Form	99	0

Department of the Treasury

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. > Go to www.irs.gov/Form990 for instructions and the latest information

Open to Public

OMB No. 1545-0047

2017

		nue Service			•		structions and			on.		inspectio	/11	
	For the	e 2017 calen	dar year, or tax	year beginr	n ing 7/0	1	, 2017,	and endin	ig 6/3			, 2018		
В	Check if	applicable:	С							D Employ	yer identi	ification number		
	Add	Iress change	CYSTINOSI			DATION					0067			
	Nan	ne change	18802 BAR		•					E Teleph	one numt	ber		
	Initi	al return	IRVINE, C	A 92612						949	-223	-7610		
	Final	l return/terminated												
	Ame	ended return								G Gross	receipts	\$ 5,217	7,542.	
	App	lication pending	F Name and add	ress of principal	officer:				H(a) Is this	• •		'``	s X _{No}	
			SAME AS C	ABOVE					H(b) Are all If 'No,'	subordinate	s included	d? Ye	s No	
I	Tax-ex	xempt status	X 501(c)(3)	501(c) ()◀ (in:	sert no.)	4947(a)(1) or	527	- /		(· · · · · · · · · · · · · · · · · · ·		
J	Web	site: ► WW	W.CYSTINOS	<u>SISRESEA</u>	RCH.ORG	_			H(c) Group	exemption n	umber 🕨	-		
ĸ		of organization:	X Corporation	Trust	Association	Other ►	LY	ear of format	ion: 2003	3 M :	State of le	egal domicile: C	A	
Pa	art I	Summar	у											
			be the organiza										<u>. </u>	
e			AND TRANS	<u>SLATIONA</u>	<u>L RESEAL</u>	<u>RCH TO</u>	<u>FIND BET</u>	T <u>ER TR</u> E	<u>EATMEN</u> T	<u>S AND</u>	<u>A C</u>	JRE FOR		
Jan	-	<u>CYSTINOS</u>	<u>15</u>											
Activities & Governance	2	Check this bo	x ► Lif the	organization	discontinuc	d its one	ations or dispo	ocod of m	oro than 2	5% of its	not ac			
g			oting members								3	3013.	20	
∞ ŏ			dependent votir								4		20	
ties			of individuals								5		1	
tivi			of volunteers (6		0	
Ac			ed business rev								7a		0.	
	br	Net unrelated	l business taxal	ole income f	rom Form 99	90-1, line	34				7b		0.	
	•	Contributions	and grants (De	vrt \/III line '	16)					rior Year		Current		
he		8 Contributions and grants (Part VIII, line 1h).9 Program service revenue (Part VIII, line 2g).									959.	4,56	9,155.	
Revenue		-	nce revenue (Part VII		•••					38,5	500	8	6,549.	
Вe			e (Part VIII, col							50,	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	0.	J, J4J.	
			e – add lines 8							,857,5	558.	4,65	5,704.	
			imilar amounts							,580,9			1,234.	
	14 E	Benefits paid	to or for memb	oers (Part IX	, column (A)), line 4).				, ,			.,	
	15 S	Salaries, othe	er compensatio	n, employee	benefits (Pa	art IX, col	umn (A), lines	5-10)		62,	729.	62	2,685.	
Expenses	16a F	Professional	fundraising fees		,									
pen	b⊺	Total fundrais	sing expenses (Part IX. colu										
Щ			es (Part IX, col			· -		<u>6,935.</u>		, 393, 8	283	1,396,414.		
			es. Add lines 13			-				,037,5),333.	
			expenses. Sub							,820,0			5,371.	
Σő			· ·							ng of Currei		End of Y		
Net Assets or Fund Balances	20 T	Fotal assets ((Part X, line 16))						3,157,4		9,12	1,015.	
Å.	21 T	Fotal liabilitie	s (Part X, line 2	26)						,722,			8,514.	
Pun	22 N	Net assets or	fund balances.	. Subtract lin	e 21 from li	ne 20			. 6	5,434,6	575.	6,832	2,501.	
Pa	art II	Signatur	e Block							1 - 1				
Unde	er penaltie	es of perjury, I de	eclare that I have exa irer (other than office	amined this retur	n, including acco	ompanying s	chedules and staten	nents, and to	the best of m	iy knowledge	and beli	ef, it is true, corre	ct, and	
comp	plete. Dec	claration of prepa	irer (other than office	er) is based on a	II Information of	which prepa	er has any knowled	age.						
		Signatu	re of officer						Da	to				
Siç He	jn ro			177										
пе	re		FFREY STAC print name and title						TRUST	LEE				
					Preparer's signa	ature		Date		Check	if	PTIN		
										Check			0	
Pa						ייא ג תארי	7			self-employ	eu	P0120982	J	
	eparei e Onl				LICK & (L			Firm's EIN		1100050		
	5 5 m			CALABAS		103				Phone no.		4489850 - 999-6967		
Mar	, th≏ I⊏	S discuse th	CALABA		91302	27 (caa in	structions			гнопе по.	οτα-	<u>-999-6967</u> . X Yes	No	
			eduction Act N				-		EA0113L 08/				90 (2017)	
		ιαροινιοικικ	Saucion ACLN		is separate	การสนบแบ		100	_, 10 I JL 00/	00/17		1 UIII 3		

Form	n 990 ((2017) CYSTINOSIS RESEARCH FOUNDATION	32-0067668	F	Page 2
Par	tⅢ	Statement of Program Service Accomplishments			
		Check if Schedule O contains a response or note to any line in this Part III			X
1		ly describe the organization's mission:			
		'S MISSION IS TO SUPPORT BENCH, CLINICAL AND TRANSLATIONAL RES	EARCH TO FI	ND BET	TER_
	IRE	ATMENTS AND A CURE FOR CYSTINOSIS			
2	Did th	ne organization undertake any significant program services during the year which were not listed on the price	r		
		990 or 990-EZ?	Y	es X	No
		es,' describe these new services on Schedule O.			
3		he organization cease conducting, or make significant changes in how it conducts, any program ser	vices? Y	∕es X	No
		s,' describe these changes on Schedule O.			
4	Secti	ribe the organization's program service accomplishments for each of its three largest program servi on 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations evenue, if any, for each program service reported.	ces, as measured s to others, the tot	by expen al expens	ses. ses,
4 a	a (Code	e:) (Expenses \$3,472,647. including grants of \$2,811,234.) (R	evenue \$)
	<u>SEE</u>	<u>SCHEDULE O</u>			
	o (Code	e:) (Expenses \$ including grants of \$) (R			<u> </u>
40			evenue 5)
40	: (Code	e:) (Expenses \$ including grants of \$) (R	evenue \$)
					· -
4 c		r program services (Describe in Schedule O.)			
		enses \$ including grants of \$) (Revenue \$)	
46	; i otal	program service expenses ► 3, 472, 647.	r	orm 000	(0017)

 Form 990 (2017)
 CYSTINOSIS
 RESEARCH
 FOUNDATION

 Part IV
 Checklist of Required Schedules

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

Form 990 (2017)

Form 990 (2017) CYSTINOSIS RESEARCH FOUNDATION
Part IV Checklist of Required Schedules (continued)

Fa	ruiv	Checkinst of Required Schedules (continued)			
				Yes	No
20a	Did tl	he organization operate one or more hospital facilities? If 'Yes,' complete Schedule H	20a		Х
		es' to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b		
21	Did tl dome	he organization report more than \$5,000 of grants or other assistance to any domestic organization or estic government on Part IX, column (A), line 1? If 'Yes,' complete Schedule I, Parts I and II	21	Х	
22	Did tl colun	he organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, nn (A), line 2? If 'Yes,' complete Schedule I, Parts I and III	22		Х
23	and for	ne organization answer 'Yes' to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current ormer officers, directors, trustees, key employees, and highest compensated employees? <i>If 'Yes,' complete dule J</i> .	23		х
24 a	the la	ne organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of ast day of the year, that was issued after December 31, 2002? <i>If 'Yes,' answer lines 24b through 24d and</i> polete Schedule K. If 'No, 'go to line 25a	24a		Х
I	b Did tl	he organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
(ne organization maintain an escrow account other than a refunding escrow at any time during the year to defease ax-exempt bonds?	24c		
(d Did tl	he organization act as an 'on behalf of' issuer for bonds outstanding at any time during the year?	24d		
25 a	a Secti trans	tion 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit action with a disqualified person during the year? If 'Yes,' complete Schedule L, Part I	25a		х
I	that t	organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and he transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If 'Yes,' complete dule L, Part I	25b		х
26	forme	ne organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or er officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? es,' complete Schedule L, Part II.	26		Х
27	contri	e organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial butor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member y of these persons? <i>If 'Yes,' complete Schedule L, Part III.</i>	27		Х
28	Was t	the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV uctions for applicable filing thresholds, conditions, and exceptions):			
ä	a A cur	rrent or former officer, director, trustee, or key employee? If 'Yes,' complete Schedule L, Part IV	28a		Х
I		nily member of a current or former officer, director, trustee, or key employee? <i>If 'Yes,' complete dule L, Part IV</i>	28b	Х	
(c An er office	ntity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an er, director, trustee, or direct or indirect owner? <i>If 'Yes,' complete Schedule L, Part IV</i>	28c		Х
29	Did tl	he organization receive more than \$25,000 in non-cash contributions? If 'Yes,' complete Schedule M	29		Х
30	Did tl	he organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation ibutions? If 'Yes,' complete Schedule M	30		х
31		he organization liquidate, terminate, or dissolve and cease operations? If 'Yes,' complete Schedule N, Part I	31		X
32		ne organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If 'Yes,' complete dule N, Part II	32		Х
33	Did th 301.7	ne organization own 100% of an entity disregarded as separate from the organization under Regulations sections 7701-2 and 301.7701-3? If 'Yes,' complete Schedule R, Part L	33		Х
	and I	the organization related to any tax-exempt or taxable entity? <i>If 'Yes,' complete Schedule R, Part II, III, or IV,</i> Part V, line 1	34	Х	
35 a	a Did tl	he organization have a controlled entity within the meaning of section 512(b)(13)?	35a	Х	
I	b If 'Ye entity	es' to line 35a, did the organization receive any payment from or engage in any transaction with a controlled within the meaning of section 512(b)(13)? If 'Yes,' complete Schedule R, Part V, line 2	35b		Х
		on 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related nization? If 'Yes,' complete Schedule R, Part V, line 2	36		Х
37	Did th treate	ne organization conduct more than 5% of its activities through an entity that is not a related organization and that is ed as a partnership for federal income tax purposes? <i>If 'Yes,' complete Schedule R, Part VI</i>	37		х
38	Note	ne organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? All Form 990 filers are required to complete Schedule O	38	Х	
				aan /	(OO17)

Form 990 (2017)

BAA

Form	990 (2017) CYSTINOSIS RESEARCH FOUNDATION 32-006766	8	F	age 5
Par		•		5
	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 1a			
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable			
	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming			
	(gambling) winnings to prize winners?	1 c		
2 a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax State-			
	ments, filed for the calendar year ending with or within the year covered by this return 2a 1			
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2 b	Х	
	Note. If the sum of lines 1a and 2a is greater than 250, you may be required to <i>e-file</i> (see instructions)			
	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3 a		Х
	If 'Yes,' has it filed a Form 990-T for this year? If 'No' to line 3b, provide an explanation in Schedule Q.	3 b		
4 a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a	4.0		х
L	financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4a		Λ
L.	See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).	-		
5 0	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a		Х
	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5a 5b		X
	If 'Yes,' to line 5a or 5b, did the organization file Form 8886-T?	5 D		Л
		50		
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?	6 a		Х
b	If 'Yes,' did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b		
7	Organizations that may receive deductible contributions under section 170(c).	0.0		
а	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?	7 a		Х
	If 'Yes,' did the organization notify the donor of the value of the goods or services provided?	7 b		
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7 c		Х
d	If 'Yes,' indicate the number of Forms 8282 filed during the year	70		
	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e		Х
	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7 f		X
	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899			
5	as required?	7 g		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7 h		
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?	8		
9	Sponsoring organizations maintaining donor advised funds.			
а	Did the sponsoring organization make any taxable distributions under section 4966?	9 a		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9 b		
10	Section 501(c)(7) organizations. Enter:			
а	Initiation fees and capital contributions included on Part VIII, line 12 10a			
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities 10b			
11	Section 501(c)(12) organizations. Enter:			
а	Gross income from members or shareholders 11 a			
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)			
12 a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a		
	If 'Yes,' enter the amount of tax-exempt interest received or accrued during the year 12b			
	Section 501(c)(29) qualified nonprofit health insurance issuers.			
	Is the organization licensed to issue qualified health plans in more than one state?	13a		
	Note. See the instructions for additional information the organization must report on Schedule O.			
h	-			
	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			
	Enter the amount of reserves on hand			
	Did the organization receive any payments for indoor tanning services during the tax year?	14a		Х
-	If 'Yes,' has it filed a Form 720 to report these payments? If 'No,' provide an explanation in Schedule O	14b		
BAA	TEEA0105L 08/08/17	⊦orm	990	(2017)

32-0067668

Page 6

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.
<u> </u>	

Sec	ction 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 20 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 a 20			
	b Enter the number of voting members included in line 1a, above, who are independent 1b 20			
	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	Х	
3	of officers, directors, or trustees, or key employees to a management company or other person?	3		Х
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4		Х
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
-	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
	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		Х
0	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by	7.5		
0	the following:			
	a The governing body?	8 a	Х	
	b Each committee with authority to act on behalf of the governing body?	8 b	Х	
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? <i>If 'Yes,' provide the names and addresses in Schedule O</i>	9		Х
Sec	ction B. Policies (This Section B requests information about policies not required by the Internal Re	eveni	ie Co	ode.)
			Yes	No
10	a Did the organization have local chapters, branches, or affiliates?	10 a		Х
	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		
	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	Х	
	b Describe in Schedule O the process, if any, used by the organization to review this Form 990. SEE SCHEDULE O			
	a Did the organization have a written conflict of interest policy? If 'No,' go to line 13	12a	Х	
	b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	Х	
	c Did the organization regularly and consistently monitor and enforce compliance with the policy? If 'Yes,' describe in Schedule O how this was done SEE. SCHEDULE . Q.	12c	Х	
13	Did the organization have a written whistleblower policy?	13	Х	
14	Did the organization have a written document retention and destruction policy?	14	Х	
15	Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?			
	a The organization's CEO, Executive Director, or top management official	15a		Х
	b Other officers or key employees of the organization	15b		Х
	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		Х
	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			
<u>C - </u>	organization's exempt status with respect to such arrangements?	16b		
-	List the states with which a copy of this Form 990 is required to be filed NONTE			
17				<u> </u>
18	Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (Section 501(c)(3)s for public inspection. Indicate how you made these available. Check all that apply.	only)	availa	able
	X Own website X 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 availa the public during the tax year. SEE SCHEDULE O	ole to		
20	State the name, address, and telephone number of the person who possesses the organization's books and records:			

20	State the hame	, auuress,	anu telepi		or the pe	rson who pos	58855	ses the org	anizatio	DITS DOOKS AND RECORDS	5.
	GEOFFREY	STACK	18802	BARDEEN	AVE	IRVINE	CA	92612	949	756-5959	

Form 990 (2017) CYSTINOSIS RESEARCH FC	דידי ארוואדו	ON			32-00676	68 Page 7
Part VII Compensation of Officers, Directo			y Employe	es, Highest C		
Independent Contractors	or poto to	ony line in	this Dart \//			
Check if Schedule O contains a response of Section A. Officers, Directors, Trustees, Ke		-				·····
 1 a Complete this table for all persons required to be listed organization's tax year. List all of the organization's current officers, direcompensation. Enter -0- in columns (D), (E), and (F) if List all of the organization's current key employe List the organization's five current highest compensization and any related organizations. List all of the organization's former officers, key of reportable compensizion rom the organization and any List all of the organization's former directors or trustee organization, more than \$10,000 of reportable compensition. 	. Report co ectors, true f no comp ees, if any ensated e W-2 and/ employee related org	ompensation stees (wheth ensation way . See instru- mployees (c for Box 7 of es, and high ganizations. evived, in the	for the calend ner individua as paid. ctions for de other than ar Form 1099-1 est compens capacity as a	dar year ending wit ls or organization finition of 'key en officer, director, MISC) of more that ated employees v former director or t	h or within the s), regardless of an nployee.' trustee, or key emp nn \$100,000 from th vho received more t rustee of the	bloyee) e
List persons in the following order: individual trustees of employees; and former such persons. X Check this box if neither the organization nor any relate	or director	rs; institutio	nal trustees;	officers; key emp	oloyees; highest con	npensated
(A) Name and Title	(B) Average hours per week (list any hours for related organiza- tions below dotted line)	than one box, is both an o director	Former into check more unless person officer and a /trustee) Highest compensated Key employee	(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
(1) NANCY STACK CHAIR - TRUSTEE	<u>40</u>	X		0.	0.	0.

(1) NANCY STACK	40						
CHAIR - TRUSTEE	0	Х			0	. 0.	0.
(2) GEOFFREY STACK	0						
VICE CHAIR-TTEE	0	Х			0	. 0.	0.
(3) DONALD L. SOLSBY	2						
TREASURER - TTE	0	Х			0	. 0.	0.
(4) BRUCE CRAIR	0						
TRUSTEE	0	Х			0	. 0.	0.
(5) STEPHANIE CHERQUI	0						
TRUSTEE	0	Х			0	. 0.	0.
(6) MARCU ALEXANDER	0						
TRUSTEE	0	Х			0	. 0.	0.
(7) DAVID W. MOSSMAN	0						
TRUSTEE	0	Х			0	. 0.	0.
(8) JOHN S. HAGESTAD	0						
TRUSTEE	0	Х			0	. 0.	0.
<u>(9) ERIN_LITTLE</u>	0						
TRUSTEE	0	Х			0	. 0.	0.
(10) MICHAEL K. HAYDE	0						
TRUSTEE	0	Х			0	. 0.	0.
(11) KEVIN PARTINGTON	0						
TRUSTEE	0	Х			0	. 0.	0.
(12) TERESA PARTINGTON	0						
TRUSTEE	0	Х			0	. 0.	0.
(13) BRIAN STURGIS	0						
TRUSTEE	0	Х			0	. 0.	0.
(14) ROBERT D. OLSON	0						
TRUSTEE	0	Х			0	. 0.	0.
ВАА	TEEA0	107L	08/08/17	 			Form 990 (2017)

32-0067668 Page 8

Par	t VII Section A. Officers, Directors, Tru	stees,	Key	Em	plo	bye	es,	and	d Highest Com	pensated Emp	oyees (continued)
		(B)			(C)					
	(A) Name and title	Average hours per week (list any hours for related organiza - tions	box,	unles er an	ss pe nd a c	erson	e is bott or/trus Highest compensated	h an tee)	(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
		below dotted line)	ustee	rustee		8	pensated				
(15)	DENICE FLERCHINGER	<u> 0 </u>	x						0.	0.	0.
(16)	JOHN C. MANLY	0	х						0.	0.	0.
(17)	JODY STRAUSS TRUSTEE	0	X						0.	0.	0.
(18)	THOMAS A. GENDRON TRUSTEE	0	x						0.	0.	0.
(19)	TRACI GENDRON	0	X						0.	0.	0.
(20)	STEPHEN L. JENKINS, MD TRUSTEE	0	X						0.	0.	0.
(21)											
(22)											
(23)											
(24)											
(25)											
1 b	Sub-total							►	0.	0.	0.
c	Total from continuation sheets to Part VII, Section	on A						►	0.	0.	0.
	Total (add lines 1b and 1c)							►	0.	0.	0.
2	Total number of individuals (including but not limited from the organization b 0							ved			
3	Did the organization list any former officer, direct on line 1a? <i>If 'Yes,' complete Schedule J for sucl</i>	tor, or tru	stee,	key	' em	nplo	yee,	or h	ighest compensat	ted employee	Yes No
4	For any individual listed on line 1a, is the sum of the organization and related organizations greate such individual	reportab r than \$1	le coi 50,00	mpe 00?	nsa If 'Y	ition <i>Yes,</i>	and ' <i>con</i> r	oth 1 <i>ple</i>	er compensation te Schedule J for	from	4 X
5	Did any person listed on line 1a receive or accrue for services rendered to the organization? If 'Yes	e comper ,' <i>comple</i>	nsatio ete Sc	n fro ched	om a Jule	any <i>J fo</i>	unre r suc	late	ed organization or erson	individual	
Sect	ion B. Independent Contractors										<u> </u>
1	Complete this table for your five highest compens compensation from the organization. Report compens	sated ind	epeno the ca	dent	cor dar v	ntra vear	ctors endi	tha ng v	t received more the or	nan \$100,000 of ganization's tax year	
	(A) Name and business addr					Joan	orrai		(B) Description of	- -	(C) Compensation
·											
	Total number of independent contractors (including b \$100,000 of compensation from the organization		ited to	o tho	se li	isteo	d abo	ve)	who received more	than	

BAA

Form 990 (2017) CYSTINOSIS RESEARCH FOUNDATION

Part VIII Statement of Revenue

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

	Check if Schedule O contains a response of hole to any	(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 campaigns1 ab Membership dues1 bc Fundraising events1 cd Related organizations1 de Government grants (contributions)1 e				
Contributi and Other	f All other contributions, gifts, grants, and similar amounts not included above	4,569,155.			
e Revenue	2 a Business Code b				
Program Service Revenue	cd				
rog	q Total. Add lines 2a-2f				
	3 Investment income (including dividends, interest and other similar amounts)	60,752.	60,752.		
	4 Income from investment of tax-exempt bond proceeds 5 Royalties				
	6a Gross rents b b Less: rental expenses c c Rental income or (loss) d d Net rental income or (loss)				
	7 a Gross amount from sales of assets other than inventory (i) Securities (ii) Other 587,635.				
	b Less: cost or other basis and sales expenses 561,838. c Gain or (loss) 25,797. d Net gain or (loss) •	25,797.	25,797.		
levenue	8a Gross income from fundraising events (not including. \$ <u>3,109,295.</u> of contributions reported on line 1c). See Part IV, line 18 a	23,131.	23,131.		
Other Rever	b Less: direct expenses b c Net income or (loss) from fundraising events ►				
	9 a Gross income from gaming activities. See Part IV, line 19a b Less: direct expensesb				
	c Net income or (loss) from gaming activities► 10a Gross sales of inventory, less returns and allowancesa				
	b Less: cost of goods sold b c Net income or (loss) from sales of inventory ► Miscellaneous Revenue Business Code				
	11a b				
	d All other revenue				
BAA	12 Total revenue. See instructions	4,655,704.	86,549.	0	. 0. Form 990 (2017)

32-0067668

Page 9

Π

Form 990 (2017) CYSTINOSIS RESEARCH FOUNDATION

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).

32-	067668	Page 7	10

7 Other salaries and wages 58,014. 58,014. 8 Pension plan accruats and contributions (include section 401(k) and 403(b) employer contributions) 58,014. 58,014. 9 Other employee benefits 4,671. 4,671. 10 Payroll taxes 4,671. 4,671. 11 Fees for services (non-employees): 4,671. 4,671. a Management 25,962. 23,225. d Lobbying 49,187. 25,962. 23,225. d Lobbying 9 9 10 10 10 e Professional fundraising services. See Part IV, line 17. 9 10 10 10 g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule 0.) 130,159. 8,175. 121,984 13 Office expenses 130,159. 121,984 121,984 14 Information technology. 10 10 10 10 16 Occupancy. 10 10 10 10 10	Check if Schedule O contains a response or note to any line in this Part IX.							
arganizations and domestic governments. 2, 361, 084 2, 361, 084 2, 361, 084 2 Grants and other assistance to foreign arganizations, foreign governments, and bo- eign individuals. See Part V, lines 15 and 16 Compensation rol or calculations, lines 15, and 10, and 403(b) employer contributions; Compensation rol or calculations, lines 15, and 16 Compensation rol or calculations, lines 15, and 10, and 403(b) employer contributions; Concentrations, lines 11, lines 15, and 16 Compensation rol or calculations, lines 16, and 17 Concentrations, lines 10, and 26, and 17 Concentration, lines 16, and 26, and 17 Concentration, lines 16, and 26, and 17 Concentration, and mentization, lines 16, and 10, and 13, and 15, and 18, and 19, and 19	Do i 6b,	not include amounts reported on lines 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	Program service	Management and	Fundraising		
Individuals. See Part IV, line 22	1	organizations and domestic governments. See Part IV, line 21	2,361,084.	2,361,084.				
3 Grants and other assistance to foreign eign individuals. See Part IV, lines 15 and 16 Benetis paid to or for members	2	individuals. See Part IV, line 22						
5 Compensation of current officers, directors, disputible previous (see direct of the disputible previous (see direct of the direct of the disputible previous (see direct o	3	Grants and other assistance to foreign	450,150.	450,150.				
6 Compensation for included above, to disquilified persons, (as defined under section 4956()(1)) and persons described in section 4956()(1)) and contributions 0 0 0 0 7 Other satares and wages 58,014. 58,014. 0 0 0 8 Persion persons do contributions employer contributions) 0 0 0 0 0 0 9 Other employee benefits 0 0 4,671 4,671 10 Payoil taxes 4,671 4,671 4,671 11 Frees for services (non-employees): 49,187 25,962 23,225 4 blegal 4,671 4,671 4,671 11 Frees for services (non-employees): 49,187 25,962 23,225 4 blegal 4,671 4,671 4,671 12 Adventsing and promotion 130,159 8,175 121,984 13 Other expenses 130,159 8,175 121,984 1	-	Compensation of current officers, directors,	0	0	0	0		
7 Other salaries and wages. 58,014. 58,014. 8 Pension plan accurate and contributions employee contributions). 58,014. 58,014. 9 Other employee benefits. 0 0 10 Payroll taxes. 4,671. 4,671. 11 Fees for services (non-employees): 44,671. 4,671. a Management. 0 49,187. 25,962. 23,225 d Lobbying 49,187. 25,962. 23,225 d Lobbying 49,187. 25,962. 23,225 d Lobbying 0 130,159. 8,175. 121,984 30 Other employee benefits. 0 130,159. 8,175. 121,984 d lobbying 130,159. 8,175. 121,984 0 d hormation technology 130,159. 8,175. 121,984 14 Information technology 35,020. 1,410. 9,254. 24,356 Payments of travel or entertainment expenses for any federal, statle, or local public officials 0 0 0 12 Payments to affinitales. 0 0 0 0 0 0 0 0 0 0 0 <	6	Compensation not included above, to				0.		
8 Pension plan acculate and contributions include section 401 (b) and 403(b) employer contributions). 0 + 0 + 0 + 0 + 0 + 0 + 0 + 0 + 0 + 0 +	7			0.				
10 Payroll taxes 4, 671. 4, 671. 11 Fees for services (non-employees): 4, 671. 4, 671. a Management blegal 25, 962. 23, 225. d Lobbying. 90 the: (file 11g anout caseds 10% of line 25, olumn (A) amount, list line 11g expenses on Schedule 0). 130, 159. 8, 175. 121, 984 13 Office expenses. 130, 159. 8, 175. 121, 984 14 Information technology. 1 130, 159. 24, 356. 17 Travel. 35, 020. 1, 410. 9, 254. 24, 356. 19 Conferences, conventions, and meetings. 0 0 0 0 10 Interest. 0	8	Pension plan accruals and contributions (include section 401(k) and 403(b)	50,011.			30,011.		
11 Fees for services (non-employees): a Management	9							
a Management			4,671.			4,671.		
b Legal 49,187. 25,962. 23,225 d Lobbying 49,187. 25,962. 23,225 d Investment management fees 90ter, (file 119 anout ecceds 10% of ite 25, column (A) anount, list line 119 expenses on Schedule 0). 130,159. 8,175. 121,984 3 Office expenses 130,159. 8,175. 121,984 13 Office expenses 130,159. 8,175. 121,984 16 Occupancy 130,159. 8,175. 121,984 17 Travel. 35,020. 1,410. 9,254. 24,356 18 Payments of travel or entertainment expenses for any federal, state, or local public officials. 1000000000000000000000000000000000000								
c Accounting		-						
d Lobbying								
e Professional fundraising services. See Part IV, line 17		-	49,187.		25,962.	23,225.		
f Investment management fees		5 0						
9 Other. (f line 11g around texceeds 10% of line 25. column (A) amount, list line 11g expenses on Schedule 0								
(A) amount, list line 11g expenses on Schedule 0.) 130, 159. 8, 175. 121, 984 12 Advertising and promotion 130, 159. 8, 175. 121, 984 13 Office expenses		5						
13 Office expenses Information technology 14 Information technology Information technology 15 Royalties Image: Comparison of the expenses of any federal, state, or local public officials 17 Travel 35,020 1,410 9,254 24,356 18 Payments of travel or entertainment expenses for any federal, state, or local public officials Image: Comparison of the expenses, and meetings Image: Comparison of the expenses, and meetings 19 Conferences, conventions, and meetings Image: Comparison of the expenses, itemize expenses not covered above (List miscellaneous expenses in line 24e, of line 24e, and une vaceeds 10% of line 25e, column (A) amount, list line 24e expenses on Schedule O.) 298,143 298,143 106,989 2 Other expenses. 167,690 56,307 4,406 106,977 2 OUTSIDE_SERVICES 166,877 30,353 45,657 90,867 d CORNEAL_CYSTINOSIS-NANOWAFER 158,173 Image: Complete this line only if the organization reported in column (B) joint costs from a combined ducational campaign and fundraising solicitation. 4,270,333 3,472,647 180,751 616,935 26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined ducational campaign an		(A) amount, list line 11g expenses on Schedule 0.)	130,159,	8,175,		121,984		
15 Royalties			100/1001	0/1/01		101/0011		
16 Occupancy	14							
16 Occupancy	15	Royalties						
18 Payments of travel or entertainment expenses for any federal, state, or local public officials. 0,10001 <td< td=""><td>16</td><td>-</td><td></td><td></td><td></td><td></td></td<>	16	-						
18 Payments of travel or entertainment expenses for any federal, state, or local public officials.	17	Travel	35,020.	1,410.	9,254.	24,356.		
20 Interest	18	expenses for any federal, state, or local			.,			
21 Payments to affiliates	19	Conferences, conventions, and meetings						
22 Depreciation, depletion, and amortization 6, 989. 6, 989. 23 Insurance	20							
23 Insurance 6,989. 6,989. 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.) 298,143. 298,143. a EDUCATION 298,143. 298,143. b PRINTING_AND_PUBLICATIONS 167,690. 56,307. 4,406. 106,977. c OUTSIDE_SERVICES 166,877. 30,353. 45,657. 90,867. d CORNEAL_CYSTINOSIS-NANOWAFER 158,173. 158,173. e All other expenses. 384,176. 108,852. 88,483. 186,841 25 Total functional expenses. Add lines 1 through 24e. 4,270,333. 3,472,647. 180,751. 616,935 26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ► if following Check here ► if following		-						
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.). 298,143. 298,143. a EDUCATION 298,143. 298,143. b PRINTING AND PUBLICATIONS 167,690. 56,307. 4,406. 106,977. c OUTSIDE SERVICES 166,877. 30,353. 45,657. 90,867. d CORNEAL CYSTINOSIS-NANOWAFER 158,173. 158,173. e All other expenses. Add lines 1 through 24e 4,270,333. 3,472,647. 180,751. 616,935 26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ► if following if following								
a EDUCATION		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	6,989.		6,989.			
b PRINTING_AND_PUBLICATIONS 167,690. 56,307. 4,406. 106,977. c OUTSIDE_SERVICES 166,877. 30,353. 45,657. 90,867. d CORNEAL_CYSTINOSIS-NANOWAFER 158,173. 158,173. 158,173. e All other expenses. 384,176. 108,852. 88,483. 186,841 25 Total functional expenses. Add lines 1 through 24e. 4,270,333. 3,472,647. 180,751. 616,935 26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ► if following if following	-		200 1/2	200 142				
c OUTSIDE SERVICES 166,877. 30,353. 45,657. 90,867. d CORNEAL CYSTINOSIS-NANOWAFER 158,173. 158,173. 158,173. e All other expenses. 384,176. 108,852. 88,483. 186,841 25 Total functional expenses. Add lines 1 through 24e 4,270,333. 3,472,647. 180,751. 616,935 26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ► if following					1 106	106 077		
d CORNEAL CYSTINOSIS-NANOWAFER 158,173. 158,173. e All other expenses. 384,176. 108,852. 88,483. 186,841 25 Total functional expenses. Add lines 1 through 24e 4,270,333. 3,472,647. 180,751. 616,935 26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ► if following								
e All other expenses. 384,176. 108,852. 88,483. 186,841 25 Total functional expenses. Add lines 1 through 24e 4,270,333. 3,472,647. 180,751. 616,935 26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ► if following if following					43,037.	30,007.		
25 Total functional expenses. Add lines 1 through 24e 4,270,333. 3,472,647. 180,751. 616,935 26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ► ☐ if following 616,935					88,483	186.841		
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ► ☐ if following								
	26	Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ► if following SOP 98-2 (ASC 958-720)	, ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	, , , , , , , , , , , , , , , , , , , ,				

Form 990 (2017) CYSTINOSIS RESEARCH FOUNDATION

Balance Sheet

Part X

Page 11

Check if Schedule O contains a response or note to any line in this Part X (B) End of year (A) Beginning of year 1 1 Cash – non-interest-bearing. Savings and temporary cash investments..... 5,569,068 2 7,214,243. 2 3 3 Pledges and grants receivable, net..... 162,250. 977,583 Accounts receivable, net 4 4 Loans and other receivables from current and former officers, directors, 5 Part II of Schedule L 5 Loans and other receivables from other disgualified persons (as defined under 6 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 Notes and loans receivable, net..... 7 61. 7 13,916 Assets Inventories for sale or use..... 8 8 Prepaid expenses and deferred charges..... 9 68,996 9 133,730. **10a** Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D. 10 a 56,838. **b** Less: accumulated depreciation..... 10b 56,838. 10 c Investments – publicly traded securities..... 11 11 1,527,861 1,610,731. 12 **12** Investments – other securities. See Part IV, line 11..... Investments – program-related. See Part IV, line 11..... 13 13 14 14 Intangible assets. 15 Other assets. See Part IV, line 11..... 15 Total assets. Add lines 1 through 15 (must equal line 34)..... 16 16 8,157,424 9,121,015 133, 17 Accounts payable and accrued expenses 42,022 17 427 18 Grants payable 1,680,727. 18 2,155,087 19 Deferred revenue 19 20 20 Tax-exempt bond liabilities 21 Escrow or custodial account liability. Complete Part IV of Schedule D..... 21 Liabilities 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 Unsecured notes and loans payable to unrelated third parties..... 24 24 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 25 Total liabilities. Add lines 17 through 25..... 26 1,722,749 26 2,288,514. Organizations that follow SFAS 117 (ASC 958), check here ► X and complete Balances lines 27 through 29, and lines 33 and 34. Unrestricted net assets..... 27 27 6,434,675 6,832,501. Temporarily restricted net assets..... 28 28 29 Fund Permanently restricted net assets..... 29 Organizations that do not follow SFAS 117 (ASC 958), check here > and complete lines 30 through 34. 5 30 Capital stock or trust principal, or current funds..... 30 ø Net Asse Paid-in or capital surplus, or land, building, or equipment fund..... 31 31 32 Retained earnings, endowment, accumulated income, or other funds..... 32 33 Total net assets or fund balances..... 6,434,675 33 6,832,501. 34 Total liabilities and net assets/fund balances. 8,157,424 34 9,121,015.

BAA

Form 990 (2017)

Form	1 990 (2017) CYSTINOSIS RESEARCH FOUNDATION 32-	0067668	3	Pa	ige 12
Par	t 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	4,6	55,7	704.
2	Total expenses (must equal Part IX, column (A), line 25).	2	4,2		
3	Revenue less expenses. Subtract line 2 from line 1	3			371.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4			575.
5	Net unrealized gains (losses) on investments.	5			155.
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	6,8	32,5	501.
Par	t 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: Cash X Accrual 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?		2a		Х
	If 'Yes,' check a box below to indicate whether the financial statements for the year were compiled or reviewed	ed on a			
	separate basis, consolidated basis, or both:				
	Separate basis Consolidated basis Both consolidated and separate basis				
b	Were the organization's financial statements audited by an independent accountant?		2 b	Х	
	If 'Yes,' check a box below to indicate whether the financial statements for the year were audited on a separate	ate			
	basis, consolidated basis, or both:				
	X Separate basis Consolidated basis Both consolidated and separate basis				
С	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?		2 c	Х	
			20	Λ	
	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				77
	Audit Act and OMB Circular A-133?		3a		Х
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				
BAA			Form	990	(2017)

SCHEDULE A (Form 990 or 990-EZ)

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust. ► Attach to Form 990 or Form 990-EZ.

2017 Dubli

OMB No. 1545-0047

Departr Internal	Department of the Treasury Internal Revenue Service Go to www.irs.gov/Form990 for instructions and the latest information. Inspection						Inspection	
Name o	Name of the organization Employer identification number						ation number	
CYS	CYSTINOSIS RESEARCH FOUNDATION 32-0067668							
Part				rganizations must (tions.
The o	rganization is not	a private found	dation because it is: (For lines 1 through 12,	check o	only one	box.)	
1				hurches described in sec			(i).	
2				Schedule E (Form 990 of				
3		•		ization described in se				
4		-	ition operated in conju	unction with a hospital	describe	ed in sec	ction 170(b)(1)(A)(iii). E	inter the hospital's
-	name, city, a							
5	An organizati	on operated for b)(1)(A)(iv). (Co	the benefit of a colle omplete Part II.)	ege or university owned	or oper	ated by	a governmental unit de	escribed in
6	A federal, sta	ite, or local gov	ernment or governme	ental unit described in s	ection 1	1 70(b)(1))(A)(v).	
7	X An organizatio	on that normally i 0(b)(1)(A)(vi). (receives a substantial p Complete Part II.)	part of its support from a	governm	iental un	it or from the general pul	blic described
8	A community	trust described	l in section 170(b)(1)((A)(vi). (Complete Part	l.)			
9	An agricultura	l research organi	ization described in sec	ction 170(b)(1)(A)(ix) oper	ated in c	onjunctio	on with a land-grant colle	ege
	-	r a non-land-gra	nt college of agriculture	e (see instructions). Ente	the nan	ne, city,	and state of the college of	or
	university:							
10	from activities	s related to its e come and unre	exempt functions-sul	33-1/3% of its support fi bject to certain exception e income (less section Part III.)	ons, and	(2) no	more than 33-1/3% of i	ts support from gross
11				ely to test for public saf	ety. See	section	n 509(a)(4).	
12	An organizati	on organized a	nd operated exclusive	ely for the benefit of, to	perform	n the fur	nctions of, or to carry of	ut the purposes of one
	or more publi	cly supported of	organizations describe	ed in section 509(a)(1) o	or section	on 509(a)(2). See section 509(a)(3). Check the box in
а				supporting organization				, the supported
ű	organization(s) the power to re	gularly appoint or elect	d, or controlled by its sup t a majority of the directo	rs or trus	stees of	the supporting organization	on. You must
	·	t IV, Sections A						
b	management	oporting organized of the supporting the supporting the supporting the support of	organization vested in	controlled in connection the same persons that c	with its ontrol or	support manage	ted organization(s), by the supported organizat	having control or ion(s). You
C	Type III function	onally integrated s) (see instructi	. A supporting organizations). You must com	tion operated in connectio plete Part IV, Sections	n with, a A, D, an	nd functi d E.	onally integrated with, its	supported
d	functionally in instructions).	Inctionally integ Integrated. The of You must com	rated. A supporting orgorganization generally plete Part IV. Section	ganization operated in con y must satisfy a distribu is A and D, and Part V.	nnection tion req	with its s uiremen	supported organization(s) it and an attentiveness) that is not requirement (see
е	·		•	en determination from	the IRS	that it is	s a Type I, Type II, Typ	e III functionally
	integrated, or	Type III non-fu	inctionally integrated	supporting organization	ı.			-
			organizations n about the supported	d organization(c)				
	i) Name of supported of	-	(ii) EIN		6.0	ic the	(v) Amount of monetary	(vi) Amount of other
,		ganzation		(iii) Type of organization (described on lines 1-10 above (see instructions))	organiza	ls the tion listed joverning	support (see instructions)	support (see instructions)
					docui	ment?		
					Yes	No		
(A)								
(B)								
(C)								
<u>(D)</u>								
<u>(E)</u>								

Total

Schedule A (Form 990 or 990-EZ) 2017	CYSTINOSIS	RESEARCH	FOUNDATION
Part II Support Schedule for Or	ganizations De	escribed in S	Sections 170(b)

32-0067668

Page 2

art II	Support Schedul	le for Organization	s Described in	Sections 170(b)(1)(A)(iv)	and 170(b)(1)(A)(vi)
	(Complete only if you o	checked the box on line 5	, 7, or 8 of Part I or	r 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) 2013 (b) 2014 (c) 2015 (d) 2016 (e) 2017 1 Gifts, grants, contributions, and membership fees received. (Do not include any 'unusual grants.) 3, 130, 529. 3, 324, 548. 3, 213, 127. 4, 818, 959. 4, 095, 889. 18 2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf	(f) Total 8,583,052.						
membership fees received. (Do not include any 'unusual grants.)	8,583,052.						
organization's benefit and either paid to or expended on its behalf							
3 The value of services or	0.						
facilities furnished by a governmental unit to the organization without charge	0.						
4 Total. Add lines 1 through 3 3,130,529. 3,324,548. 3,213,127. 4,818,959. 4,095,889. 18	8,583,052.						
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 18	8,583,052.						
Section B. Total Support							
Calendar year (or fiscal year beginning in) ► (a) 2013 (b) 2014 (c) 2015 (d) 2016 (e) 2017	(f) Total						
7 Amounts from line 4 3,130,529. 3,324,548. 3,213,127. 4,818,959. 4,095,889. 18	8,583,052.						
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	28,254.						
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.						
	8,611,306.						
12 Gross receipts from related activities, etc. (see instructions). 12	0.						
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here.	····· ► 🗌						
Section C. Computation of Public Support Percentage							
14Public support percentage for 2017 (line 6, column (f) divided by line 11, column (f))1415Public support percentage from 2016 Schedule A, Part II, line 1415	99.85%						
	99.68 %						
16a 33-1/3% support test—2017. If the organization did not check the box on line 13, and line 14 is 33-1/3% or more, check thi and stop here. The organization qualifies as a publicly supported organization.	6a 33-1/3% support test-2017. 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► X						
b 33-1/3% support test-2016. If the organization did not check a box on line 13 or 16a, and line 15 is 33-1/3% or more, chec and stop here. The organization qualifies as a publicly supported organization	ck this box · · · · · · ►						
17a 10%-facts-and-circumstances test-2017. 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 the organization meets the 'facts-and-circumstances' test. The organization qualifies as a publicly supported organization.	7a 10%-facts-and-circumstances test-2017. 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-2016. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is or more, and if the organization meets the 'facts-and-circumstances' test, check this box and stop here. Explain in Part VI organization meets the 'facts-and-circumstances' test. The organization qualifies as a publicly supported organization	how the ►						
	ictions 🕨						

Schedule A (Form 990 or 990-EZ) 2017

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.)

Sec	tion A. Public Support						
	lar year (or fiscal year beginning in) ►	(a) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(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						
	Total. Add lines 1 through 5 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						
с	Add lines 7a and 7b						
8	Public support. (Subtract line 7c from line 6.)						
Sec	tion B. Total Support						
Calen	dar year (or fiscal year beginning in) 🕨	(a) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
	Amounts from line 6						
	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						
с 11	Add lines 10a and 10b 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.)						
	Total support. (Add lines 9, 10c, 11, and 12.)						
	First five years. If the Form 990 organization, check this box and	stop here		nd, third, fourth, c	r fifth tax year as	a section 501(c)(3	³⁾ ▶□
	tion C. Computation of Pu						0
	Public support percentage for 20						00
-	Public support percentage from					16	00
	tion D. Computation of Inv						
17	Investment income percentage f						00
18	Investment income percentage f						010
	33-1/3% support tests—2017. If is not more than 33-1/3%, check	this box and sto	p here. The orgar	nization qualifies a	as a publicly supp	orted organization	
	33-1/3% support tests—2016. If the line 18 is not more than 33-1/3%	, check this box a	and stop here. Th	e organization qu	alifies as a public	ly supported organ	nization 🕨 🔄
20	Private foundation. If the organi	zation did not che	ck a box on line	14, 19a, or 19b, c	heck this box and	I see instructions	· · · · · · · · · · · · · · · · · · ·

32-0067668

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

No Yes Are all of the organization's supported organizations listed by name in the organization's governing documents? 1 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. 1 2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If 'Yes,' explain in Part VI how the organization determined that the supported organization was 2 described in section 509(a)(1) or (2). 3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If 'Yes,' answer (b) and (c) below. 3a **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)? If 'Yes,' describe in **Part VI** when and how the organization made the determination. 3b c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If 'Yes,' explain in **Part VI** what controls the organization put in place to ensure such use. 3c 4a Was any supported organization not organized in the United States ('foreign supported organization')? If 'Yes' and if you checked 12a or 12b in Part I, answer (b) and (c) below. 4a **b** Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? 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. Δh **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)? 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. 4c 5a Did the organization add, substitute, or remove any supported organizations during the tax year? 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 5a amendment to the organizing document). 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? 5b c Substitutions only. Was the substitution the result of an event beyond the organization's control? 5c 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 6 or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of 6 the filing organization's supported organizations? If 'Yes,' provide detail in Part VI. 7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(Č)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If 'Yes,' complete Part I of Schedule L (Form 990 or 990-EZ). 7 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If 'Yes,' 8 complete Part I of Schedule L (Form 990 or 990-EZ). 8 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))? If 'Yes,' provide detail in Part VI. 9a **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? *If 'Yes,' provide detail in Part VI.* 9b 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? *If 'Yes,' provide detail in Part VI*. 9c 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)? If 'Yes,' answer 10b below. 10a **b** Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.) 10b

32-0067668

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?	11a		
b A family member of a person described in (a) above?	11b		
c A 35% controlled entity of a person described in (a) or (b) above? If 'Yes' to a, b, or c, provide detail in Part VI.	11c		

Section B. Type I Supporting Organizations

- Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint 1 or elect at least a majority of the organization's directors or trustees at all times during the tax year? 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.
- 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? 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.

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)? 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).	1		

Section D. All Type III Supporting Organizations

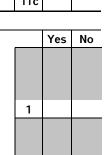
Yes No 1 Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the 1 organization's governing documents in effect on the date of notification, to the extent not previously provided? 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? If 'No,' explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s). 2 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? If 'Yes,' describe in Part VI the role the organization's supported organizations played 3 in this regard.

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).
 - The organization satisfied the Activities Test. Complete line 2 below. а
 - The organization is the parent of each of its supported organizations. Complete line 3 below. h
 - The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions). С

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? 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.
- 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? 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.
- 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? Provide details in Part VI.
- **b** Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If 'Yes,' describe in **Part VI** the role played by the organization in this regard.



2

Schedule A (Form 990 or 990-EZ) 2017 CYSTINOSIS RESEARCH FOUNDATION Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

_				-
F	Ра	a	e	6

ection 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		
ection B – Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
 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		
ection 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		

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) 2017

Part V Type III Non-Functionally Integrated 509(a)(3) Su	pporting Organiza	ations (continued)	· · · · · · · · · · · · · · · · · · ·
Section D – Distributions			Current Year
1 Amounts paid to supported organizations to accomplish exempt pu	rposes		
2 Amounts paid to perform activity that directly furthers exempt purposes of in excess of income from activity	of supported organizatior	IS,	
3 Administrative expenses paid to accomplish exempt purposes of su	upported 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 organizati in Part VI). See instructions.	on is responsive (provide	e details	
9 Distributable amount for 2017 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-2017	(iii) Distributable Amount for 2017
1 Distributable amount for 2017 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2017 (reasonable cause required – explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2017			
а			
b From 2013			
c From 2014			
d From 2015			
e From 2016			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2017 distributable amount			
i Carryover from 2012 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
4 Distributions for 2017 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2017 distributable amount			
c Remainder. Subtract lines 4a and 4b from 4.			
5 Remaining underdistributions for years prior to 2017, 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 2017. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.			
7 Excess distributions carryover to 2018. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2013			
b Excess from 2014			
c Excess from 2015			
d Excess from 2016			
e Excess from 2017			

BAA

Schedule A (Form 990 or 990-EZ) 2017

► Attach to Form 990. Form 990-EZ, or Form 990-PF. t information. OMB No. 1545-0047

2017	7
------	---

Employer identification number

Department of the Treasury Internal Revenue Service

► Go to www.irs.gov/Form990			
	101	uie	lates

Name of the organization

CYSTINOSIS RESEARCH FOUNDATION	N	32-0067668
Organization type (check one):		
Filers of:	Section:	
Form 990 or 990-EZ	\overline{X} 501(c)(3) (enter number) organization	
	4947(a)(1) nonexempt charitable trust not treated as a p	private foundation
	527 political organization	
Form 990-PF	501(c)(3) exempt private foundation	
	4947(a)(1) nonexempt charitable trust treated as a priva	te foundation
	501(c)(3) taxable private foundation	

Check if your organization is covered by the General Rule or a Special Rule.

Note. Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

General Rule

For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

Special Rules

X For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33-1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of (1) \$5,000 or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II.

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

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions exclusively for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an exclusively religious, charitable, etc., purpose. Don't complete any of the parts unless the General Rule applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions totaling \$5,000 or more during the year

Caution. An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990, 990-EZ, or 990-PF), but it **must** answer 'No' on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990-PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

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

Schedule B (Form 990, 990-EZ, or 990-PF) (2017)

Schedule B (Form 990, 990-EZ, or 990-PF) (2017)	Page	1	of	1	of Part I
Name of organization	Employer	identifi	cation nu	ımber	
CYSTINOSIS RESEARCH FOUNDATION	32-00	676	58		

Part I	Contributors (see instructions). Use duplicate copies of Part I if additional space	is needed.	
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
<u>1</u>	JENNA AND PATRICK'S FOUNDATION FOR 1216 ROBERTSON WAY SACRAMENTO, CA 95818	\$254,880.	Person X Payroll
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
<u>2</u>	24 HOURS FOR HANK 565 WHISKEY JACK CIRCLE SANDPOINT, ID 83864	\$165,798.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
	HEARTS FOR HADLEY 3010 N. ALAMO ROAD BOISE, ID 83704	\$124,378.	Person X Payroll
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)

Schedule B (Form 990, 990-EZ, or 990-PF) (2017)	Page	1	to	1	of Part II
Name of organization		Emp	loyer ider	ntification	number
CYSTINOSIS RESEARCH FOUNDATION		32	-0067	668	
Part II Noncash Property (see instructions). Use duplicate copies of Part II if additional sp	ace is neede	ed.			

		litional space is needed.	1
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
]	N <u>/A</u>		
		\$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
-			
		 \$	
(a) No. from	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
Part I		(See instructions.)	
-		 \$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		 \$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
] \$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		1	

	6 (Form 990, 990-EZ, or 990-PF) (2017)			Page	1 to	1	of Part III		
Name of organ	ization SIS RESEARCH FOUNDATION				Employer ide 32-006		n number		
		to contributions to organ	aizationa d	lacaribad			<u>-)(7) (0)</u>		
rartin	Exclusively religious, charitable, et or (10) that total more than \$1,000 for t						C)(7), (8),		
	the following line entry. For organizations of	ompleting Part III, enter the tota	al of exclusive	ely religious	. charitable.	etc.,			
	contributions of \$1,000 or less for the year.	(Enter this information once. Se	ee instruction	ıs.)	►\$		N/A		
	Use duplicate copies of Part III if additional	•							
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift		Des	(d) cription of ho	ow gift i	s held		
1 41(1	N/A								
				+					
		(e) Transfer of gift							
	Transferee's name, addres		Rela	tionshin of	transferor to	transf	eree		
			Trefe			, autor			
(a) No. from	(b)	(c) Use of gift		_	(d) cription of ho				
No. from Part I	Purpose of gift	Use of gift		Dese	cription of ho	ow gift i	s held		
		(e) Transfer of gift							
	Transferee's name, addres	Transfer of gift Transferee's name, address, and ZIP + 4 Rela			lationship of transferor to transferee				
	Transieree's name, address, and Zir + 4 Re					, autor			
(a) No. from	(b) Purpose of gift	(c) Use of gift		Des	(d) cription of ho	ow aift i	s held		
Part I						J .			
		(2)							
		(e) Transfer of gift							
	Transferee's name, addres	s, and ZIP + 4	Rela	ationship of	transferor to	o transfe	eree		
	_		·						
	4.5				())				
(a) No. from	(b) Purpose of gift	(c) Use of gift		Des	(d) cription of ho	ow qift i	s held		
Part I					•	3			
				├					
		1-1		l					
		(e) Transfer of gift							
	Transferee's name, addres		Rela	ationship of	transferor to	transf	eree		
	_		·						
			~ '	dula D (T					
BAA			Sche	aule B (Forr	n 990, 990-EZ	, or 990-	·rr)(2017)		

SCHEDULE D	Sun	plemental Financial	Statements			OMB No. 1545-0047
(Form 990)	► Comple	te if the organization answere 6, 7, 8, 9, 10, 11a, 11b, 11c, 11	ed 'Yes' on Form 990, d, 11e, 11f, 12a, or 12b.			2017
Department of the Treasury Internal Revenue Service	► Go to www.irs	Attach to Form 99 a.gov/Form990 for instruction	s and the latest informa	tion.		Open to Public Inspection
Name of the organization					Employer id	dentification number
CVSTINOS	IS RESEARCH FOUNDA	ΨΤ∩N				
		or Advised Funds or Oth	her Similar Funds o		32-006 Junts	1668
Complete	if the organization ans	wered 'Yes' on Form 99	0, Part IV, line 6.		untsi	
		(a) Donor advised	l funds	(b) Fu	nds and	other accounts
	end of year					
	ntributions to (during year).					
	ants from (during year)					
5 Did the organizat	ion inform all donors and do	nor advisors in writing that the organization's exclusive lega	e assets held in donor a	dvised fu	unds	Yes No
6 Did the organizat for charitable pur	ion inform all grantees, donc poses and not for the benefi	ors, and donor advisors in writ t of the donor or donor adviso	ting that grant funds can	n be used ose confe	d only erring] Yes □ No
	tion Easements.					
		wered 'Yes' on Form 99				
		y the organization (check all t		- 4		addread area
	of land for public use (e.g., i natural habitat	recreation or education)	Preservation of a his Preservation of a ce	-	•	
	of open space			, uncu m	1310110 311	ucture
	through 2d if the organization	held a qualified conservation co	ntribution in the form of a	conserva	ation ease	ment on the
					eld at the	End of the Tax Year
		ments		2 a 2 b		
6		ified historic structure included		20 2c		
		in (c) acquired after 7/25/06, a				
structure listed in	the National Register			2 d		
3 Number of conserv tax year ►	vation easements modified, trai	nsferred, released, extinguished	, or terminated by the orga	anization	during th	e
· · · · ·	where property subject to conse	ervation easement is located ►				
5 Does the organiz	ation have a written policy re	egarding the periodic monitori				¬
		nts it holds?				Yes No
7 Amount of expense ►\$	es incurred in monitoring, inspe	ecting, handling of violations, ar	nd enforcing conservation	easemen	its during	the year
8 Does each conse	rvation easement reported o	n line 2(d) above satisfy the r	equirements of section	170(h)(4))(B)(i)	Yes No
include, if applica	able, the text of the footnote	s conservation easements in its to the organization's financial	revenue and expense statements that describ	tement, a bes the o	and balan organizati	ce sheet, and on's accounting for
conservation eas		ections of Art, Historical	Treasures, or Othe	er Simi	lar Ass	ets.
Complete	if the organization ans	wered 'Yes' on Form 99	0, Part IV, Íine 8.			
art, historical treas	sures, or other similar assets he	er SFAS 116 (ASC 958), not to eld for public exhibition, education ncial statements that describe	on, or research in furthera	tatement ance of pu	and bala ublic servi	ance sheet works of ice, provide,
following amount	s, or other similar assets held f s relating to these items:	r SFAS 116 (ASC 958), to report public exhibition, education, or	or research in furtherance	of public	service,	e sheet works of art, provide the
		line 1				
2 If the organization amounts required	received or held works of art, I I to be reported under SFAS	historical treasures, or other sim 116 (ASC 958) relating to the	nilar assets for financial ga	ain, provi	de the fol	lowing
a Revenue included	d on Form 990, Part VIII, line	e 1			►\$	

b Assets included in Form 990, Part X			▶\$
BAA For Paperwork Reduction Act Notice, see the Instructions for Form 990.	TEEA3301L	10/11/17	Sched

Schedule D (Form 990) 2017 CYST				32-006	
Part III Organizations Mainta	ining Collection	ons of Art, Histo	rical Treasures, or	Other Similar Ass	ets (continued)
3 Using the organization's acquisition items (check all that apply):	, accession, and of	ther records, check ar	ny of the following that are	e a significant use of its o	collection
a Public exhibition		d Loan d	r exchange programs		
b Scholarly research		e Other			
c Preservation for future gener					
4 Provide a description of the organiz Part XIII.					
5 During the year, did the organiza to be sold to raise funds rather the					Yes No
Part IV Escrow and Custodia line 9, or reported an	I Arrangemen amount on Fo	ts. Complete if th rm 990, Part X, I	ne organization ans ine 21.	swered 'Yes' on Fo	rm 990, Part IV,
1 a Is the organization an agent, trus on Form 990, Part X?	stee, custodian or	other intermediary f	for contributions or othe	er assets not included	Yes No
b If 'Yes,' explain the arrangement					
					Amount
c Beginning balance				1c	
d Additions during the year					
e Distributions during the year					
f Ending balance					
2 a Did the organization include an a				-	
b If 'Yes,' explain the arrangement	in Part XIII. Cheo	ck here if the explan	ation has been provided	d on Part XIII	· · · · · · · · · · · · · · · · ·
					10
Part V Endowment Funds. C					
1 a Beginning of year balance	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
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	-	ear end balance (line	e 1g, column (a)) held a	as:	
a Board designated or quasi-endowm	ent 🕨	010			
b Permanent endowment	00				
c Temporarily restricted endowmer		00			
The percentages on lines 2a, 2b, and	nd 2c should equal	100%.			
3a Are there endowment funds not in t	he possession of the	he organization that a	re held and administered	for the	
organization by:					Yes No
(i) unrelated organizations					3a(i)
(ii) related organizations					
b If 'Yes' on line 3a(ii), are the rela	-				. 3b
4 Describe in Part XIII the intended	-	inization's endowme	nt tunas.		
Part VI Land, Buildings, and				11- 0 5 00	0 Dart V line 10
Complete if the organi					
Description of property		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. (Colum	n (d) must equal	<i>⊦orm 990, Part X, c</i>	olumn (B), line 10c.)		0.
BAA				Schedu	ule D (Form 990) 2017

Schedule D (Form 990) 2017 CYSTINOSIS RESEAR(CH FOUNDATION		32-0067668	Page 3
Part VII Investments – Other Securities. Complete if the organization answered		N/A Nart 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: Co		
(1) Financial derivatives			,	
(2) Closely-held equity interests				
(3) Other				
(A)				
(B)				
(C)				
(D) (E)				
(E) 				
(F)				
(<u>G)</u>				
(l) 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), Part IV, line 11c. See		
(a) Description of investment	(b) Book value	(c) Method of valuation: Co	st or end-of-year mar	ket 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. Complete if the organization answered	N/A) Part IV/ line 11d See	Form 990 Part Y	lino 15
	escription	, Fait IV, iiile Tiu. See	(b) Book	
(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 F	Form 990 Part IV line 11	le or 11f See Form 990 Part)	K 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 000, Part X, column (P) line 25.)	•			
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 fo		nancial statements that reports the or	nanization's liability for uno	ertain
tax positions under FIN 48 (ASC 740). Check here if the text of the footnote				

tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII.

Schedule D (Form 990) 2017 CYSTINOSIS RESEARCH FOUNDATION	32-0067668	Page 4
Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per	Return. N/A	
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	
2 Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
a Net unrealized gains (losses) on investments 2a		
b Donated services and use of facilities		
c Recoveries of prior year grants		
d Other (Describe in Part XIII.)		
e Add lines 2a through 2d	2e	
3 Subtract line 2e from line 1	3	
4 Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
a Investment expenses not included on Form 990, Part VIII, line 7b 4a		
b Other (Describe in Part XIII.)		
c Add lines 4a and 4b		
5 Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.).	_	
Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses p		
Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.		
1 Total expenses and losses per audited financial statements		
2 Amounts included on line 1 but not on Form 990, Part IX, line 25:		
a Donated services and use of facilities		
b Prior year adjustments.	_	
c Other losses.	_	
d Other (Describe in Part XIII.)	_	
e Add lines 2a through 2d .	2e	
3 Subtract line 2e from line 1.		
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 75		
b Other (Describe in Part XIII.)		
c Add lines 4a and 4b	4c	
5 Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)		
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			es Outside the Unite		OMB No. 1545-0047
(Form 990)	 Complete if the or 	rganization answer ► Atta	ed 'Yes' on Form 990, Part IV, lin ach to Form 990.	e 14b, 15, or 16.	2017
Department of the Treasury Internal Revenue Service	► Go to www.irs	s.gov/Form990 for	instructions and the latest inform	nation	Open to Public Inspection
Name of the organization CYST	INOSIS RESEAR	CH FOUNDATI	ON		fication number
Part I General Infor	mation on Activiti	es Outside th	e United States. Complet	32-00676 te if the organizatio	
	Part IV, line 14b.	intain records to	substantiate the amount of its	grants and other assist	ance,
the grantees' eligibility	for the grants or assi	stance, and the s	selection criteria used to award	the grants or assistant	e?XYes No
2 For grantmakers. Descr United States.	ibe in Part V the organi	zation's procedure	s for monitoring the use of its gra	ants and other assistance	outside the
3 Activities per Region.	(The following Part I,	line 3 table can b	e duplicated if additional space	e 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) FRANCE			GRANTS	MEDICAL RESEARCH	150,000.
(2) ITALY			GRANTS	MEDICAL RESEARCH	150,150.
(3) SWITZERLAND			GRANTS	MEDICAL RESEARCH	240,000.
(4) CANADA			GRANTS	MEDICAL RESEARCH	150,000.
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
3 a Sub-total b Total from continuation sheets to Part I	n				690,150.
c Totals (add lines 3a and 3b)0	0			690,150.

 c Totals (add lines 3a and 3b)...
 0
 0

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

690,150. Schedule F (Form 990) 2017

Schedule F (Form 990) 2017 CYSTINOSIS RESEARCH FOUNDATION

32-0067668

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)
				MEDICAL					
(1)			CANADA	RESEARCH	150,000.	CHECK			
				MEDICAL					
(2)			FRANCE	RESEARCH	150,000.	CHECK			
(2)				MEDICAL					
(3)			ITALY	RESEARCH	150,150.	CHECK			
				MEDICAL	0.4.0.000	aunau			
(4)			SWITZERLAND	RESEARCH	240,000.	CHECK			
(5)									
(6)									
(-)									
(7)									
(8)									
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									
2 Er	nter total number of recipient organiza e grantee or counsel has provided	ations listed above that a	re recognized as ch	arities by the forei	gn country, recogniz	ed as tax-exempt b	y the IRS, or for whi	ich 🕨	3
	nter total number of other organiza		-						
BAA									 F (Form 990) 2017

Page 2

Schedule F (Form 990) 2017 CYSTINOSIS RESEARCH FOUNDATION

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)							
BAA	1	1		1	1	Schedule F	(Form 990) 2017

32-0067668

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 X 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 Trust With a U.S. Owner (see Instructions for Form 3520 and 3520-A Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Form 3520 and 3520-A; do not file with Form 990) □ Yes X 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 X 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). □ Yes X 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 8655). □ Yes X No 6 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 8655). □ Yes X <t< th=""><th></th><th>Toreign Forms</th><th></th><th></th></t<>		Toreign Forms		
 required to separately file Form 3520, Annual Řeturn To Report Transactions with Foreign Trusts and Réceipt 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)	1	organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign	Yes	X No
 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). 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). 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). 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	2	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.	Yes	X No
 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). 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). 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 	3	organization may be required to file Form 5471, Information Return of U.S. Persons With Respect To Certain	Yes	X No
 organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865). 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	4	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	Yes	X No
If 'Yes,' the organization may be required to separately file Form 5713, International Boycott Report (see	5	organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign	Yes	X No
	6	If 'Yes,' the organization may be required to separately file Form 5713, International Boycott Report (see	Yes	X No

BAA

TEEA3505L 08/10/17

Schedule F (Form 990) 2017

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:

- (1) UNIVERSITY OF PARIS DESCARTES, 245 RUE DES SAINT-PERES, 75006 PARIS, FRANCE
- (2) BAMBINO GESU HOSPITAL, PIAZZA S. ONOFRIA 4, 00165 ROME, ITALY
- (3) UNIVERSITY HOSPITAL, ZURICH, SWITZERLAND
- (4) MCGILL UNIVERSITY HEALTH CENTER, MONTREAL, QUEBEC, CANADA

	Supplemental Information Regarding Fundraising or Gaming Activities						OMB No. 1545-0047			
SCHEDULE G (Form 990 or 990-EZ)	Comple	te if the organizat	ion answere	d 'Yes' on Fo ore than \$15	orm 990, Part IV, line 17, 18 ,000 on Form 990-EZ, line 6	, or 19, or if the a.	2017			
Department of the Treasury Internal Revenue Service		 Attach to Form 990 or Form 990-EZ. Go to www.irs.gov/Form990 for the latest instructions. 								
Name of the organization						Employer identif				
CYSTINOSIS RES						32-00676	68			
Part I Fundraising Form 990-E	Activities. Comple Z filers are not re	te if the organiza quired to comp	ation answe lete this p	ered 'Yes' o art.	on Form 990, Part IV, line	e 17.				
					owing activities. Check	all that apply.				
a Mail solicitat	ions			е	Solicitation of non-	government grants				
b Internet and	email solicitations	5		f	Solicitation of gove	-				
c Phone solicit				g	X Special fundraising	j events				
d In-person so										
employees listed	in Form 990, Par	t VII) or entity	in connect	ion with p	including officers, directo rofessional fundraising	services?				
b If Yes,' list the I compensated at	0 highest paid inc least \$5,000 by th	lividuals or enti le organization.	ties (fundi	raisers) pl	irsuant to agreements i		aiser is to be			
(i) Name and addre or entity (fund		(ii) Activity	have custo	fundraiser dy or control ibutions?	(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										
			<u> </u>	<u> </u>						
Total							0.			
3 List all states in w or licensing. <u>CA</u>	hich the organizatio	on is registered (ontributions or has been	notified it is exempt fro	m registration			

Schedule G (Form 990 or 990-EZ) 2017 CYSTINOSIS RESEARCH FOUNDATION

32-0067668 Page 2

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.

R			(a) Event #1 <u>ANNUAL FUNDRAI</u> (event type)	(b) Event #2	(c) Other events NONE	(d) Total events (add column (a) through column (c))				
R E V E N U E	1	Gross receipts	3,109,295.			3,109,295.				
Ĕ	2	Less: Contributions	3,109,295.			3,109,295.				
	3	Gross income (line 1 minus line 2)								
	4	Cash prizes.								
D	5	Noncash prizes								
1	6	Rent/facility costs								
R E C T	7	Food and beverages								
EXPENSE	8	Entertainment								
N S E	9	Other direct expenses								
S	10 11	Direct expense summary. Add lines 4 thr Net income summary. Subtract line 10 fr								
Par	t III	Gaming. Complete if the organiza \$15,000 on Form 990-EZ, line 6a.	tion answered 'Yes	s' on Form 990, Pa	rt IV, line 19, or re	ported more than				
REVENUE			(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add column (a) through column (c))				
Ŭ	1	Gross revenue								
F	2	Cash prizes								
EXPENSES	3	Noncash prizes								
ĊS TE S	4	Rent/facility costs								
	5	Other direct expenses								
	6	Volunteer labor	Yes% No	Yes% No	Yes [%] 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?										
	10 a Were any of the organization's gaming licenses revoked, suspended, or terminated during the tax year?									

Schedule G (Form 990 or 990-EZ) 2017

Schedule G (Form 990 or 990-EZ) 2017 CYSTINOSIS RESEARCH FOUNDATION	32-0067668	Page 3
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 administer charitable gaming?	to Yes	No
13 Indicate the percentage of gaming activity conducted in:a The organization's facility.	12.	00
b An outside facility.		
14 Enter the name and address of the person who prepares the organization's gaming/special events books and record		
Name ►		
Address ►		
 15 a Does the organization have a contract with a third party from whom the organization receives gaming reverse b If 'Yes,' enter the amount of gaming revenue received by the organization ► \$ and of gaming revenue retained by the third party ► \$ c If 'Yes,' enter name and address of the third party: 	enue? Yes	No
Name ►		1
Address ►		ا ا
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?		No
b Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent		
organization's own exempt activities during the tax year 🕨 \$		
Part IV Supplemental Information. Provide the explanations required by Part I, line 2b, of and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide a information. See instructions.	columns (iii) and (any additional	v);

SCHEDULE I	Gra	ants and Ot	her Assistance	to Organization	IS.		OMB No. 1545-0047
(Form 990)	Gove	ernments, a	nd Individuals in on answered 'Yes' on F	n the United Sta	ates		2017
Department of the Treasury Internal Revenue Service	Complet	-	► Attach to Form 99 s.gov/Form990 for the late	0.	.1 01 22.		Open to Public Inspection
Name of the organization CYSTINOSIS RES	SEARCH FOUNDAT	ION	-			Employer identifie 32-006766	
Part I General Information on Gra	ants and Assista	nce					
1 Does the organization maintain records to the selection criteria used to award the							X Yes No
2 Describe in Part IV the organization's pro	•						
Part II Grants and Other Assistan	9	5		ernments. Comple	te if the organizat	tion answered 'Y	'es' on
Form 990, Part IV, line 21,							
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 gran or assistance
(1) UNIVERSITY OF CALIFORNIA, SD 9500 GILMAN DRIVE, DEPT 0935 LA JOLLA, CA 92093	95-6006144		1,108,167.	0.			MEDICAL RESEARCH
(2) THE SCRIPPS RESEARCH INSTITUT			1/100/10/1				
10550 N. TORREY PINES ROAD							MEDICAL
LA JOLLA, CA 92037	33-0435954		300,000.	0.			RESEARCH
(3) MA GENERAL HOSPITAL 101 HUNTINGTON AVENUE, SUITE BOSTON, MA 02199	04-1564655		169,234.	0.			MEDICAL RESEARCH
(4) SEATTLE CHILDREN'S HOSPITAL PO BOX 5371 M/S S-200 SEATTLE, WA 98145	91-0564748		234,458.	0.			MEDICAL RESEARCH
(5) UNIVERSITY_OF_PITTSBURGH_SCHO	11 2700051		162,010				MEDICAL
PITTSBURGH, PA 15213 (6) <u>THIOGENICS_THERAPEUTICS, INC_</u> 4795 KESWICK COURT	11-3708851		163,819.	0.			RESEARCH MEDICAL
SAN DIEGO, CA 92130	81-1567704		153,900.	0.			RESEARCH
(7)							
(8)							

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

Schedule I (Form 990) (2017)

Schedule | (Form 990) (2017) CYSTINOSIS RESEARCH FOUNDATION

32-0067668

Page 2

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

SCHEDULE	ι		Transa	ction	s Witl	h Inte	erested F	Persons				O	MB No.	1545-00	47	
(Form 990 or 99		► Complete if t	28b, or	28c. or l	Form 990)-EZ, P	art V. line 38	a or 40b.	a, 25b, 2	26, 27,	28a,		20	17		
Department of the Tr Internal Revenue Se	reasury rvice	► Go	to www.irs.g	Attach	to Form	1 990 o	r Form 990-E	Ζ.	mation	I.		0	pen To Inspe	o Pub ection	ublic on	
Name of the organiz										nployer i			mber			
		EARCH FOUNI			01 () (2		L. 501/			2-00						
Part I Ex	Cess E molete it	Senefit Transa f the organization	actions (Se a answered 'Y	Ction 5 'es' on F	01(C)(3 orm 990	5), Seo Part I	Ction 501(C IV line 25a o	:)(4), and : or 25b, or Fou	5UI(C) rm 990-	(29) (F7 P	orgar art V	line 40	ONS ()h	oniy).		
			1		o between d			. 200, 01 1 01		, , 、	are v,			(d) Cor		
1 (a) Na	me of disq	ualified person	(5)		ind organiza			(c) [Descriptior	n of trans	action			Yes	No	
(1)																
(2)																
(3)																
(4)																
(5)																
(6)															<u> </u>	
2 Enter the section 49	amount 958	of tax incurred b	by the organiz	ation ma	anagers	or disq	ualified perso	ons during th	ne year	under	. ►ş					
	amount	of tax, if any, or	n line 2, above	e, reimb	ursed by	the or	ganization	<u></u>			.►\$					
Cor	nplete if	and/or From the organization	answered 'Yes	s' on For	rm 990-E	Z, Part	V, line 38a oi	r Form 990, F	Part IV,	line 26	; or if	the				
(a) Name of intere		n reported an am	(c) Purpose	(d) Lo	an to or	(e) Original	(f) Balance	e due	(g) In (default?		proved	(i) W		
		with organization	of loan	organization?				r	cómr	ard or hittee?	agree					
				То	From					Yes	No	Yes	No	Yes	No	
(1)				-						_						
(2) (3)				-												
(4)																
(5)																
(6)																
(7)																
(8)																
(9)				_												
(10)																
Total							►\$									
Part III Gr Cor	nplete if	r Assistance the organization	answered 'Yes	s' on For	rm 990, F	Part IV,	s. line 27.									
(a) Na	ame of inter	rested person	(b) Relationshi and	p between d the organ	interested p ization	person	(c) Amount o	of assistance	(d) Ty	pe of as	sistance	(e)	Purpose	e of assi	stance	
(1)																
(2)																
(3)																
(4)																
(5)																
(6)																
(7) (8)																
(8)																
(10)																

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

Schedule L (Form 990 or 990-EZ) 2017

Schedule L	. (Form 990	or 990-EZ) 2017	CYSTINOSIS	RESEARCH	FOUNDATION

Part IV Business Transactions Involving Interested Persons. Complete if the organization answered 'Yes' on Form 990, Part IV, line 28a, 28b, or 28c.

(b) Relationship between interested person and the organization	(c) Amount of transaction	(d) Description of transaction	(e) Sha organiz rever	aring of zation's nues?
			Yes	No
WIFE OF OFFICER		COMPENSATION		Х
	organization	(b) Relationship between interested person and the organization (c) Amount of transaction WIFE OF OFFICER	organization	organization rever Yes

Part V Supplemental Information Provide additional information for responses to questions on Schedule L (see instructions).

SUPPLEMENTAL INFORMATION

SEE NOTE 1 TO SCHEDULE L

SCHEDULE O (Form 990 or 990-EZ)

Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

Open to Public Inspection

Department of the Treasury Internal Revenue Service Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

Employer identification number 32-0067668

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

HISTORY AND RESEARCH

"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.

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 IS DEDICATED TO FINDING BETTER TREATMENTS TO IMPROVE THE QUALITY OF LIFE FOR THOSE WITH CYSTINOSIS AND TO ULTIMATELY FIND A CURE FOR THIS DEVASTATING DESEASE. CRF HAS AN AGGRESSIVE RESEARCH AGENDA. CRF ISSUES GRANTS FOR BENCH AND CLINICAL RESEARCH STUDIES BI-ANNUALLY IN AN EFFORT TO ACCELERATE THE RESEARCH PROCESS AND ENSURE THAT CYSTINOSIS RESEARCH IS ONGOING AND FOCUSED ON NOVEL TREATMENTS AND A CURE.

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

TEEA4901L 08/09/17

CYSTINOSIS UNTIL THE DAY A CURE IS FOUND.

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

SINCE 2003, THE CYSTINOSIS RESEARCH FOUNDATION (CRF) HAS BECOME THE LARGEST FUND PROVIDER OF CYSTINOSIS RESEARCH IN THE WORLD – RAISING MORE THAN \$45 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.

WE ARE PLEASED TO ANNOUNCE THAT DURING THE 12 MONTHS PERIOD ENDING JUNE 30, 2018, CRF ISSUED 16 NEW GRANTS TOTALING MORE THAN \$2.8 MILLION FOR CYSTINOSIS RESEARCH. THE NEW GRANTS BRING US THAT MUCH CLOSER TO BETTER TREATMENTS AND A CURE.

CRF HAS ISSUED GRANTS FUNDED, EQUIPMENT PURCHASES AND ONGOING STUDIES TO THE BEST AND BRIGHTEST RESEARCHERS IN THE WORLD. TO DATE, WE HAVE FUNDED 175 MULTI-YEAR RESEARCH STUDIES AT LEADING RESEARCH INSTITUTIONS IN 12 COUNTRIES. CRF-FUNDED RESEARCHERS HAVE PUBLISHED MORE THAN 72 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, Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

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

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 (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.

IN 2016, CRF FORMED NANOWAFER, INC., FORMALLY KNOWN AS CORNEAL CYSTINOSIS, INC., 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 WAS DISCOVERED BY A SCIENTIST AT BAYLOR COLLEGE OF MEDICINE. CRF IS COMMITTED TO THIS PROJECT AND EXPECTS TO FILE A NEW DRUG APPLICATION IN 2019.

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 2018. 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.

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

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

DISEASES, KIDNEY DISEASES AND GENETIC AND SYSTEMIC DISEASES SIMILAR TO CYSTINOSIS. SUPPORT FOR CYSTINOSIS RESEARCH HAS REACHED FAR BEYOND THE CYSTINOSIS COMMUNITY. Α 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 2018, 61 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 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,

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

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.

BOARD MEMBERS, KEVIN AND TERESA PARTINGTON, ARE HUSBAND AND WIFE.

BOARD MEMBERS, 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.

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

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

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.

SCHEDULE R (Form 990)

Related Organizations and Unrelated Partnerships

Complete if the organization answered 'Yes' on Form 990, Part IV, line 33, 34, 35b, 36, or 37.
 Attach to Form 990.

► Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public Inspection

Department of the Treasury Internal Revenue Service Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

Employer identification number 32-0067668

Part I Identification of Disregarded Entities. Complete if the organization answered 'Yes' on Form 990, Part IV, line 33.

	(a) Name, address, and EIN (if applicable) of disregarded en	itity	(b) Primary ac	ctivity	(c Legal dom or foreign	;) icile (state i country)	Тс	(d) tal income	End-c	(e) of-year assets	Dire	(f) ct contro entity	olling
(1)													
(2)													
(3)													
Par	t II Identification of Related Tax-Exempt Or had one or more related tax-exempt orga	ganization:	ons. Complete s during the ta	if the org ax year.	ganization	answered	d 'Yes'	on Form 990), Part	t IV, line 34,	becau	se it	
	(a) Name, address, and EIN of related organization	Prima	(b) ary activity	Legal dom or foreigr	c) licile (state n country)	(d) Exempt (sectio	Code n	(e) Public charity (if section 501	status (c)(3))	(f) Direct contro entity	olling	(g Sec 512 controlled Yes	(b)(13) d entity? No
												103	110
(3)													

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

Schedule R (Form 990) 2017 CYSTINOSIS RESEARCH FOUNDATION

Part III Identification of Related Organizations Taxable as a Partnership Complete if the organization answered 'Yes' on Form 990, Part IV, line 34, because it had one or more related organizations treated as a partnership during the tax year.

		5						5	,							
(a) Name, address, and EIN of related organization	(b) Primary activity	(c) Legal domicile (state or foreign	(d) Direct controllin entity	ng (i	(e) redominant i related, unre excluded from under secti	elated, m tax ons	(f) Share o incoi	of total	Sha end-c	g) ire of of-year sets	Dispi tior	h) ropor- nate itions?	K-1 (Form	x man	ral or aging	(k) Percentage ownership
		country)			512-514))					Yes	No	10`65)	Yes	No	
<u>(1)</u>																
(2)																
line 34, becaus	of Related Orga se it had one or	more rela	Taxable a ated organ	ization	s treated	d as a	a corpora	ation or	trust du	rganizat uring the (f)	tax y	ear.		Form 99		
(a) Name, address, and EIN	of related organizat	ion Prim	ary activity	(state c	(c) domicile or foreign intry)	cor	(d) Direct htrolling entity	Type of (C corp or t	e) of entity , S corp, rust)	Share total in	e of	Sh	(g) are of end-of- year assets	Percentag ownershi	contr	(i) 512(b)(13) olled entity?
(1) CORNEAL CYSTINOL 18802 BARDEEN AVI IRVINE, CA 92612 81-1666461	 E		EDICAL SEARCH		'X		N/A	сс	ORP	-292	2,829		2,437.	100.0	Ye	
<u>(3)</u>																
BAA		I		1	TEEA	5002L	11/29/17					<u> </u>	ç	Schedule F	(Form	990) 2017

(5)

(6) BAA

Part V Transactions With Related Organizations. Complete if the organization answered 'Yes' on Form 990, Part IV, line 34, 35b, or 36.

Note: Complete line 1 if any entity is listed in Parts II, III, or IV of this schedule.				Yes	No
1 During the tax year, did the organization engage in any of the following transactions with one or more related organizations lis	sted in Parts II-IV?				-
a Receipt of (i) interest, (ii) annuities, (iii) royalties, or (iv) rent from a controlled entity			1a		Х
b Gift, grant, or capital contribution to related organization(s)					X
c Gift, grant, or capital contribution from related organization(s).			1c		X
d Loans or loan guarantees to or for related organization(s).				Х	
e Loans or loan guarantees by related organization(s).					Х
f Dividends from related organization(s).			1f		Х
g Sale of assets to related organization(s)			1g		Х
h Purchase of assets from related organization(s)			1h		Х
i Exchange of assets with related organization(s)			1i		Х
j Lease of facilities, equipment, or other assets to related organization(s)			1j		Х
k Lease of facilities, equipment, or other assets from related organization(s)			1k		Х
Performance of services or membership or fundraising solicitations for related organization(s)			11		Х
m Performance of services or membership or fundraising solicitations by related organization(s)			1m		Х
n Sharing of facilities, equipment, mailing lists, or other assets with related organization(s)			1n		Х
o Sharing of paid employees with related organization(s)			10		Х
p Reimbursement paid to related organization(s) for expenses			1p		Х
q Reimbursement paid by related organization(s) for expenses.			-		X
r Other transfer of cash or property to related organization(s).			1r		Х
s Other transfer of cash or property from related organization(s)			1s		Х
2 If the answer to any of the above is 'Yes,' see the instructions for information on who must complete this line, including cover	ed relationships and trans	saction thresholds.	Į		
(a) Name of related organization	_ (b)	(c) Amount involved	(Method of	d)	
Name of related organization	Transaction type (a-s)	Amount involved	amount		
			antoant		
(1) CORNEAL CYSTINOLYSIS, INC	D	650,000.			
() CORNERL CISTINOLISIS, INC	D	030,000.			
(2)					
(3)					
(4)					

Part VI Unrelated Organizations Taxable as a Partnership. Complete if the organization answered 'Yes' on Form 990, Part IV, line 37.

Provide the following information for each entity taxed as a partnership through which the organization conducted more than five percent of its activities (measured by total assets or gross revenue) that was not a related organization. See instructions regarding exclusion for certain investment partnerships.

(a) Name, address, and EIN of entity	(b) Primary activity	(c) Legal domicile (state or foreign country)	income (related, unre- lated, excluded	Are all sec 501(organiz	e) partners stion (c)(3) zations?	(f) Share of total income	(g) Share of end-of-year assets	tior	h) ropor- nate tions?	(i) Code V-UBI amount in box 20 of Schedule K-1 (Form 1065)	Gene mana part	i) ral or aging ner?	(k) Percentage ownership
			from tax under sections 512-514)	Yes	No			Yes	No	(Yes	No	1
(1)													
	-												
	-												
(2)	-												
	-												
(3)													
(3)]												
(4)													
	-												
	-												
(5)	-												
(6)													
	1												
(7)													
	1												
	<u> </u>												
(8)	-												
	1												
DAA										Sabadul			

BAA

Part VII Supplemental Information.

Provide additional information for responses to questions on Schedule R. See instructions.

6/30/18

2017 FEDERAL BOOK SUMMARY DEPRECIATION SCHEDULE

CLIENT 3745FY

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

PAGE 1

<u>no.</u> Forn	DESCRIPTION M 990/990-PF	DATE ACQUIRED	DATE SOLD	COST/ BASIS	BUS. PCT.	CUR 179/ SDA	PRIOR 179/ SDA/ DEPR.	METHOD	<u>LIFE</u>	CURRENT DEPR.
MA	ACHINERY 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 EQUIPM	IE		56,838		0	56,821			0
	TOTAL DEPRECIATION			56,838		0	56,821		-	0
	GRAND TOTAL DEPRECIATION			56,838		0	56,821		=	0

6/30/18

2017 FEDERAL BOOK DEPRECIATION SCHEDULE

PAGE 1

CLIENT 3745FY

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

<u>NO.</u> FORM	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 <u>REDUCT</u>	DEPR. BASIS	PRIOR DEPR.	METHOD	LIFE _RATE_	CURRENT DEPR
MA	CHINERY 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						<u> </u>	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		-	56,838		0	0	(0 <u> </u>	0	56,838	56,821			0
	GRAND TOTAL DEPRECIATION		-	56,838		0	0	(<u>0 </u>	0	56,838	56,821			0

2017

FEDERAL SUPPLEMENTAL INFORMATION

PAGE 1

CLIENT 3745FY

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 (1) - SCHEDULE L - PART IV

NOTE (1)

TRUSTEE DONALD SOLSBY'S WIFE, ZOE SOLSBY, IS A CONSULTANT TO THE FOUNDATION. MRS. SOLSBY RECEIVED COMPENSATION OF APPROXIMATELY \$54,000 FOR THE YEAR ENDED JUNE 30,2018.

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.