? If 'yes,' provide an attachment indicating whether the program is operated by the charity or whether the organization contracts with a commercial fundraiser for charitable purposes.	<input type="checkbox"/>	<input checked="" type="checkbox"/>
9 Did your organization have prepared an audited financial statement in accordance with generally accepted accounting principles for this reporting period?	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Organization's area code and telephone number 949-223-7610
 Organization's e-mail address INFO@CYSTINOSISRESEARCH.ORG

I declare under penalty of perjury that I have examined this report, including accompanying documents, and to the best of my knowledge and belief, it is true, correct and complete.

<u>GEOFFREY STACK</u> <small>Signature of authorized officer</small>	<u>TRUSTEE</u> <small>Printed Name</small>	 <small>Title</small>	 <small>Date</small>
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