## Form **990**

# SHORT YEAR

OMB No. 1545-0047

2017

Department of the Treasury Internal Revenue Service

Return of Organization Exempt From Income Tax
Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except 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

A	For th	ne 2017 calen	dar year, or ta	x vear begi	nning Tal Af	1100001	1 20	17, and endi	na 🖊	WE 3	2	nispecti	
В		f applicable:	С	,	3 M.4	Unite	, , 20	17, and endi	ilg 🔾			JOI7	
	Ad	Idress change	CYSTINOS	וכ הדכה:	ADCH FOIR	מסדייגתו							
	$\vdash$	me change	18802 BAR	RDEEN AV	JE	NDATION					0067		
		tial return	IRVINE, (	A 92612	2					E Teleph			
	$\vdash$	al return/terminated			-			949	<del>-223</del>	-7610			
	$\vdash$												
	$\vdash$	nended return					G Gross r			9,382.			
	Apı	plication pending	F Name and add		al officer:					a group retur			s X No
_			SAME AS C						H(b) Are a	ll subordinates ' attach a list.	include	d? Ye	
		exempt status	X 501(c)(3)	501(c) (		sert no.)	4947(a)(1)	or 527	11 140,	allacii a iist.	(see ins	tructions)	
J	Web	osite: ► WW	W.CYSTINO	SISRESE	ARCH.ORG				H(c) Group	exemption n	ımber 🕨		
K		of organization:	X Corporation	Trust	Association	Other ►		L Year of format				egal domicile: C	מי
P	art I	Summary	/										
43 =	1	Briefly describ	e the organiza	ation's miss	sion or most s	significant ac	ctivities:C	RF'S MIS	STON T	S TO S	IDPO	рт вемец	
a		CLINICAL	AND TRAN	SLATION	AL RESEA	RCH TO F	TIND BE	TTER TRE	CATMEN	מואב פיד	יס דיס	IDE EUD	<u></u>
S		CYSTINOS:	īs							-5-1110-	<u> </u>	TE TOK	
Ĕ	١.						E .						
Activities & Governance	2 (	Check this bo	x ► if the	organizatio	on discontinue	ed its operat	tions or di	sposed of mo	ore than 2	25% of its	net as	 sets	
ى «×	3 (	Number of vol	ing members	of the gove	rnina bodv (F	art VI. line	la).			ì	3		20
S	4	number of inc	lependent voti	ng member	's of the gove	rning body (	(Part VI. li	ine 1b).		7200	4		20
iŧie	5	otal number	of individuals	employed i	n calendar ve	ar 2017 (Pa	rt V. line :	2a)			5		1
댨	6	rotai number	ot volunteers (	(estimate if	necessary)						6		0
٨		i otai unrelate	a business rev	enue from	Part VIII, colu	umn (C). line	e 12.				7a		0.
_	DI	vet unrelated	business taxa	ble income	from Form 99	90-T, line 34	1222			52.22	7b	2.	0.
		Danakuthi ikti							F	rior Year		Current \	
ē	8 (	contributions	and grants (Pa	art VIII, line	: 1h)				4	1,818,9	59.	4.095	5,889.
Revenue	9 F	rogram servi	ce revenue (P	art VIII, line	e 2g)			******		· ·			,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,
}e∧	10 1	nvestment ind	ome (Part VII	i, column (	A), lines 3, 4,	and 7d)		000000000000000000000000000000000000000		38,5	99.	48	3,222.
_	11 (	Jiner revenue	(Part VIII, col	umn (A), lii	nes 5, 6d, 8c,	9c, 10c, an	ıd 11e)	***************************************					
-	12 T	total revenue	- add lines 8	through 11	(must equal	Part VIII, co	olumn (A),	line 12)	4	857,5	58.	4,144	1,111.
	13 0	arants and sir	nilar amounts	paid (Part	IX, column (A	(), lines 1-3)			1	,580,9	36.		9,350.
	14 5	<ul> <li>Benefits paid to or for members (Part IX, column (A), line 4).</li> <li>Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10).</li> </ul>											
ø	15 8									62,729.		30	0,627.
Expenses	16a F	Professional fu	indraising fees	(Part IX, o	column (A), lii	ne 11e)	<i>18</i> 5						7021.
(be			ng expenses (					399,192.					No. of Concession,
ற	17 C	Other expense	s (Part IX, col	umn (A) lii	nes 11a-11d	11f-2/le)		333,132.		222			A SHIPPY
	18 T	otal expenses	s. Add lines 13	8-17 (must	equal Part IX	column (A)	۱ کات محقا	**************************************		,393,8			,424.
	19 R	Revenue less	expenses. Sub	tract line 1	8 from line 10	, coluitiii (~)	), IIIIC 23)	111111111111111111111111111111111111111		,037,5			,401.
۶ <del>0</del>			- Apolitoo. Out	race into 1	o nomine 12			**********		,820,0			710.
anc	20 T	otal assets (F	art X, line 16)							g of Current		End of Y	
Ass	21 T	otal liabilities	(Part X, line 2	26)						,325,1			,424.
Net Assets Fund Balanc										,802,7		1,722	,749.
	rt II		und balances.	Subtract	ne 21 from lin	ne 20			4	,522,42	20.	6,434	,675.
		Signature	and the second second second										-
comp	lete. Deci	s of perjury, I decl aration of prepare	are that I have exa r (other than officer	mined this retu	rn, including acco	mpanying sched	dules and stat	tements, and to the	he best of m	y knowledge a	nd belief	, it is true, correc	t, and
_		N V	13.1		11/	1	as any lines	icage.	- 1-	-1	1		
Sig	n	Signature	of officer	ny	por					5/9	1201	8	
3ig Her	ii B	11.							Dai	ie *			
ICI	C	Type or pr	REY STAC	K					TRUSI	EE			
		Print/Type pre			Duran								
					Precarer's signal	ture	_	Date /	~	Check	if P	TIN	
Paid			ONTGOMERY		11100	P	1	5/3/2	018	self-employed	P	01209820	
	parer	Firm's name	► MONTGO		LICK & C		1	1					
JSE	Only	Firm's address	23801		AS RD ST					Firm's EIN 🟲	954	120250	
			CALABA	SAS, CA	91302					Phone no (	210_0	999-6967	
Иay	the IRS	discuss this	return with the	e preparer	shown above	? (see instri	uctions)			. none no. (	) TO - 2	X Yes	
2 1 1	Fax D		livette a A st No			Application of the state of the		2232 0000				A Tes	No

Form	1 990 (2017) CYSTINOSIS RESEARCH FOUNDATION	32-0	06/668	raye 2
Par	till Statement of Program Service Accomplishments			
	Check if Schedule O contains a response or note to any line in this Part III.		***********	X
`1	Briefly describe the organization's mission:			
	CRF'S MISSION IS TO SUPPORT BENCH, CLINICAL AND TRANSLATIONAL	RESEARCH	TO FIND	BETTER
	TREATMENTS AND A CURE FOR CYSTINOSIS			
2	Did the organization undertake any significant program services during the year which were not listed on the			
	Form 990 or 990-EZ?		· Yes	X No
	If 'Yes,' describe these new services on Schedule O.			
3	Did the organization cease conducting, or make significant changes in how it conducts, any program	services?	Yes	X No
	If 'Yes,' describe these changes on Schedule O.			
4	Describe the organization's program service accomplishments for each of its three largest program section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and alloca and revenue, if any, for each program service reported.	services, as itions to othe	measured by ers, the total	expenses. expenses,
_	a (Code: ) (Expenses \$ 1,149,350. including grants of \$	) (Revenue	Ś	)
4 8				
	SEE SCHEDULE O			
			- <b>-</b>	
41	b (Code: ) (Expenses \$ 304,247. including grants of \$	) (Revenue	\$	)
		- <b>-</b>		
		. <b></b>		
				<b></b>
4	c (Code: ) (Expenses \$ 292,829. including grants of \$	) (Revenue	\$	)
•				
				- <b></b>
	d Other program services (Describe in Schedule O.)			
4	(Expenses \$ including grants of \$ ) (Revenue	\$		)
-	e Total program service expenses ► 1,746,426.			
4	e Total program Service expenses - 1,740,440.		En	m 900 (2017)

			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 I.	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? If 'Yes,' complete Schedule D, Part II	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? If 'Yes,' complete Schedule D, Part V	10		Х
11		TO N		
i	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	
	b Did the organization report an amount for investments — other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part VII	11 b		Х
1	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
1	d Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? If 'Yes,' complete Schedule D, Part IX	11 d		Х
ŀ	e Did the organization report an amount for other liabilities in Part X, line 25? If 'Yes,' complete Schedule D, Part X	11 e		X
1	f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If 'Yes,' complete Schedule D, Part X	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	
	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	12 b		Х
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If 'Yes,' complete Schedule E	13		Х
14:	a Did the organization maintain an office, employees, or agents outside of the United States?	14a		X
	b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? If 'Yes,' complete Schedule F, Parts I and IV	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) CYSTINOSIS RESEARCH FOUNDATION
Part IV Checklist of Required Schedules (continued)

2	Oa Did the organization operate one or more hospital facilities? If 'Yes,' complete Schedule Harrisses		Yes	_
			4	X
2	b If 'Yes' to line 20a, did the organization attach a copy of its audited financial statements to this return?	. 20t	)	
_	1 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? If 'Yes,' complete Schedule I, Parts I and II.	. 21	X	
2	2 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? If 'Yes,' complete Schedule I, Parts I and III.	22		X
2	3 Did the organization answer 'Yes' to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? If 'Yes,' complete Schedule J.	23		x
2	4a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? If 'Yes,' answer lines 24b through 24d and complete Schedule K. If 'No. 'go to line 25a			X
	biblid the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b	-	Α.
	c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	04		
	a bid the organization act as an 'on behalf of' issuer for bonds outstanding at any time during the year?	24d	_	
2	<b>Sa Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations.</b> Did the organization engage in an excess benefit transaction with a disqualified person during the year? If 'Yes,' complete Schedule L, Part L	25a		х
	b is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If 'Yes,' complete Schedule L, Part I.			X
26		200		
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? If 'Yes,' complete Schedule L, Part III.	26		X
	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):	5.0	in the	
	a A current or former officer, director, trustee, or key employee? If 'Yes,' complete Schedule L, Part IV.	28a	TEQUE.	X
	b A family member of a current or former officer, director, trustee, or key employee? If 'Yes,' complete Schedule L, Part IV	28b	х	
	c.An entity of which a current or former officer, director, trustee, or less are less and less are les	F 2.4	^	
29	of the story trustee, or direct or inclinect owner? If res, complete Schedule L, Part IV.	4 4 4 1		X
30		29		Х
31	Did the organization liquidate terminate or discolus and access an	30		X
-	Did the organization liquidate, terminate, or dissolve and cease operations? If 'Yes,' complete Schedule N, Part I.	31		X
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If 'Yes,' complete Schedule N, Part II.	32		X
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? If 'Yes,' complete Schedule R, Part I	33		
34	Was the organization related to any tax-everyot or taxable on the 3 K Was I are 1 a great and 1 a gr	33	-	<u>X</u>
35 :	and Part V, line 1	34 35a	X	_
ı	olf 'Yes' to line 35a, did the organization receive any payment from or engage in any transaction with a controlled			
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? If 'Yes,' complete Schedule R, Part V, line 2	35b 36		<u>X</u>
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? If 'Yes,' complete Schedule R, Part VI	37	+	X
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19?	38	х	
BAA				

	rm 990 (2017) CYSTINOSIS RESEARCH FOUNDATION 32-006766	8	F	age
P	art V Statements Regarding Other IRS Filings and Tax Compliance			
	Check if Schedule O contains a response or note to any line in this Part V.		2	[
			Yes	No
- 1	a Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable		Lail	Louis .
	<b>b</b> Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable		Fred	100
	c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?			
	(gambling) winnings to prize winners?	1 c		
2	a Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return 2 a			
	<b>b</b> If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b	Х	- Boyeron
	Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)			
3	a Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a		X
	<b>b</b> If 'Yes,' has it filed a Form 990-T for this year? If 'No' to line 3b, provide an explanation in Schedule 0.	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 financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4 a		Х
	b If 'Yes,' enter the name of the foreign country: ▶		2.39	
	See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).			
5	a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a	(IIII)	Х
	<b>b</b> Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5 b		X
	c If 'Yes,' to line 5a or 5b, did the organization file Form 8886-T?	5 c		
		3 C		
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?			37
		6 a		X
	b If 'Yes,' did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	C L		
7	Organizations that may receive deductible contributions under section 170(c).	6b	HOROGEN	
	a Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?		amb <sub>i</sub>	PRES
	<b>b</b> If 'Yes,' did the organization notify the donor of the value of the goods or services provided?	7 a		
	c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file	7 b		
	Form 8282?	7 c		
	d If 'Yes,' indicate the number of Forms 8282 filed during the year	76		
	e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?			BHOL
	f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7 e		-
		7 f		
	g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7		
	h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a	7 g		_
	roim 1098-Cr	7h		
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring	undrigue.	SPORTED IN	SHILLY
	organization have excess business holdings at any time during the year?	8		
9			1	N/A
	a Did the sponsoring organization make any taxable distributions under section 4966?	9a		THE R. P. LEWIS CO., LANSING
	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:	30	SHOWER DE	GEORGE VI
	a Initiation fees and capital contributions included on Part VIII, line 12			
	b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities 10b			
	Section 501(c)(12) organizations. Enter:			
	Cross income from manch on an almost at			
'	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?	E203		
1	h If Wood ontow the assessment of the surround that the surround that the surround	12 a		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.			
			SA P	
•	a Is the organization licensed to issue qualified health plans in more than one state?	13 a		
	Note. See the instructions for additional information the organization must report on Schedule O.			
1	b Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans		120	
	a Embarable assessment of second and the second and			
` 1⊿ •	a Did the organization receive any navments for indeer tanning continue during the terms.	138		
، ۰۰۰ ا	a Did the organization receive any payments for indoor tanning services during the tax year?	14a		X
ΔΔ	of If 'Yes,' has it filed a Form 720 to report these payments? If 'No,' provide an explanation in Schedule O	14b		

D	32 000700	9		raye
P	art VI Governance, Management, and Disclosure For each 'Yes' response to lines 2 through 7b to a 'No' response to line 8a, 8b, or 10b below, describe the circumstances, processes, or characteristic of the schedule O. See instructions.	nges	in	
Se	Check if Schedule O contains a response or note to any line in this Part VIection A. Governing Body and Management			Х
_	reading body and management			
1	I a Enter the number of voting members of the governing body at the end of the tax year	0	Yes	No
	h Enter the number of voting members included in line 1s, shows who are the second sec			
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee? SEE SCHEDULE O			
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, or trustees, or key employees to a management company or other person?	2	X	\
4	Did the organization make any significant changes to its governing documents			X
_	since the prior Form 990 was filed?	4		X
5	and a significant diversion of the organization's assets?	5		X
6	The state of the mean and the mean and the state of the s	6		Х
	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		Х
	<b>b</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
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:	70		A
	a The governing body?		Name of Street	
	<b>b</b> Each committee with authority to act on behalf of the governing body?	8 a	X	
9	Is there any officer, director, trustee, or key employee listed in Part VII. Section A, who cannot be reached at the	8 b	Х	
Ser	organization's mailing address? If 'Yes,' provide the names and addresses in Schedule Q	9		X
	ction B. Policies (This Section B requests information about policies not required by the Internal R	evenu	ie Co	ode.)
10	a Did the organization have local chapters, branches, or efficience	,	Yes	No
	a Did the organization have local chapters, branches, or affiliates?	10 a		X
	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 Ь		
Н	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	
ا	b Describe in Schedule O the process, if any, used by the organization to review this Form 990. SEE SCHEDULE O	1700	STATE OF	BRAN
120	a Did the organization have a written conflict of interest policy? If 'No,' go to line 13	12a	Х	manus (21)
	b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	х	
•	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 . O.	12 c	Х	
13	Did the organization have a written whistleblower policy?	13	X	
14	Did the organization have a written document retention and destruction policy?	14	X	
15	Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?		A	
2	The organization's CEO, Executive Director, or top management official	15 -		V
t	Other officers or key employees of the organization	15 a		X
	If 'Yes' to line 15a or 15b, describe the process in Schedule O (see instructions).	15 b	30,515	X
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?			
b	of Yes, did the organization follow a written policy or procedure requiring the organization to evaluate its	16 a	<b>集個</b>	X
	organization's exempt status with respect to such arrangements?	16 b		TITO
	tion C. Disclosure	100		_
7	List the states with which a copy of this Form 990 is required to be filed ► NONE			
	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) a	 availal	ble
•	X Own website			
	Describe in Schedule 0 whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available the public during the tax year.  SEE SCHEDULE 0   C	le to		
0	State the name, address, and telephone number of the person who possesses the organization's books and records:			

32-0	1067668	Page

Form 990 (2017) CYSTINOSIS RESEARCH FOUNDAT	Form 990 (2017)	CYSTINOSIS	RESEARCH	FOUNDATIO
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Part VII | Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors

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

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

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

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

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

				(C)							
(A) Name and Title	(B) Average hours per	than is	n one i s both dire	box, an o ector	unles fficer truste		on	(D)  Reportable compensation from the prognization	(E) Reportable compensation from	(F) Estimated amount of other compensation	
	per week (list any hours for related organiza- tions below dotted tine)	individual truslee or director	institutional trustee	Officer	Key employee	Highest compensated employee	Former	the organization (W-2/1099-MISC)	ielalód organizations (W-2/1099-MISC)	from the organization and related organizations	
(1) NANCY STACK	40										
CHAIR - TRUSTEE	0	X						0.	0.,	0.	
(2) GEOFFREY STACK VICE CHAIR-TTEE	0 -	X						0	0.	0.	
(3) DONALD L. SOLSBY	2		П								
TREASURER - TTE	0	X						0	0.	0.	
(4) BRUCE CRAIR											
TRUSTEE	0	X			_		_	0,	0.	0.	
(5) STEPHANIE CHERQUI TRUSTEE		X						0.4	0::	0.	
(6) MARCU ALEXANDER	0										
TRUSTEE	0	X						0.	0.	٥.	
(7) DAVID W. MOSSMAN TRUSTEE		Х					ı.	0,	0.	0.	
(8) JOHN S. HAGESTAD	0										
TRUSTEE	0	X	1					0.	0.	0.	
(9) ERIN LITTLE	0									_	
TRUSTEE	0	X						0.	0.	0.	
(10) MICHAEL K. HAYDE	0									_	
TRUSTEE	0	X	$\vdash$	_			_	0.	0.	0.	
(11) KEVIN PARTINGTON		١								,	
TRUSTEE	0	X	1			$\vdash$	_	0,,	0.	0.	
(12) TERESA PARTINGTON TRUSTEE		х						0.	0.	0.	
(13) BRIAN STURGIS	0					1	-				
TRUSTEE	O	X						0.	0.	0.	
(14) ROBERT D. OLSON	0								_	_	
TRUSTEE	0	X	20/00					0	0.	5 0	

Part VII Section A. Officers, Directors, 1rt	(B)	Rey			) (2)	C3,	an	i riigiicat con	iperisated Emp	loyces (a	типиси
(A) Name and title	Average hours per week	box	, unle	check ess pe nd a o	erson direct	than is bot or/trus	h an stee)	(D)  Reportable compensation from	(E)  Reportable compensation from related organizations	Estima amount o compens	ated of other
19	(list any hours for related organiza - tions below dotted line)	or director	Institutional trustee	Officer	Key employee	employee	Former	the organization (W-2/1099-MISC)	(W-2/1099-MISC)	from organiz and rel organiza	the ation ated
(15) DENICE FLERCHINGER TRUSTEE	0	X						0.	0.		0.
(16) JOHN C. MANLY TRUSTEE	00	X						0.	0.		0.
(17) JODY STRAUSS TRUSTEE	0 0	X						0.	0.		0.
(18) THOMAS A. GENDRON TRUSTEE	0 0	X						0.	0.		0.
(19) TRACI GENDRON TRUSTEE	0 0	X						0.	0.		0.
(20) STEPHEN L. JENKINS, MD TRUSTEE	0	X						0.	0.		0.
(21)		21						J.			
(22)											
(23)		-									
(24)		3									
(25)											
1 b Sub-total							<b>F</b>	0.	0.		0.
c Total from continuation sheets to Part VII, Secti d Total (add lines 1b and 1c)							-	0.	0.		0.
2 Total number of individuals (including but not limited from the organization ▶ 0	to those I	isted	abo	ve) v	who	rece	ived			pensation	
										Ye	es No
3 Did the organization list any former officer, direct on line 1a? If 'Yes,' complete Schedule J for suc	ch individu	ıal				• • • •				3	X
4 For any individual listed on line 1a, is the sum of the organization and related organizations greate such individual.	er than \$1	150,0	00?	If "	Yes,	' cor	nple	ite Schedule J for	from	4	X
5 Did any person listed on line 1a receive or accru for services rendered to the organization? If 'Yes	e comper s,' <i>comple</i>	nsatio	on fr chec	om dule	any J fo	unre or su	elate ch p	ed organization or person	individual	5	X
Section B. Independent Contractors  1 Complete this table for your five highest compen	sated ind	epen	den	t co	ntra	ctors	s tha	at received more t	han \$100,000 of		
compensation from the organization. Report compensation from the organization. Report compensation from the organization. Report compensation from the organization.		the c	alen	idar	yeaı	end	ing \	Description		r. (C) Compensa	etion
Name and business add	1622							Description	or services	Compense	1011
2 Total number of independent contractors (including to		ited t	o tha	ose	liste	d abo	ove)	who received more	than	1-101-1	The second second
\$100,000 of compensation from the organization	0									248 A.A.	

	Part VIII	Statement of Revenue
ı	rait viii	Statement of Revenue

	Check if Schedule O contains a resp	onse or note to an	y line in this Part VII	L.,	g	
			<b>(A)</b> Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514
ats Tts	1 a Federated campaigns 1 a					
rar	b Membership dues 1 b					
s, c	c Fundraising events	3,004,235.				
ar.	d Related organizations. 1 d					
s, (	e Government grants (contributions) 1 e					
Contributions, Gifts, Grants and Other Similar Amounts	f All other contributions, gifts, grants, and similar amounts not included above 1 f g Noncash contributions included in lines 1a-1f: \$	1,091,654.				
Cor	h Total. Add lines 1a-1f		4,095,889.			
Te m		Business Code				
Program Service Revenue	2 a		and the same of th	The state of the s		DEFENDE DESCRIPTION
Be .	b					
<u>8</u>	c					
Šer.	d					
Ë	e					
<u>g</u>	f All other program service revenue					
P.	g Total. Add lines 2a-2f		1	A PER LINE VILLE IN		
-	3 Investment income (including dividends	, interest and	20			
	other similar amounts)		23,864.	23,864.		
	4 Income from investment of tax-exempt					
	5 Royalties					
	(i) Real	(ii) Personal				
	6a Gross rents					
	b Less: rental expenses					
	c Rental income or (loss)					
	d Net rental income or (loss)					
	7 a Gross amount from sales of (i) Securities	(ii) Other				
	assets other than inventory 289, 629.					
	b Less: cost or other basis and sales expenses					
	<b>c</b> Gain or (loss)					
			24,358.	24,358.		
Ä	8a Gross income from fundraising events (not including \$\\$\\$\\$\\$\\$\\$\\$\\$\.\\$\.\					
Ver	of contributions reported on line 1c).					
Be	See Part IV, line 18 a					
ē	b Less: direct expenses b					
Other Revent	c Net income or (loss) from fundraising e		MARKET HAVE TO THE			
J	9 a Gross income from gaming activities. See Part IV, line 19 a	r -				
	b Less: direct expenses b					
	c Net income or (loss) from gaming activi	ties			TOTAL PROPERTY COME	Hamilton Street Cons
	10 a Gross sales of inventory, less returns and allowances					
	<b>b</b> Less: cost of goods sold					
	c Net income or (loss) from sales of inver					
	Miscellaneous Revenue	Business Code				
Ī	11 a					
	b					*
	С					<del>-</del>
	d All other revenue					
	e Total. Add lines 11a-11d					B. 作品。
	12 Total revenue. See instructions	(4 · · · (4 · · (4 · · (4 · · (4 · · · (4 · · · ·	4,144,111.	48,222.	0.	0.

# 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).

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

Grants and other assistance to domestic stands of the processing operations of the processing operations of the processing operations of the processing operations, See Part IV, lines 15 and 16	Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	Total expenses	(B) Program service expenses	(C) Management and general expenses	( <b>D)</b> Fundraising
2 Grants and other assistance to domestic individuals. See Part IV, the 22.  3 Grants and other assistance to foreign ceight individuals. See Part IV, the 22.  4 Banefits paid to of for members.  5 Compensation of current officers. directors, trustees, and key employees case defined under section 4958(c)(3)(6).  6 Compensation or included above. In disqualified persons (as defined under section 4958(c)(3)(6).  7 Other saliants and wages.  9 Other employee benefits.  9 Other employee benefits.  10 Payroll taxes.  2 2,370.  11 R. 118.  118.  2 2,370.  118.  118.  2 3 2,370.  118.  119.  1	See Part IV, line 21	693 500		general expenses	expenses
3 Grants and other assistance to foreign organizations, foreign operations, foreign op	2 Grants and other assistance to domestic	000,000.	683,590.		
4 Benefits paid to or for members. Compensation of current officers, directors, trustees, and key employees. Compensation of current officers, directors, trustees, and key employees. Compensation of current officers, directors, trustees, and key employees continued above, to disqualified persons (as defined under some continuous and contributions (as defined under some continuous and contributions (as defined under some continuous and contributions (as defined under some continuous).  9 Other employee benefits. 10 Payroll taxes. 2, 370. 118. 118. 2, 118. 2, 118. 2, 119. 118. 118. 2, 119. 119. 119. 119. 119. 119. 119. 119.	3 Grants and other assistance to foreign				
Compensation of current officers, directors, trustes, and key employees.	A Repetits paid to or for your 1	465,760.	465,760.		
Compensation not included above, to discopiling persons (as defined under of in section 498(0)(3)(3)(4)(4)(4)(4)(4)(4)(4)(4)(4)(4)(4)(4)(4)	5 Compensation of current officers directors				Unicipality of the Section
6 disputishation not included above, to dispute the process of the	trustees, and key employees		0		THE PERSON NAMED IN
7 Other salaries and wages.  8 Pension plan accruats and contributions (include section 401(k) and 403(b) employer contributions).  9 Other employee benefits.  10 Payroll taxes.  11 Fecs for services (non-employees):  a Management. b Legal.  c Accounting.  d Lobbying.  Professional fundraising services. See Part IV, line 17. I Investment management fees.  9 Other, (If line I) amount crede logs of line 25, column (A) amount, list line 19 (penness on Schedule 0.).  3 Office expenses.  10 Cocupancy.  114,864.  3,070.  111,866.  4, expenses on Schedule 0.).  114,864.  3,070.  111,866.  4, expenses for any federal, state, or local public officials.  117,912.  5,027.  12,6  20,186.  20,186.  21,186.  22,282.  292,829.  292	section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	0			
8 Persion plan accruals and contributions (include section 401(%) and 403(%) employer contributions). 9 Other employee benefits. 10 Payroll taxes. 11 Fees for services (non-employees): a Management. b Legal. c Accounting. d Lobbying. d Lobbying. e Professional fundraising services. See Part IV, line 17. I Investment management fees. 9 Other, off line 1 paramont excess 10% of line 25, column (A) amount in the professional fundraising services. See Part IV, line 17. I Information technology. 5 Royalties. 6 Occupancy. 7 Travel. 8 Payments of travel or entertainment expenses for any federal, state, or local public officials. 9 Conferences, conventions, and meetings. 1 Interest. 1 Payments to affiliates. 9 Depreciation, depletion, and amortization. 1 Insurance. 1 Payments of travel or entertainment expenses for any federal, state, or local public officials. 9 Depreciation, depletion, and amortization. 1 Insurance. 1 Payments of travel or entertainment expenses for any federal, state, or local public officials. 9 Depreciation, depletion, and amortization. 1 Insurance. 1 Payments of travel or entertainment expenses for any federal, state, or local public officials. 9 Depreciation, depletion, and amortization. 1 Insurance. 1 Payments of travel or entertainment expenses for any federal, state, or local public officials. 9 Depreciation, depletion, and amortization. 1 Insurance. 1 Payments of travel or entertainment expenses for any federal, state, or local public officials. 9 Depreciation, depletion, and amortization. 1 Insurance. 1 Payments of travel or entertainment expenses for any federal, state, or local public officials. 9 Depreciation, depletion, and amortization. 1 Insurance. 1 Payments of travel or entertainment expenses for any federal, state, or local public officials. 9 Depreciation, depletion, and amortization. 1 Insurance. 1 Payments of travel or entertainment expenses for any federal, state, or local public officials. 9 Depreciation, depletion, and amortization. 1 Insurance. 1 Payments of travel or enterta	7 Other salaries and wages	0.			
99 Other employee benefits. 10 Payroll taxes. 11 Fees for services (non-employees): a Management. b Legal. c Accounting. d Lobbying. 16,679. 11,806. 4, e Professional fundraising services. See Part IV, line 17. f Investment management fees. 9 Other (If line 1)g amount exceeds 10% of line 25, column (A) amount, list line 1)g expenses on Schedule C). 2 Advertising and promotion. 114,864. 3,070. 1111, 3 Office expenses. 1 Information technology. 5 Royalties. 6 Occupancy. 7 Travel. 8 Payments of travel or entertainment expenses for any federal, state, or local public officials. 9 Conferences, conventions, and meetings. 1 Interest. 1 Payments to affiliates. 2 Depreciation, depletion, and amortization. Insurance. 3,595. 3,595. 3,595. 4 Conferences, conventions, and meetings. 1 Interest. 1 Payments to affiliates. 2 Depreciation, depletion, and amortization. 2 Insurance. 3,595. 3,595. 3,595. 4 Conferences, conventions, and meetings. 3 Interest. 4 Depreciation, depletion, and amortization. 2 Insurance. 3,595. 3,595. 3,595. 4 Conferences, conventions, and meetings. 3 Interest. 4 Depreciation, depletion, and amortization. 5 Insurance. 3,595. 3,595. 5 Conferences, conventions, and meetings. 1 Interest. 2 Payments to affiliates. 2 Depreciation, depletion, and amortization. 2 Insurance. 3,595. 3,595. 3,595. 5 Conferences, conventions, and meetings. 3 Interest. 3 Conferences, conventions, and meetings. 3 Interest. 3 Conferences, conventions, and meetings. 3 Interest. 3 Conferences, conventions, and meetings. 3 Interest. 4 Payments to affiliates. 5 Depreciation, depletion, and amortization. 5 Repart to a service of the convention of the c	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions).	20/201.	1,413.	1,413.	25, 43
10   Payroll taxes.   2, 370.   118.   118.   2,	9 Other employee benefits				
1	10 Payroll taxes		110	110	
b Legal.	11 Fees for services (non-employees):		110.	118.	2,134
d Lobbying.   16,679.   111,806.   4,   Professional fundraising services. See Part IV, line 17.   Investment management fees.   9 Other, (if line 1) generate seeds 10% of line 25 column (A) amount, list line 1) generates on Schedule 0.).   Advertising and promotion.   114,864.   3,070.   3 Office expenses.   114,864.   3,070.   111,	a Management				
d Lobbying	b Legal				
e Professional fundraising services. See Part IV, line 17.  f Investment management fees.  9 Other (if line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule 0.). 2 Advertising and promotion. 3 Office expenses. 4 Information technology. 5 Royattles. 6 Occupancy. 7 Travel. 17, 912. 5 , 027. 12, 8 expenses for any federal, state, or local public officials. Payments of travel or entertainment expenses for any federal, state, or local public officials. Payments to affiliates Depreciation, depletion, and amortization. Insurance. 1 Insurance. 2 Onferences, conventions, and meetings linterest. Payments to affiliates Depreciation, depletion, and amortization. Insurance. 3 , 595. 3 , 595. 3 , 595.  CORNEAL, CYSTINOSIS - NANOWAFER 292, 829. 292,	c Accounting	16,679.		11 906	4 070
f Investment management fees.	d Lobbying			11,000.	4,873
g Other (If line 1)g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule 0.)  2 Advertising and promotion.  3 Office expenses.  4 Information technology.  5 Royalties.  6 Occupancy.  7 Travel.  8 Payments of travel or entertainment expenses for any federal, state, or local public officials.  9 Conferences, conventions, and meetings.  1 Interest.  Payments to affiliates.  Depreciation, depletion, and amortization.  1 Insurance.  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.).  2 CORNEAL CYSTINOSIS NANOWAFER  2 92, 829.  2 92, 829.  4 DUCATION  2 PRINTING AND PUBLICATIONS  4 OUTSIDE SERVICES  98, 800.  2 11, 250.  39, 177.  48, 3  2 00, 008.  9, 231.  6 2, 091.  1 28, 6  5 0.  5 0.  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).	e Professional fundraising services. See Part IV, line 17			1.50 (2005) (150)	
(v) aniouni, it in Fig expenses on Schedule 0.)  Advertising and promotion  1114,864. 3,070. 1111,  Office expenses. 1114,864. 3,070. 1111,  Office expenses. 1111,  Information technology. 5 Royalties. 5 Royalties. 5 Occupancy. 7 Travel. 17,912. 5,027. 12,8  Payments of travel or entertainment expenses for any federal, state, or local public officials. Conferences, conventions, and meetings interest.	Other (If line 11s arranged to				
3 Office expenses.	(A) distutil list line 110 expenses on Schedule (1)	174 964	2.070		
4 Information technology 5 Royalties	3 Office expenses.	114,004.	3,070.		111,794
5 Royalties 6 Occupancy. 7 Travel	4 Information technology				
7 Travel. 3 Payments of travel or entertainment expenses for any federal, state, or local public officials	5 Royalties				
7 Travel	6 Occupancy				
a Payments of travel or entertainment expenses for any federal, state, or local public officials.  Defreciation, depletion, and amortization. Insurance.  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.).  CORNEAL CYSTINOSIS –NANOWAFER 292,829.  EDUCATION 232,086. 232,086.  CPRINTING AND PUBLICATIONS 114,651. 47,079. 2,556. 65,0 0UTSIDE SERVICES 98,800. 11,250. 39,177. 48,3 do in the expenses. Add lines 1 through 24e. 2,271,401. 1,746,426. 125,783. 399,1 1 1,746,426. 125,783. 399,1 1 1,746,426. 125,783. 399,1 1 1,746,7426. 125,783.	7 Travel			5 005	
Conferences, conventions, and meetings Interest Payments to affiliates Depreciation, depletion, and amortization. Insurance. 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.)  CORNEAL CYSTINOSIS NANOWAFER DUCATION CORNEAL CYSTINOSIS NANOWAFER DUCATION DIVINITY OF CORNEAL CYSTINOSIS NANOWAFER DUCATION DUCATION DIVINITY OF CORNEAL CYSTINOSIS NANOWAFER DUCATION DUCA	Payments of travel or entertainment expenses for any federal, state, or local public officials	11,312.		5,027.	12,885
Payments to affiliates  Depreciation, depletion, and amortization.  Insurance.  Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)  a CORNEAL CYSTINOSIS - NANOWAFER 292, 829.  b EDUCATION 232, 086.  c PRINTING AND PUBLICATIONS 114,651. 47,079. 2,556. 65,0 OUTSIDE SERVICES 98,800. 11,250. 39,177. 48,3 200,008. 9,231. 62,091. 128,6 2,271,401. 1,746,426. 125,783. 399,1 Interest or	9 Conferences, conventions, and meetings				
Depreciation, depletion, and amortization.  Insurance.  Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.).  a CORNEAL CYSTINOSIS-NANOWAFER  DEDUCATION  CPRINTING AND PUBLICATIONS  OUTSIDE SERVICES  All other expenses.  All other expenses. Add lines 1 through 24e.  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  I if following SOP 98-2 (ASC 958-720).	Interest				
Insurance    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.).    CORNEAL CYSTINOSIS - NANOWAFER   292,829.   292,829.     EDUCATION   232,086.   232,086.     C PRINTING AND PUBLICATIONS   114,651.   47,079.   2,556.   65,0     OUTSIDE SERVICES   98,800.   11,250.   39,177.   48,3     E All other expenses   200,008.   9,231.   62,091.   128,6     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 ▶					
tother expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.).  a CORNEAL CYSTINOSIS - NANOWAFER 292, 829.  b EDUCATION 232, 086. 232, 086.  c PRINTING AND PUBLICATIONS 114, 651. 47, 079. 2,556. 65, 0  d OUTSIDE SERVICES 98,800. 11,250. 39,177. 48,3  e All other expenses 200,008. 9,231. 62,091. 128,6  Total functional expenses. Add lines 1 through 24e. 2,271,401. 1,746,426. 125,783. 399,1  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).					
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 C.).  a CORNEAL CYSTINOSIS - NANOWAFER 292,829. 292,829.  b EDUCATION 232,086. 232,086.  c PRINTING AND PUBLICATIONS 114,651. 47,079. 2,556. 65,0  d OUTSIDE SERVICES 98,800. 11,250. 39,177. 48,33  e All other expenses 200,008. 9,231. 62,091. 128,6  Total functional expenses. Add lines 1 through 24e. 2,271,401. 1,746,426. 125,783. 399,13  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).	Other expenses Itemize expenses and	3,595.		3.595	
a CORNEAL CYSTINOSIS NANOWAFER b EDUCATION c PRINTING AND PUBLICATIONS d OUTSIDE SERVICES e All other expenses. Total functional expenses. Add lines 1 through 24e.  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).	in line 24e. If line 24e amount exceeds 10% of line 25. column (A) amount list line 246.			2,333.	
b EDUCATION       232,086       232,086         c PRINTING AND PUBLICATIONS       114,651       47,079       2,556       65,0         d OUTSIDE SERVICES       98,800       11,250       39,177       48,3         e All other expenses       200,008       9,231       62,091       128,6         Total functional expenses. Add lines 1 through 24e       2,271,401       1,746,426       125,783       399,1         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)		292 920	202 000		
C PRINTING AND PUBLICATIONS       114,651.       47,079.       2,556.       65,0         d OUTSIDE SERVICES       98,800.       11,250.       39,177.       48,3         e All other expenses.       200,008.       9,231.       62,091.       128,6         Total functional expenses. Add lines 1 through 24e.       2,271,401.       1,746,426.       125,783.       399,1         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).	b EDUCATION_				
d OUTSIDE SERVICES  e All other expenses	C PRINTING AND PUBLICATIONS			0	
e All other expenses	d OUTSIDE SERVICES				65,016.
Total functional expenses. Add lines 1 through 24e	e All other expenses				48,373.
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)	Total functional expenses. Add lines 1 through 24e				128,686.
	joint costs from a combined educational campaign and fundraising solicitation.  Check here		27.107120,	123,783.	399,192.
TECADATAL AGRADA					Form <b>906</b> (2017)

**Balance Sheet** 

Check if Schedule O contains a response or note to any line in this Part X..... (A) Beginning of year End of year Cash — non-interest-bearing ..... 1 4,672,285 2 2 Savings and temporary cash investments...... 5,569,068. 3 Pledges and grants receivable, net..... 63,746. 3 977,583. Accounts receivable, net..... 4 Loans and other receivables from current and former officers, directors trustees, key employees, and highest compensated employees. Complete 5 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions). Complete Part II of Schedule L.... 6 Notes and loans receivable, net ..... 7 13,916. Inventories for sale or use ..... 8 68,996. Prepaid expenses and deferred charges ..... 122,507. 9 Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D..... 10 a 56,838. 56,838. 10 c 11 Investments - publicly traded securities..... 1,466,645. 11 1,527,861. Investments – other securities. See Part IV, line 11. 12 Investments - program-related. See Part IV, line 11. 13 13 14 14 Intangible assets..... Other assets. See Part IV, line 11..... 15 15 8,157,424 16 Total assets. Add lines 1 through 15 (must equal line 34)..... 6,325,183. 16 Accounts payable and accrued expenses ..... 63,761. 17 17 42,022. Grants payable..... 1,739,002. 18 1,680,727 18 Deferred revenue..... 19 19 20 Tax-exempt bond liabilities..... 20 Escrow or custodial account liability. Complete Part IV of Schedule D..... 21 21 Loans and other payables to current and former officers, directors, trustees, 22 22 23 Secured mortgages and notes payable to unrelated third parties..... 23 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 Total liabilities. Add lines 17 through 25..... 26 1,802,763. 1,722,749 X and complete Organizations that follow SFAS 117 (ASC 958), check here > or Fund Balances lines 27 through 29, and lines 33 and 34. 27 4,522,420. 6,434,675. 28 Temporarily restricted net assets..... 28 29 Organizations that do not follow SFAS 117 (ASC 958), check here and complete lines 30 through 34. 30 Capital stock or trust principal, or current funds ..... 30 Net Assets 31 32 32 4,522,420. 33 33 Total net assets or fund balances..... 6,434,675. 6,325,183. 34 8,157,424. 34

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Princers of the last of the la		32-00676	68	P	age 12
Pa	rt XI Reconciliation of Net Assets				500.00
	Check if Schedule O contains a response or note to any line in this Part XI		0000000000		
1	Control of the contro	1	4,1	44,	111.
- 2	Total expenses (must equal Part IX, column (A), line 25)	2			401.
3					710.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	-			420.
5	Net unrealized gains (losses) on investments				545.
6	Donated services and use of facilities	6			
7	Investment expenses				
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)).		6.4	34,	
Pa	rt XII Financial Statements and Reporting		0, 3	34,	115.
	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			15,72	EDITOR .
	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	BUNGS	Х
	If 'Yes,' check a box below to indicate whether the financial statements for the year were compiled or rev separate basis, consolidated basis, or both:  Separate basis  Consolidated basis  Both consolidated and separate basis			do	
-	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 se basis, consolidated basis, or both:  X Separate basis Consolidated basis Both consolidated and separate basis		20		
•	c If 'Yes' to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the a review, or compilation of its financial statements and selection of an independent accountant?	udit,	2 c	Х	
	If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.				
	a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Sing Audit Act and OMB Circular A-133?		За		х
	b If 'Yes,' did the organization undergo the required audit or audits? If the organization did not undergo the required or audits, explain why in Schedule O and describe any steps taken to undergo such audits	audit	3b		
BAA			Form	990	(2017)

#### SCHEDULE A (Form 990 or 990-EZ)

Department of the Treasury Internal Revenue Service

## **Public Charity Status and Public Support**

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

Attach to Form 990 or Form 990-EZ. ► Go to www.irs.gov/Form990 for instructions and the latest information.

Name of the organization

2017

OMB No. 1545-0047

Open to Public Inspection

Employer identification number

CYSTINOSIS RESEARCH FOUNDATION 32-0067668 Part I Reason for Public Charity Status (All organizations must complete this part.) See instructions. The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.) A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i). 2 A school described in section 170(b)(1)(A)(ii). (Attach Schedule E (Form 990 or 990-EZ).) 3 A hospital or a cooperative hospital service organization described in section 170(b)(1)(A)(iii). 4 A medical research organization operated in conjunction with a hospital described in section 170(b)(1)(A)(iii). Enter the hospital's name, city, and state: 5 An organization operated for the benefit of a college or university owned or operated by a governmental unit described in section 170(b)(1)(A)(iv). (Complete Part II.) 6 A federal, state, or local government or governmental unit described in section 170(b)(1)(A)(v). 7 X An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi).** (Complete Part II.) A community trust described in section 170(b)(1)(A)(vi). (Complete Part II.) 8 An agricultural research organization described in section 170(b)(1)(A)(ix) operated in conjunction with a land-grant college 9 or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university: An organization that normally receives: (1) more than 33-1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33-1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after 10 June 30, 1975. See section 509(a)(2). (Complete Part III.) 11 An organization organized and operated exclusively to test for public safety. See section 509(a)(4). 12 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2). See section 509(a)(3). Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g. Type I. A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. You must complete Part IV, Sections A and B. Type II. A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). You must complete Part IV, Sections A and C. **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.** Type III non-functionally integrated. A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). You must complete Part IV, Sections A and D, and Part V. Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization. f Enter the number of supported organizations..... g Provide the following information about the supported organization(s). (i) Name of supported organization (iii) Type of organization (described on lines 1-10 above (see instructions)) (v) Amount of monetary (iv) Is the organization listed (vi) Amount of other support (see instructions) support (see instructions) in your governing document? Yes (A) (B) (C) (D) (E) Total

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

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

on A. Public Support						
dar year (or fiscal year	<b>(a)</b> 2013	<b>(b)</b> 2014	<b>(c)</b> 2015	<b>(d)</b> 2016	<b>(e)</b> 2017	(f) Total
	3,130,529.	3,324,548.	3,213,127.	4,818,959.	4,095,889.	18,583,052.
Tax revenues levied for the organization's benefit and either paid to or expended						0.
facilities furnished by a						0.
Total. Add lines 1 through 3	3,130,529.	3,324,548.	3,213,127.	4,818,959.	4,095,889.	18,583,052.
contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount						0.
						18,583,052.
ion B. Total Support			1			T .
ndar year (or fiscal year nning in) ►	<b>(a)</b> 2013	<b>(b)</b> 2014	, <b>(c)</b> 2015	(d) 2016	<b>(e)</b> 2017	(f) Total
Amounts from line 4	3,130,529.	3,324,548.	3,213,127.	4,818,959.	4,095,889.	18,583,052.
Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	19,064.	9,190.				28,254.
Net income from unrelated business activities, whether or not the business is regularly carried on						0.
gain or loss from the sale of capital assets (Explain in						0.
through 10						18,611,306.
Gross receipts from related acti	vities, etc. (see in	structions)	TTTTTT		12	0.
First five years. If the Form 990 is organization, check this box and	for the organization	n's first, second, t	hird, fourth, or fifth	tax year as a sect	ion 501(c)(3)	9999
tion C. Computation of Pu	ıblic Support	Percentage				
Public support percentage for 2	017 (line 6, colun	nn (f) divided by l	ine 11, column (f	))	14	99.85%
Public support percentage from	2016 Schedule A	, Part II, line 14.				33.00 %
and stop here. The organization	n qualifies as a pi	abliciy supported	organization			21
and stop here. The organization	n qualifies as a p	ublicly supported	organization			
or more, and if the organization the organization meets the 'fac	n meets the facts ts-and-circumstar	ices' test. The org	ganization qualifie	es as a publicly su	ipported organizat	ion
or more, and if the organization	n meets the Tacts	test. The organi	zation qualifies a	s a publicly suppo	rted organization.	· · · · · · · · · · · · · · · · · · ·
Private foundation. If the organ	nization did not ch	neck a box on line	e 13, 16a, 16b, 17			
	on securities loans, rents, royalties, and income from similar sources.  Net income from unrelated business activities, whether or not the business is regularly carried on.  Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.).  Total support. Add lines 7 through 10.  Gross receipts from related activities of capital assets (Explain in Part VI.).  Total support. Add lines 7 through 10.  Gross receipts from related activities of capital assets (Explain in Part VI.).  Total support. Add lines 7 through 10.  Gross receipts from related activities of ganization, check this box and tion C. Computation of Pt. Public support percentage from 33-1/3% support test—2017. If and stop here. The organization and stop here. The organization of the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets the 'facts-and-circumstances' or more, and if the organization meets	diffs, grants, contributions, and membership fees received. (Do not include any unusual grants.)	dar year (or fiscal year ning in) >  (a) 2013 (b) 2014  (b) 2014  (c) 2013 (b) 2014  (d) 2013 (b) 2014  (e) 2014  (e) 2013 (b) 2014  (e) 2014  (e) 2014  (e) 2013 (b) 2014  (fist, grafts, contributions, and membership fees received. (Do not include any unusual grants.).  3, 130, 529. 3, 324, 548.  3, 130, 529. 3, 324, 548.  The value of services or facilities furnished by a governmental unit to the organization without charge.  Total. Add lines 1 through 3  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).  Public support. Subtract line 5 from line 4  Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources  Net income from unrelated business activities, whether or not the business is regularly carried on.  Net income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.).  Total support. Add lines 7 through 10.  Gross receipts from related activities, etc. (see instructions).  First five years. If the Form 990 is for the organization's first, second, torganization, check this box and stop here.  Total support percentage from 2016 Schedule A, Part II, line 14.  33-1/3% support test—2017. If the organization did not check the and stop here. The organization qualifies as a publicly supported 10%-facts-and-circumstances test—2016. If the organization did not check a be and stop here. The organization meets the 'facts-and-circumstances' test. The organiza	dar year (or fiscal year ning in) -  fills, gants, contributions, and membership fees received. (Do not include any "unusual grants.)  Tax revenues levied for the organization's benefit and either paid to or expended on its behalf.  The value of services or facilities furnished by a governmental unit to the organization without charge.  Total. Add lines 1 through 3.  The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 11, column (f).  Public support. Subtract line 5 from line 4.  Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources.  Net income from unrelated business activities, whether or not the business is regularly carried on.  Cher income. Do not include gain or loss from the sale of capital assets (Explain in Part VI).  Total support. Add lines 7 through 10.  First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth organization, check this box and stop here.  The organization of Public Support Percentage  Public support percentage for 2017 (line 6, column (f) divided by line 11, column (f) Public support percentage for 2017 (line 6, column (f) divided by line 11, column (f) and stop here. The organization qualifies as a publicly supported organization.  10%-facts-and-circumstances test—2017. If the organization did not check a box on rore, and if the organization meets the 'facts-and-circumstances' test, check the rore or more, and if the organization meets the 'facts-and-circumstances' test, check the organization meets the 'facts-and-circumstances' test. The organization or more, and if the organization meets the 'facts-and-circumstances' test. The organization organization or more, and if the organization meets th	dar year (or fiscal year ring in) - filts, gasts, contributions, and stifts, gasts, contributions is and stop here. The organization of the organization without charge.  3, 130, 529. 3, 324, 548. 3, 213, 127. 4, 818, 959. The value of services or facilities furnished by a governmental unit to the organization without charge. Total. Add lines 1 through 3. The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 11, column (i). Public support. Subtract line 5 from line 4. Silon B. Total Support and are year (or fiscal year rining in) - Amounts from line 4. Silon B. Total Support and are year (or fiscal year rining in) - Amounts from line 4. Silon B. Total Support on the business activities, whether or not the business as regularly contributions by seach person (or public support business activities, whether or not the business is regularly contributions from unrelated business activities, whether or not the business is regularly contributions from similar sources.  19,064. 9,190. Silon S	dar year (or fiscal year ning in) - (a) 2013 (b) 2014 (c) 2015 (d) 2016 (e) 2017 (fifts, grants, contributions, and membership fees received. (Do not micude any vinusual grants.)

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						
Calen	dar year (or fiscal year beginning in) >	(a) 2013	<b>(b)</b> 2014	(c) 2015	(d) 2016	<b>(e)</b> 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						
	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5	The value of services or facilities furnished by a governmental unit to the organization without charge						
6 7a	<b>Total.</b> Add lines 1 through 5 Amounts included on lines 1, 2, and 3 received from disqualified persons						
	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						
	Public support. (Subtract line 7c from line 6.)						
	tion B. Total Support						
	dar year (or fiscal year beginning in)	<b>(a)</b> 2013	<b>(b)</b> 2014	(c) 2015	(d) 2016	<b>(e)</b> 2017	(f) Total
	Amounts from line 6						
	Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources.						
	Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 Add lines 10a and 10b						
11	Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.).						*
	<b>Total support.</b> (Add lines 9, 10c, 11, and 12.)						
	First five years. If the Form 990 organization, check this box and	stop here	<i></i>	d, third, fourth, o	or fifth tax year as	a section 501(c)(3	3) ▶
	tion C. Computation of Pub			- 12			
15	Public support percentage for 20	17 (line 8, column	n (f) divided by lin	e 13, column (f))	************	15	%
10	Public support percentage from 2	orb Schedule A,	Part III, line 15		***********	16	%
	ion D. Computation of Investment income persons for				(0)	1	
1/ 10	Investment income percentage for	or ZUI/ (line 10c,	column (f) divide	a by line 13, colu	ımn (t))	17	%
	Investment income percentage fr						%
	33-1/3% support tests—2017. If the is not more than 33-1/3%, check 33-1/3% support tests—2016. If the	this box and stop	<b>o here.</b> The organ	ization qualifies a	as a publicly suppo	orted organization.	▶
	line 18 is not more than 33-1/3%	, check this box a	and <b>stop here.</b> The	e organization qu	alifies as a publicl	y supported organ	nization
<b>Z</b> V	Private foundation. If the organize	ation did not che	ck a box on line 1	<ol><li>4. 19a. or 19b. c</li></ol>	heck this hox and	see instructions	▶ □

Part IV Supporting Organizations

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

#### Section A. All Supporting Organizations

_	11, 3 3			
_			Yes	No
1	Are all of the organization's supported organizations listed by name in the organization's governing documents? If 'No,' describe in <b>Part VI</b> 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 <b>Part VI</b> how the organization determined that the supported organization was described in section 509(a)(1) or (2).	2		
3	a 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>B</b> W
ı	<b>b</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 <b>Part VI</b> when and how the organization made the determination.	3b		
	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If 'Yes,' explain in <b>Part VI</b> what controls the organization put in place to ensure such use.	3c		
	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	200	
k	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.	4b		
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 <b>Part VI</b> 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 <b>Part VI</b> , including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).	5a		
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		
6	Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If 'Yes,' provide detail in <b>Part VI</b> .	6		
7	Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If 'Yes,' complete Part I of Schedule L (Form 990 or 990-EZ).	7		
8	Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If 'Yes,' 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 <b>Part VI</b> .	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 <b>Part VI</b> .	9b	240	W 87
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 <b>Part VI</b> .	9c		
	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		700 11
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.)	104		

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Pa	rt IV Supporting Organizations (continued)			
		28	Yes	No
	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	ye 11,81	ALS AG
	<b>b</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		
Sec	ction B. Type I Supporting Organizations			
_			Yes	No
1	Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? If 'No,' describe in <b>Part VI</b> 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.	1		
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 <b>Part VI</b> how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.	2		
Sec	ction 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 <b>Part VI</b> how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).	1		
Sec	ction D. All Type III Supporting Organizations			
			Yes	No
1	Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?	1		
2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? If 'No,' explain in <b>Part VI</b> how the organization maintained a close and continuous working relationship with the supported organization(s).	2		
3	By reason of the relationship described in (2), did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? If 'Yes,' describe in <b>Part VI</b> the role the organization's supported organizations played in this regard.	3		
Sec	ction 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.			
	b The organization is the parent of each of its supported organizations. Complete line 3 below.			
•	c The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see	instruc	tions).	
2	Activities Test. Answer (a) and (b) below.		Yes	No
;	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.	2a		
ı	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.	2b		
3	Parent of Supported Organizations. Answer (a) and (b) below.			
	a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>Provide details in Part VI.</i>	3a		
	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.	3b		

Pa	rt V   Type III Non-Functionally Integrated 509(a)(3) Supporting Orga	nizati	ons	
1	Check here if the organization satisfied the Integral Part Test as a qualifying trust instructions. All other Type III non-functionally integrated supporting organization	t on No ns must	v. 20, 1970 (explain i complete Sections A	n Part VI). <b>See</b> A through E.
Sec	tion 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		
Sec	tion B — Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):			
á	Average monthly value of securities	1a		
ŀ	Average monthly cash balances	1b		
	Fair market value of other non-exempt-use assets	1c		
	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		
Sec	tion C — Distributable Amount	(C) (C)		Current Year
	Adjusted net income for prior year (from Section A, line 8, Column A)	1		
2	Enter 85% of line 1.	2		
3	Minimum asset amount for prior year (from Section B, line 8, Column A)	3		
4	Enter greater of line 2 or line 3.	4		
5	Income tax imposed in prior year	5		
6	<b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6		
7	Check here if the current year is the organization's first as a non-functionally integ (see instructions).	grated 7	Type III supporting org	ganization
BAA			Schodule A (E.	orm 990 or 990 E7) 2017

Pa	rt V Type III Non-Functionally Integrated 509(a)(3) Su	upporting Organiza	ations (continued)	07000 Tage
Sec	tion D — Distributions			Current Year
1	Amounts paid to supported organizations to accomplish exempt pu	ırposes		
2	Amounts paid to perform activity that directly furthers exempt purposes of in excess of income from activity	of supported organization	S,	
_ 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 organization Part VI). See instructions.	on is responsive (provide	details	
9	Distributable amount for 2017 from Section C, line 6			
10	Line 8 amount divided by line 9 amount			
Sec	tion 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			This is the same of	
	From 2013			
_	From 2014.			
	From 2015			
е	From 2016.			
f	<b>Total</b> of lines 3a through e			
g	Applied to underdistributions of prior years			
h	Applied to 2017 distributable amount		EN PHEMEINTHE	
i	Carryover from 2012 not applied (see instructions)			E PROPERTY OF THE PARTY OF
j	Remainder. Subtract lines 3g, 3h, and 3i from 3f.	Name of the last o		
4	Distributions for 2017 from Section D, line 7:			
а	Applied to underdistributions of prior years			
	Applied to 2017 distributable amount			No. 10 April 19 April
С	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.			many many mentang tidah (1944) mentang
7	Excess distributions carryover to 2018. Add lines 3j and 4c.			
8	Breakdown of line 7:			
a	Excess from 2013	Manager Williams		
	Excess from 2014			
	Excess from 2015			
d	Excess from 2016.			

e Excess from 2017...... BAA

Schedule A (Form 990 or 990-EZ) 2017

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

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

Department of the Treasury Internal Revenue Service **Schedule of Contributors** 

► Attach to Form 990, Form 990-EZ, or Form 990-PF. ► Go to www.irs.gov/Form990 for the latest information. OMB No. 1545-0047

2017

Name of the organization		Employer identification number
CYSTINOSIS RESEARCH FOUNDATION	N	32-0067668
Organization type (check one):		
Filers of:	Section:	
Form 990 or 990-EZ	X 501(c)( 3 ) (enter number) organization	
	4947(a)(1) nonexempt charitable trust <b>not</b> treated as a	private foundation
	527 political organization	
Form 990-PF	501(c)(3) exempt private foundation	
	4947(a)(1) nonexempt charitable trust treated as a priv	ate 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) orga	anization can check boxes for both the General Rule and a S	Special Rule. See instructions.
General Rule		
For an organization filing Form 990, 990-F7	, or 990-PF that received, during the year, contributions tota	aling \$5,000 or more (in money or
property) from any one contributor. Comple	te Parts I and II. See instructions for determining a contribu	tor's total contributions.
Special Rules		
X For an organization described in section 50	1(c)(3) filing Form 990 or 990-EZ that met the 33-1/3% supp	port test of the regulations
under sections 509(a)(1) and 1/0(b)(1)(A)(vi), received from any one contributor, during the	that checked Schedule A (Form 990 of 990-EZ), Part II, life 13, he vear, total contributions of the greater of (1) \$5,000 or (2	Toal or rool and mai
Form 990, Part VIII, line 1h; or (ii) Form 99	0-EZ, line 1. Complete Parts I and II.	
The continuation described in continue 50	1(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 <i>exclusively</i> for religious, charitable, scientific, lib children or animals. Complete Parts I, II, and III.	terary, 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 50	1(c)(7), (8), or (10) filing Form 990 or 990-EZ that received	from any one contributor,
during the year, contributions exclusively to \$1,000. If this boy is checked, enter here the	or religious, charitable, etc., purposes, but no such contributione total contributions that were received during the year for	an <i>exclusively</i> religious.
charitable, etc., purpose. Don't complete ar	ny of the parts unless the General Rule applies to this organ	nization because
it received nonexclusively religious, charitat	ole, etc., contributions totaling \$5,000 or more during the ye	ar 🕨 🤊
- DON DEV but it muset answer 'No' on Part IV Jir	the General Rule and/or the Special Rules doesn't file Schene 2, of its Form 990; or check the box on line H of its Form	99U-EZ 01 011 IIS FOITH 99U-FF.
Part I, line 2, to certify that it doesn't meet the	filing requirements of Schedule B (Form 990, 990-EZ, or 99	0-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
Name of erganization	Employer (dentification number
ONCONTROCTE DECEMBED FOUNDATION	32-0067668

Part I	Contributors (see instructions). Use duplicate copies of Part 11 additional space		
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
	CECEEDEY AND NANCY STACK		Person X
يحس سترختية	GEOFFREY AND NANCY STACK		Payroli
	18802 BARDEEN AVE	\$800,000.	Noncash
4	IRVINE, CA 92612		(Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
2	24 HOURS FOR HANK		Person X
£ 100 miles		\$ 200,800.	Payroll Noncash
i.e	565 WHISKEY JACK CIRCLE		(Complete Part II for
	SANDPOINT, ID 83864	-	noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
2	THOMAS AND TRACT GENDRON		Person X
3		\$ 500,000 <u>.</u>	Payroll Noncash
	3825 HARBOR WALK LN	T	(Complete Part II for
	FORT COLLINS, CO 80525		noncash contributions.)
(a)	(b) Name, address, and ZIP + 4	(c) Total	(d) Type of contribution
Number	Nailly, dudiess, glid Air T 4	contributions	1900.00
		contributions	Person X
Number 4	THOMAS AND SUSAN MORAN	contributions	Person X Payrolt
		\$ 176,000.	Person X Payrolt Noncash
	THOMAS AND SUSAN MORAN	contributions	Person X Payrolt
	THOMAS AND SUSAN MORAN  1 N FRANKLIN ST, #700  CHICAGO, IL 60606	contributions	Person X Payroll Noncash Complete Part II for
(a) Number	THOMAS AND SUSAN MORAN  1 N FRANKLIN ST, #700  CHICAGO, IL 60606  Name, address, and ZIP + 4	\$ 176,000.	Person X Payrolt Noncash (Complete Part II for noncash contributions.)  (d) Type of contribution Person X
4 (a)	THOMAS AND SUSAN MORAN  1 N FRANKLIN ST, #700  CHICAGO, IL 60606  (b)  Name, address, and ZIP + 4  MICHAEL HAYDE & LAURA KHOURI	\$ 176,000.	Person X Payroll Noncash (Complete Part II for noncash contributions.)  (d) Type of contribution  Person X Payroll
(a) Number	THOMAS AND SUSAN MORAN  1 N FRANKLIN ST, #700  CHICAGO, IL 60606  Name, address, and ZIP + 4	\$ 176,000.	Person X Payrolt Noncash (Complete Part II for noncash contributions.)  (d) Type of contribution  Person X Payroll Noncash
(a) Number	THOMAS AND SUSAN MORAN  1 N FRANKLIN ST, #700  CHICAGO, IL 60606  (b)  Name, address, and ZIP + 4  MICHAEL HAYDE & LAURA KHOURI	\$ 176,000.	Person X Payroll Noncash (Complete Part II for noncash contributions.)  (d) Type of contribution  Person X Payroll
(a) Number	THOMAS AND SUSAN MORAN  1 N FRANKLIN ST, #700  CHICAGO, IL 60606  Name, address, and ZIP+4  MICHAEL HAYDE & LAURA KHOURI  8 EXECUTIVE CIRCLE  IRVINE, CA 92614	\$ 176,000.	Person X Payrolt
(a) Number 5	THOMAS AND SUSAN MORAN  1 N FRANKLIN ST, #700  CHICAGO, IL 60606  Name, address, and ZIP + 4  MICHAEL HAYDE & LAURA KHOURI  8 EXECUTIVE CIRCLE  IRVINE, CA 92614  Name, address, and ZIP + 4	\$ 176,000.  (c) Total contributions  \$ 101,250.	Person X Payrolt
(a) Number	THOMAS AND SUSAN MORAN  1 N FRANKLIN ST, #700  CHICAGO, IL 60606  Name, address, and ZIP + 4  MICHAEL HAYDE & LAURA KHOURI  8 EXECUTIVE CIRCLE  IRVINE, CA 92614  Name, address, and ZIP + 4  DAVID PYLE	\$ 176,000.  \$ 176,000.  (c) Total contributions  \$ 101,250.  (c) Total contributions	Person X Payrolt
(a) Number 5	THOMAS AND SUSAN MORAN  1 N FRANKLIN ST, #700  CHICAGO, IL 60606  Name, address, and ZIP + 4  MICHAEL HAYDE & LAURA KHOURI  8 EXECUTIVE CIRCLE  IRVINE, CA 92614  Name, address, and ZIP + 4	\$ 176,000.  (c) Total contributions  \$ 101,250.	Person X Payrolt Noncash  (Complete Part II for noncash contributions.)  (d) Type of contribution  Person X Payroll Noncash  (Complete Part II for noncash contributions.)  (Type of contributions.)  (d) Type of contribution  Person X Payroll Noncash
(a) Number 5	THOMAS AND SUSAN MORAN  1 N FRANKLIN ST, #700  CHICAGO, IL 60606  Name, address, and ZIP + 4  MICHAEL HAYDE & LAURA KHOURI  8 EXECUTIVE CIRCLE  IRVINE, CA 92614  Name, address, and ZIP + 4  DAVID PYLE	\$ 176,000.  \$ 176,000.  (c) Total contributions  \$ 101,250.  (c) Total contributions	Person X Payrolt

2 of Part I

CYSTIN	NOSIS RESEARCH FOUNDATION		32-0067668
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 contribution	(d) Type of contribution
7	HORIZON PHARMA 150 S SAUNDERS RD	\$ 132,	Person X Payroll  500. Noncash
	LAKE FORREST , IL 60045		(Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contribution	(d) Type of contribution
8 1 ET (7)	THOMAS HAAS P.O. BOX 21948 PORTSMOUTH , NH 03802	\$453 <i>;</i>	Person X Payroll Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contribution	(d) Type of contribution
ಕರ್ಷ ಭನ್ನಡಚಿ		\$	Person Payroll Noncash  (Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contribution	(d) Type of contribution
<del></del>		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contribution	(d) Type of contribution
च्च ,रागे '=		\$	Person Payroll Noncash  (Complete Part II for noncash contributions.)
(a) Number	(b) Name, address, and ZIP + 4	(c) Total contribution	(d) Type of contribution
Marie Tarrie agus	د المراجعة الم	\$	Person Payroll Noncash Complete Part II for
PAA	TEFA0703 08/09/17	Schodula P /E	noncash contributions.)

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

2 of Part I

Page

2 of

Page

1 to

1 of Part II Employer identification number

Name of organization

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

Part II	Noncash Property (see instructions). Use duplicate copies of Part II if additional	al space is needed.	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date receive
	N/A		
		\$	
(a) No. from Part I	(b)  Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date receive
(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
(a) No. from Part I	(b)  Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
-		\$	

Name of organization CYSTINOSIS RESEARCH FOUNDATION 1 to 1 of Part III 32-0067668

Part III	or (10) that total more than \$1,000 for the following line entry. For organizations of contributions of \$1,000 or less for the year. Use duplicate copies of Part III if additional	ne year from any one contrib ompleting Part III, enter the tota (Enter this information once. So space is needed.	ral of <i>exclusively</i> religious, charitable, etc., see instructions.)			
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift		(d) Description of how gift is held		
	N/A					
	Transferee's name, addres	(e) Transfer of gift s, and ZIP + 4	Rela	ationship of transferor to transferee		
	765	(2)				
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift		(d) Description of how gift is held		
	Transferee's name, addres	(e) Transfer of gift s, and ZIP + 4	Rela	ntionship of transferor to transferee		
(a) No. from	(b)	(c)		(d) Description of how gift is held		
No. from Part I	(a) (b) (c) . from Purpose of gift Use of gift			Description of how gift is held		
	(e)					
	Transferee's name, addres	Relationship of transferor to transferee				
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift		(d) Description of how gift is held		
				<b></b>		
	Transferee's name, addres	(e) Transfer of gift s, and ZIP + 4	Rela	ntionship of transferor to transferee		

# SCHEDULE D (Form 990)

Department of the Treasury Internal Revenue Service Name of the organization

Supplemental Financial Statements

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

Attach to Form 990.

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

OMB No. 1545-0047

Open to Public Inspection
Employer identification number

	CYSTINOSIS RESEARCH FOUNDAT	ION		32-006	7668	
Par	1 Organizations Maintaining Dono	r Advised Funds or Other S	imilar Fund	ds or Accounts.		
	Complete if the organization answ	vered 'Yes' on Form 990, Pa	art IV, line 6	ō.		
		(a) Donor advised fund	S	(b) Funds and	other acco	ounts
1	Total number at end of year					
2	Aggregate value of contributions to (during year).					
3	Aggregate value of grants from (during year)					
4	Aggregate value at end of year					
5	Did the organization inform all donors and don are the organization's property, subject to the	organization's exclusive legal cont	rol?		Yes	No
6	Did the organization inform all grantees, donor for charitable purposes and not for the benefit impermissible private benefit?	s, and donor advisors in writing the of the donor or donor advisor, or	nat grant funds for any other p	s can be used only ourpose conferring	Yes	No
Par	t II Conservation Easements.	-				
	Complete if the organization answ	vered 'Yes' on Form 990, Pa	art IV, line	7		
1	Purpose(s) of conservation easements held by	the organization (check all that a	pply).			
	Preservation of land for public use (e.g., re	ecreation or education)	reservation of	a historically importa	nt land are	ea
	Protection of natural habitat	P	reservation of	a certified historic st	ructure	
	Preservation of open space					
2	Complete lines 2a through 2d if the organization h last day of the tax year.	eld a qualified conservation contribut	tion in the form	of a conservation ease	ment on th	ie
	last day of the last your			Held at the	End of the	e Tax Year
	a Total number of conservation easements			. 2a		
1	<b>b</b> Total acreage restricted by conservation easer	nents		2 b		
•	c Number of conservation easements on a certif	ied historic structure included in (a	a)	. 2c		
•	Number of conservation easements included in structure listed in the National Register			. 2 d		
3	Number of conservation easements modified, tran tax year ►	sferred, released, extinguished, or te	rminated by the	e organization during th	ie	
4	Number of states where property subject to conse	vation easement is located 🟲				
5	Does the organization have a written policy regard enforcement of the conservation easemen	ts it holds?			Yes	No
6	Staff and volunteer hours devoted to monitoring, in	nspecting, handling of violations, and	d enforcing con	servation easements di	uring the ye	ear
7	Amount of expenses incurred in monitoring, inspe ▶\$	cting, handling of violations, and enf	orcing conserva	ation easements during	the year	
8	Does each conservation easement reported or and section 170(h)(4)(B)(ii)?			_	Yes	No
9	In Part XIII, describe how the organization reports include, if applicable, the text of the footnote to conservation easements.	conservation easements in its reven o the organization's financial state	nue and expens ements that de	e statement, and balan escribes the organizat	ce sheet, a ion's accoi	ind unting for
Pa	Organizations Maintaining Collection Complete if the organization answers	ctions of Art, Historical Tre vered 'Yes' on Form 990, P	asures, or art IV, line	<b>Other Similar Ass</b> 8.	ets.	
1:	a If the organization elected, as permitted under art, historical treasures, or other similar assets he in Part XIII, the text of the footnote to its finan	ld for public exhibition, education, or	research in fui	ue statement and bal rtherance of public serv	ance sheet ice, provide	t works of
ı	b If the organization elected, as permitted under historical treasures, or other similar assets held for following amounts relating to these items:	r public exhibition, education, or res	earch in further	ance of public service,	provide the	orks of art,
	(i) Revenue included on Form 990, Part VIII,	line 1		▶\$		
	(ii) Assets included in Form 990, Part X					
2	amounts required to be reported under SFAS	istorical treasures, or other similar a 116 (ASC 958) relating to these ite	ssets for finance ems:	cial gain, provide the fo	lowing	
	a Revenue included on Form 990, Part VIII, line	1				
- 1	b Assets included in Form 990, Part X			▶\$		

Description of property

(a) Cost or other basis (investment)

1 a Land

b Buildings

c Leasehold improvements
d Equipment

e Other.

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

Schedule **D** (Form 990) 2017

0.

Page 3

te if the organization answered rity or category (including name of security) res	(b) Book value	O, Part IV, line 11b. See Form 99  (c) Method of valuation: Cost or end-of-	
es	si,	(c) meniod of variation, cost of end-of-	year market value
y interests.			
	-		
	-		
<b></b>	-		
	-		
	<b>*</b>		A SEE E
ents – Program Related.	d 'Vos' on Form 990	N/A ) Part IV line 11c See Form 90	10 Part V line 13
phon of investment	(b) Book value	(c) Wethod of Valuation. Cost of end-o	n-year market value
15 000 D W I 20 II 10		000000 000 At 40 A 400000000000000000000	W
ie if the organization answere	d 'Yes' on Form 990	). Part IV. line 11d. See Form 99	0. Part X. line 15
			(b) Book value
ust equal Form 990 Part X column	(B) line 15 )	<b>&gt;</b>	
	D) line 10.)		
if the organization answered 'Yes' on	Form 990, Part IV, line 11	le or 11f. See Form 990 Part X line 25	
Description of liability	(b) Book value		
axes			
ual Form 990, Part X, column (B) line 25.)			
it i	nents — Program Related. te if the organization answere ription of investment  rual Form 990, Part X, column (B) line 13.)  sesets. te if the organization answere (a) Definition of the organization answere (a) Definition (b) Inc. (b) Inc. (c) Inc. (c) Inc. (c) Inc. (c) Inc. (c) Inc. (d) Inc	te if the organization answered 'Yes' on Form 990 (b) Book value    wal Form 990, Part X, column (B) line 13.)     ssets.	nents — Program Related.  te if the organization answered 'Yes' on Form 990, Part IV, line 11c. See Form 99 (c) Method of valuation: Cost or end-organization of investment (b) Book value (c) Method of valuation: Cost or end-organization of investment (c) Method of valuation: Cost or end-organization answered 'Yes' on Form 990, Part IV, line 11d. See Form 99 (a) Description    Value

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per R	eturn.	
Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.		
1 Total revenue, gains, and other support per audited financial statements	1	4,144,111.
2 Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
a Net unrealized gains (losses) on investments		
b Donated services and use of facilities 2 b	以是其	
c Recoveries of prior year grants		
d Other (Describe in Part XIII.)		
e Add lines 2a through 2d	2 e	
3 Subtract line 2e from line 1	3	4,144,111.
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		
b Other (Describe in Part XIII.)		
c Add lines 4a and 4b.	4 c	
5 Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.).		4,144,111.
Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per	Return	
Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.		
1 Total expenses and losses per audited financial statements	1	2,271,401.
2 Amounts included on line 1 but not on Form 990, Part IX, line 25:	of the second second	
Download and down and track for differen		
a Donated services and use of facilities		_,_,_,
b Prior year adjustments		_,,
SCHOOLSTEE SCHOOLSTEE SCHOOLSTEEL SCHOOLST		
b Prior year adjustments		2,2.2,202
b Prior year adjustments	2 e	
b Prior year adjustments         2 b           c Other losses         2 c           d Other (Describe in Part XIII.)         2 d		
b Prior year adjustments		2,271,401.
b Prior year adjustments		
b Prior year adjustments	3	
b Prior year adjustments	. 3 . 4c	2,271,401.
b Prior year adjustments	. 3 . 4c	

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 D (Form 990) 2017

#### SCHEDULE F (Form 990)

Statement of Activities Outside the United States

Complete if the organization answered 'Yes' on Form 990, Part IV, line 14b, 15, or 16.

OMB No. 1545-0047 2017

75,000.

45,777.

(6) FRANCE

(7) FRANCE

(11)

(16)

Department of the Treasury			tach to Form 990.		2017
Department of the Treasury Internal Revenue Service	► Go to www.ii	rs.gov/Form990 fo	r instructions and the latest infor	mation	Open to Public Inspection
Name of the organization CYS	TINOSIS RESEAR	CH FOUNDAT	LOM	Employer id	entification number
				32-006	7668
on Form 990,	Part IV, line 14b.	ies Outside th	ne United States. Comple	te if the organiza	tion answered 'Yes'
1 For grantmakers. Doe the grantees' eligibilit	es the organization ma y for the grants or ass	intain records to istance, and the	substantiate the amount of its selection criteria used to award	grants and other assistants or assistants	istance, ance? X Yes No
2 For grantmakers. Desc United States.	ribe in Part V the organi	zation's procedure	es for monitoring the use of its gr	ants and other assistan	ce outside the
3 Activities per Region.	(The following Part I,	line 3 table can t	pe duplicated if additional spac	e is needed.) PART	V
(a) Region	<b>(b)</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 (d) is a program service, describe specific type of service(s) in the region	expenditures for and investments in the region
(1) BELGIUM			GRANTS	MEDICAL RESEARCH	53,563.
(2) FRANCE			GRANTS	MEDICAL RESEARCH	99,450.
(3) ITALY	,		GRANTS	MEDICAL RESEARCH	76,970.
(4) SWITZERLAND			GRANTS	MEDICAL RESEARCH	37,500.
5) FRANCE			GRANTS	MEDICAL RESEARCH	77,500.

GRANTS

GRANTS

(12)(13)

(14)(15)

(17)3 a Sub-total 465,760.

**b** Total from continuation sheets to Part I...... c Totals (add lines 3a and 3b). 0 0 465,760.

MEDICAL RESEARCH

MEDICAL RESEARCH

32-0067668

CYSTINOSIS RESEARCH FOUNDATION

Schedule F (Form 990) 2017 CYSTINOSIS RESEARCH FOUNDATION

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)
(0)		BELGIUM	MEDICAL	53, 563.	CHECK			
(Z)		FRANCE	MEDICAL RESEARCH	45,777. CHECK	CHECK			
6		PDANCE	MEDICAL	75 000 CHECK	XJahJ			
		TOWER	MEDICAL					
(4)		FRANCE	RESEARCH MEDICAL RESEARCH	77,500. CHECK	CHECK			
(9)		ITALY	MEDICAL	76,970. CHECK	CHECK			
0		SWITZERLAND	MEDICAL RESEARCH	37,500.	CHECK			
9								
(6)								
(10)								
E								
(12)								
(13)		arrange to						
(14)								
(15)								
(16)								
	tions listed above that a section 501(c)(3) ec	are recognized as ch juivalency letter	narities by the foreign	gn country, recogniz	ed as tax-exempt b	y the IRS, or for wh	:	9 ,
3 Enter total number of other organizations or entitles	ions or entitles		ALCONO CONTROL				Schedule F	Schedule F (Form 990) 2017

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.

.,1		opaco de la companya					
(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)			_				
9							
(8)							
(9)							a
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							
BAA						Schedule F (Form 990) 2017	Orm 990\ 2017

Schedule F (Form 990) 2017

		-0067668	Page 4
Pa	rt IV Foreign Forms		
. 1	Was the organization a U.S. transferor of property to a foreign corporation during the tax year? If 'Yes,' the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926).	Yes	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 Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A; do not file with Form 990)	Yes	X No
3	Did the organization have an ownership interest in a foreign corporation during the tax year? If 'Yes,' the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect To Certai Foreign Corporations (see Instructions for Form 5471)	n <sub>s</sub> []Yes	X No
4	Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? If 'Yes,' the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621)		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 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865).	Yes	X No
6	Did the organization have any operations in or related to any boycotting countries during the tax year?  If 'Yes,' the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; do not file with Form 990)	Yes	X No
BAA	TEEA3505L 08/10/17	Schedule F (F	orm 990) 2017

Page 5

#### 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) UNIVERSITE CATHOLIQUE DE LOUVAIN MEDICAL SCIENCES, BRUSSELS, BELGIUM
- (2) UNIVERSITY OF PARIS DESCARTES, 245 RUE DES SAINT-PERES, 75006 PARIS, FRANCE
- (3) BAMBINO GESU HOSPITAL, PIAZZA S. ONOFRIA 4, 00165 ROME, ITALY
- (4) UNIVERSITY HOSPITAL, ZURICH, SWITZERLAND
- (5) HOSPITAL NECKER, PARIS, FRANCE
- (6) CENTRE NATIONAL DE LA RECHERCHE SCIENTIFIC (CRNS), VILLEJUIF, FRANCE
- (7) ACS INSERM DELEGATION, 2 RUE D'ALESIA, 75014 PARIS, FRANCE

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

Department of the Treasury Internal Revenue Service

## Supplemental Information Regarding Fundraising or Gaming Activities

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

► Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

2017

Open to Public Inspection

Name of the organization Employer identification number CYSTINOSIS RESEARCH FOUNDATION 32-0067668 Fundraising Activities. Complete if the organization answered 'Yes' on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part. Indicate whether the organization raised funds through any of the following activities. Check all that apply. Solicitation of non-government grants Mail solicitations e а Internet and email solicitations Solicitation of government grants b Phone solicitations Special fundraising events C In-person solicitations 2 a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees, or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?..... b If 'Yes,' list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization. (v) Amount paid to (vi) Amount paid to (iii) Did fundraiser (i) Name and address of individual (iv) Gross receipts (or retained by) (ii) Activity have custody or control (or retained by) or entity (fundraiser) from activity fundraiser listed in of contributions? organization column (i) Yes No 1 2 3 4 5 6 7 8 9 10 0... List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.

Sche	edule	G (Form 990 or 990-EZ) 2017 CYSTING	SIS RESEARCH F	OUNDATION	32-00	167668 Page 2
		Fundraising Events. Complete if more than \$15,000 of fundraising List events with gross receipts gro	the organization ar	nswered 'Yes' on Fo	orm 990, Part IV, I	ine 18, or reported
R E V		` `	(a) Event #1  ANNUAL FUNDRAI  (event type)	(b) Event #2	(c) Other events  NONE  (total number)	(d) Total events (add column (a) through column (c))
N E	1	Gross receipts	3,004,235.			3,004,235
E	2	Less: Contributions	3,004,235.			3,004,235
	3	Gross income (line 1 minus line 2)				
	4	Cash prizes				
	5	Noncash prizes.				
D I R E C T	6	Rent/facility costs				
- 1	7	Food and beverages.				
X P	8	Entertainment				
EXPEZSES	9	Other direct expenses				
	11	Direct expense summary. Add lines 4 thr Net income summary. Subtract line 10 fro <b>Gaming.</b> Complete if the organiza \$15,000 on Form 990-EZ, line 6a.	om line 3, column (d) tion answered 'Yes		·····	
REVENUE			(a) Bingo	<b>(b)</b> Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add column (a) through column (c))
E	1	Gross revenue				
_	2	Cash prizes				
E D X I P R E	3	Noncash prizes.				
E N C S T E S	4	Rent/facility costs				
	5	Other direct expenses				
	6	Volunteer labor	Yes%	Yes%	Yes %	
	7	Direct expense summary. Add lines 2 thro	ough 5 in column (d)		NEEDERS	
	8	Net gaming income summary. Subtract lii	ne 7 from line 1, colum	n (d)		
а	Is th	er the state(s) in which the organization co e organization licensed to conduct gaming	nducts gaming activitie activities in each of th	s:	aserasas aserasas	. Yes No
10 a	Were	e any of the organization's gaming licenses	s revoked, suspended,	or terminated during the	e tax year?	Yes No

Sch	edule G (Form 990 or 990-EZ) 2017	CYSTINOSIS RESEAF	RCH FOUNDATION	32	-0067668	Page 3
11	Does the organization conduct gam	ing activities with nonmem	bers?		Yes	No
12	Is the organization a grantor, beneficial administer charitable gaming?	ary or trustee of a trust, or a	member of a partnership or other e	entity formed to	Yes	No
13	Indicate the percentage of gaming acti	ivity conducted in:		Ĩ		
	a The organization's facility				13a	%
	An outside facility				13b	8
14	Enter the name and address of the pe	rson who prepares the organ	ization's gaming/special events bo	oks and records:		
	Name •					
	Address					<del>-</del>
15:	a Does the organization have a contra	act with a third party from	whom the organization receives	gaming revenue	? <b>Yes</b>	□No
1	of 'Yes,' enter the amount of gaming	g revenue received by the	organization► \$	and the	e amount	Ш
	of gaming revenue retained by the	third party ► \$				
•	If 'Yes,' enter name and address of	the third party:				
	Name •		· <b></b>		~	
	Address >	·			<b></b>	
16	Gaming manager information:					
	Name ►		<b></b>			
				·		
	Gaming manager compensation >	9	•			
	Description of services provided >					
	Director/officer	Employee	Independent contractor			
17	Mandatory distributions:					
a	Is the organization required under state state	e law to make charitable dist	ributions from the gaming proceeds	s to retain the		
ŀ	Enter the amount of distributions requi	red under state law to be dis	tributed to other exempt organization	ons or spent in th	Yes	No
	organization's own exempt activities			5.10 5. op 5.11 m. t.		
Par	and Part III, lines 9, 9b, information, See instruc	10b, 15b, 15c, 16, ar	nations required by Part I nd 17b, as applicable. Also	, line 2b, colu provide any	ımns (iii) and ( additional	v);
	information. See instruc	dons.				
BAA		TEEA	3703L 09/18/17	Schedule C	(Form 990 or 99	0-EZ) 2017

# SCHEDULE I

Department of the Treasury Internal Revenue Service Name of the organization

Grants and Other Assistance to Organizations, Governments, and Individuals in the United States

Complete if the organization answered 'Yes' on Form 990, Part IV, line 21 or 22. ► Attach to Form 990.

2017

OMB No. 1545-0047<sup>-</sup>

Open to Public Inspection

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

CYSTINOSIS RESEARCH FOUNDATION

Employer identification number 32-0067668 2

X Yes

# Part I General Information on Grants and Assistance

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

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

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

	(a) Name and address of organization or government	(b) EiN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
THE SCRIPES RESERREGE INSTITUTE   Second   Sec	(1) UNIVERSITY OF CALLFORNIA, SD 9500 GILMAN DRIVE, DEPT 0935_							MEDICAL
THE SCRIPPS RESERRCH INSTITUT  10550 N. TORREY PINES ROAD  10650 N. TORREY PINES ROAD  1070 WELCH RO 4304  1070 WELCH RO 5034  107	LA JOLLA, CA 92093	95-6006144		31,448.	0.			RESEARCH
1939   N. 1976   1976		8						
BOARD OF TRISTEES, LELAND STA   100   WILLIAM   100   WILLIA		33-0435954		37 500	C			MEDICAL
PALCO ALTO, CA 94304	(3) BOARD OF TRUSTEES, LELAND STA							TOTOTOTO
94-1156365       37,500.       0.         04-1564655       48,064.       0.         94-6060626       192,791.       0.         33-0435954       75,000.       0.         74-1613878       69,095.       0.         53-0199180       37,500.       0.	700 WELCH RD #301N							MEDICAL
04-1564655       48,064.       0.         94-6060626       192,791.       0.         33-0435954       75,000.       0.         74-1613878       69,095.       0.         53-0199180       37,500.       0.	PALO ALTO, CA 94304	94-1156365		37,500.	0.			RESEARCH .
64-1564655     48,064.     0.       94-6060626     192,791.     0.       33-0435954     75,000.     0.       74-1613878     69,095.     0.       53-0199180     37,500.     0.	(4) MASSACHUSETTS GENERAL HOSPITA							
64-1564655     48,064.     0.       94-606026     192,791.     0.       33-0435954     75,000.     0.       74-1613878     69,095.     0.       53-0199180     37,500.     0.								MEDICAL
192,791.     0.       192,791.     0.       33-0435954     75,000.     0.       74-1613878     69,095.     0.       53-0199180     37,500.     0.	BOSTON, MA 02199	04-1564655		48,064.	0.			RESEARCH
-     94-6060626     192,791.     0.       -     33-0435954     75,000.     0.       -     74-1613878     69,095.     0.       -     53-0199180     37,500.     0.	1 1 1 1 1							
192,791.     0.       33-0435954     75,000.     0.       74-1613878     69,095.     0.       53-0199180     37,500.     0.	VE MC 0934							MEDICAL
33-0435954 75,000. 0. 74-1613878 69,095. 0.	LA JOLLA, CA 92093	94-6060626		192,791.	0.			RESEARCH
33-0435954     75,000.     0.       74-1613878     69,095.     0.       53-0199180     37,500.     0.	(6) THE SCRIPPS RESEARCH INSTITUT							
33-0435954     75,000.     0.       74-1613878     69,095.     0.       53-0199180     37,500.     0.	10550_N. TORREY_PINES_RD							MEDICAL
- 74-1613878 69,095. 0. - 53-0199180 37,500. 0.	LA JOLLA, CA 92307	33-0435954		75,000.	0.			RESEARCH
- 74-1613878 69,095. 0. - 53-0199180 37,500. 0.	(7) BAYLOR COLLEGE OF MEDICINE							
53-0199180 69,095. 0.	6565 FANNIN NC205							MEDICAL
 53-0199180 37,500. 0.		74-1613878		.69,095	0.			RESEARCH
53-0199180 37,500. 0.								
OSTON, MA 02115 53-0199180 37,500. 0.	1							MEDICAL
		53-0199180		37,500.	0			RESEARCH

Schedule I (Form 990) (2017)

TEEA3901L 08/10/17

3 Enter total number of other organizations listed in the line 1 table..... BAA For Paperwork Reduction Act Notice, see the Instructions for Form 990.

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

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.

in a real control of the control of			The second secon		
(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
					,
2					35
ET.					
4					
5					
9					
7					
Part IV Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.	le the information	required in Part I.	line 2: Part III, co	lumn (b): and any othe	er additional information.

3AA

TEEA3902L 11/03/16

# Continuation Sheet for Schedule I (Form 990)

ō Continuation Page 1 ► Attach to Form 990 to list additional information for Schedule I (Form 990), Part II and Part III.

N of the contaction						Employer identification number	tion number
Name of the organization  CYSTINDATION	NO					32-0067668	Ø
Part III Continuation of Grants and Other Assistance to Domestic Organizations and Domestic Governments. (Schedule   (Form 990), Part III.)	Other Assistan	ce to Domestic	Organizations and	i Domestic Govern	Iments. (Schedul	e I (Form 990), F	art II.)
(a) Name and address of organization or government	( <b>b)</b> EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non- cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
UNIVERSITY OF PITTSBURGH SCHO	11-3708851		77,742.				MEDICAL RESEARCH
	81-1567704		76, 950.				MEDICAL RESEARCH
1 1 1			-				
							,
			TEEA4001L 08/10/17			Schedule	Schedule I Cont (Form 990) 2017

### **SCHEDULE L** (Form 990 or 990-EZ)

### **Transactions With Interested Persons**

► Complete if the organization answered Yes, on Form 990, Part IV, line 25a, 25b, 26, 27, 28a, 28b, or 28c, or Form 990 EZ, Part V, line 38a or 40b.

► Attach to Form 990 or Form 990 EZ.

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

OMB No. 1545-0047 2017

Open To Public

Departmen Internal Re	t of the Treasury venue Service	► G	o to <i>www.irs.</i> g	ov/Form	n990 for	instru	ctions and th	e latest informa	ation.		0	pen 1 Insp	o Put ection	ilic
Name of th	e propinization:	T M, member a content of book		le MFF -		de acceptable o			Employer	identific	ation n	umber		
CYSTI	NOSIS RESE	ARCH FOUN	DATION				A		32-00	6766	58			
Part I	Excess Be Complete if	enefit Trans the organization	actions (se on answered 'Y	ction 5 'es' on F	01(c)( orm 990	3), se 0, Part	ction 501 (c IV, line 25a c	c)(4), and 50 or 25b, or Form	1(c)(29) 990 EZ, P	organ	nizati line 4	ions 0b.	only)	
1	(a) Name of disqua	alified nerenn	(b) F		p between		ied	(e) Dogg	winten of term				(d) Co	rrected
л	(a) Name or disqua	amed person		person a	and organiz	ation		(c) Desc	cription of tran	saction			Yes	No
(1)														
(2)														
(3)														
(4)														
(5)														
(6)														
sec	Complete if t	of tax, if any, o	n line 2, above Interested answered 'Yes	e, reimb Perso s' on For	ursed by ns. rm 990-E	the o	rganization.	*******		. ►s				
(a) Name	of interested person	man and the same and	(c) Purpose of loan	(d) Lo	oan to or m the ization?		(e) Original ncipal amount	(f) Balance du	e (g) In	default?	by bo	proved ard or hiltee?	(i) W agree	ritten ment?
				То	From	1			Yes	No	Yes	No	Yes	No
(f)		,									100		103	-10
(2)				1									-	_
(3)														
(4)														
(5)				1										
(6)														
(7)														
(8)														
(9)														
(10)														
Total , , .			-7				and the second second		4 44	201	No.			
Part III	Grants or Complete if t	Assistance he organization	Benefiting lanswered 'Yes	Interes on For	sted Pe m 990, F	erson Part IV,	<b>s.</b> line 27.							
	(a) Name of interes	sted person	(b) Relationship and	between the organ	interested p ization	person	(c) Amount o	f assistance (	(d) Type of ass	sistance	(e) F	Purpose	of assi	stance
(1)											7			
(2)														
(3)														
(4)														
(5)														
(6)														
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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)

### Supplemental Information to Form 990 or 990-EZ

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

> Attach to Form 990 or 990-EZ.

► Attach to 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 - "NATALIE'S WISH"

NATALIE'S WISH, 'TO HAVE MY DISEASE GO AWAY FOR EVER' - THOSE SEVEN WORDS PROVIDED

THE INSPIRATION TO ESTABLISH THE CYSTINOSIS RESEARCH FOUNDATION (CRF) IN 2003. WE

KNEW AT THAT MOMENT THAT WE NEEDED TO MAKE EVERY EFFORT TO MAKE NATALIE'S WISH - AND

THE WISHES OF OTHERS WITH CYSTINOSIS - A REALITY.

### RESEARCH

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

### RESEARCH GIVES US HOPE

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

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

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

WE ARE PLEASED TO ANNOUNCE THAT IN SPRING 2017 CRF ISSUED 8 NEW GRANTS TOTALING MORE THAN \$1.55 MILLION FOR CYSTINOSIS RESEARCH. THE NEW GRANTS BRING US THAT MUCH CLOSER TO BETTER TREATMENTS AND A CURE.

CRF HAS ISSUED GRANTS TO THE BEST AND BRIGHTEST RESEARCHERS IN THE WORLD. TO DATE, WE HAVE FUNDED 159 MULTI-YEAR RESEARCH STUDIES AT LEADING RESEARCH INSTITUTIONS IN 12 COUNTRIES. CRF-FUNDED RESEARCHERS HAVE PUBLISHED MORE THAN 69 ARTICLES IN PRESTIGIOUS, TOP-RATED JOURNALS. THOSE ARTICLES, AVAILABLE TO EVERYONE IN THE WORLD, HAVE ADDED TO THE UNDERSTANDING OF THE PATHOGENESIS OF CYSTINOSIS.

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

### NANOTECHNOLOGY AND CORNEAL CYSTINOSIS

WE ARE DEDICATED TO FINDING BETTER TREATMENTS FOR CORNEAL CYSTINOSIS. CORNEAL

CYSTINOSIS IS THE BUILD-UP OF CYSTINE CRYSTALS IN THE EYES THAT CAUSES PHOTOPHOBIA

(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

Employer identification number

### 32-0067668

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

DROPS. FOR MANY, COMPLIANCE IS DIFFICULT.

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

IN 2016, CRF FORMED CORNEAL CYSTINOLYSIS, INC., (CCI) RENAMED NAOWAFER, INC., FOR THE PURPOSE OF RESEARCH AND DEVELOPMENT OF A NANOWAFER TREATMENT FOR CORNEAL CYSTINOSIS.

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 DISEASES, KIDNEY DISEASES AND GENETIC AND SYSTEMIC DISEASES SIMILAR TO CYSTINOSIS. SUPPORT FOR CYSTINOSIS RESEARCH HAS REACHED FAR BEYOND THE CYSTINOSIS COMMUNITY. A CURE FOR CYSTINOSIS WILL HELP FIND CURES FOR OTHER DISEASES POTENTIALLY HELPING MILLIONS OF PEOPLE.

Employer identification number

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

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 2017, 56 FAMILIES FROM AROUND THE WORLD GATHERED ALONG WITH CRF FUNDED

RESEARCHERS TO SHARE STORIES, HOPES AND DREAMS AND BUILD LIFE-LONG FRIENDSHIPS.

LEADING CYSTINOSIS RESEARCHERS SHARED THEIR PROGRESS ON GENE AND STEM CELL THERAPIES,

NOVEL EYE RESEARCH AND NEUROLOGICAL CHALLENGES RELATED TO CYSTINOSIS. THE CONFERENCE

ALLOWS FAMILIES TO LEARN MORE ABOUT THE ONGOING CYSTINOSIS RESEARCH AND THE HOPE IT

BRINGS TO OUR COMMUNITY.

CURE CYSTINOSIS INTERNATIONAL REGISTRY

THE CURE CYSTINOSIS INTERNATIONAL REGISTRY (CCIR) WAS LAUNCHED IN 2010 AND NOW HAS APPROXIMATELY 576 CYSTINOSIS PATIENTS REGISTERED FROM 44 COUNTRIES. THE CYSTINOSIS RESEARCH FOUNDATION IN PARTNERSHIP AND COLLABORATION WITH THE CYSTINOSIS FOUNDATION AND TWELVE OTHER CYSTINOSIS FAMILY FOUNDATIONS FROM AROUND THE WORLD, ESTABLISHED THIS COMPREHENSIVE, GLOBAL PATIENT REGISTRY FOR CYSTINOSIS. THE CCIR QUESTIONNAIRE WAS DEVELOPED BY MEDICAL AND SCIENTIFIC EXPERTS SPECIFICALLY FOR THE CYSTINOSIS COMMUNITY. TO IMPROVE ACCESSIBILITY, THE CCIR HAS BEEN TRANSLATED INTO SPANISH, PORTUGUESE, DUTCH AND FRENCH. IT IS OUR MISSION TO REGISTER EVERY PERSON WITH CYSTINOSIS, THUS CONNECTING THEM TO THE RESEARCH COMMUNITY IN AN EFFORT TO FIND A CURE FOR CYSTINOSIS. THE CCIR IS A CENTRAL HUB OF INFORMATION AND IS AN ESSENTIAL TOOL FOR THE GLOBAL CYSTINOSIS RESEARCH COMMUNITY. WE ARE CERTAIN THAT THE

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

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
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) Department of the Treasury Internal Revenue Service

Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

Related Organizations and Unrelated Partnerships

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

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

2017

OMB No. 1545-0047

Open to Public Inspection

Employer identification number

32-0067668

Partil 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 entity	(b) Primary activity		(c) Legal domicile (state or foreign country)	(d) Total income	(e) End-of-year assets		(f) Direct controlling entity
					en e		
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Part II Identification of Related Tax-Exempt Organizations. Complete if the organization answered 'Yes' on Form 990, Part IV, line 34, because it had one or more related tax-exempt organizations during the tax year.	nizations. Complete	if the organizati ax year.	on answered	Yes' on Form 99	30, Part IV,	line 34, beca	iuse it
(a) Name, address, and EIN of related organization	(b) Primary activity	(c) Legal domicile (state or foreign country)	te Exempt Code section	de Public charity status (if section 501(c)(3))	- Caran	(f) Direct controlling entity	(g) Sec 512(b)(13) controlled entity?
							Yes No
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BAA For Paperwork Reduction Act Notice, see the Instructions for Form 990.	s for Form 990.		TEEA5001L 11/29/17	71/6		Schedule R	Schedule R (Form 990) 2017

32-0067668

Schedule R (Form 990) 2017 CYSTINOSIS RESEARCH FOUNDATION

Partil 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.

Under Sections 512-514)  Yes. No.	(a) Name, address, and EIN of related organization	(b) Primary activity	(C) Legal domicile (state or	(d) Direct controlling entity	F 5 8	(f) The Share of total d, income	,	(g) Share of end-of-year assets	(h) Disproportionate allocations?	Code V-UBI amount in box s? 20 of Schedule	General or managing e partner?	or Percentage
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and the second of the second o	•	3		(e)		9	Ξ	8
Name, address, and EIN of related organization Primary activity	Primary activity	Legal domicile (state or foreign	Direct	Type of entity (C corp, S corp,	Share of total income	Share of end-of- Pe	f- Percentage S ownership co	Sec 512(b)(13) controlled entity?
		country)		or trust)		, des		Yes No
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32-0067668

Schedule R (Form 990) 2017 CYSTINOSIS RESEARCH FOUNDATION

Party 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 school ite			The state of the s
T During the tax year, did the progning the majority transmission with			Yes No
a Receipt of (1) interest, (ii) annuities, (iii) royalties or (iii) ro	listed in Parts II-IV?		
b Giff, grant, or capital contribution to related organization(s)	世界の大田田町を中の日の日の日の日の日の日の日の日の日の日の日の日の日の日の日の日の日の日の日	四年五年 医非常 医甲形形形形形形 化医乳形形形形形形	Ta X
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g Sale of assets to related organization(s) is a position of the second organization or the second organization orga	一年 (本) 日 (本	· · · · · · · · · · · · · · · · · · ·	
h Purchase of assets from related organization(s)	医多种性性 医线性 医线性 医甲基甲基甲基甲基甲基甲基甲基甲基甲基甲基甲基甲基甲基甲基甲基甲基甲基甲基甲基	化二十二十二十二十二十二十二十二十二十二十二十二十二十二十二十二十二十二十二十	
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k Lease of facilities, equipment, or other assets from related organization(s):			
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o Sharing of paid employees with related organization(s).		4	1
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q Reimbursement paid by related organization(s) for expenses		(中)中有(中)中国的人的人的人的人的人的人的人的人的人的人的人的人的人的人的人的人的人的人的人	2 7
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Z If the answer to any of the above is 'Yes,' see the instructions for information on who must complete this line, including covered relationships and transaction thresholds.	ed relationships and tran	saction thresholds.	4
(a) Name of related organization	(b) Transaction	(c)	(b)
	type (a-s)	Altiouni ilivoived	wethod of determining amount involved
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Schedule R (Form 990) 2017 CYSTINOSIS RESEARCH FOUNDATION

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

Page 4

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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 reventle) that was not a related organization. See instructions regarding exclusion for certain investment partnerships.

Name address (a)	9	9	(9)	9	9					
Name, address, and Env of entity		Legal domicile (state or foreign country)	Predominant income (related, unre- lated, excluded	Are all partners section 501(c)(3) organizations?	Share of total income	(9) Share of end-of-year assets	Oisproportionate tionate allocations?	Code V-UBI amount in box 20 of Schedule	General or managing partner?	Percentage ownership
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Schedule R (Form 990) 2017 CYSTINOSIS RESEARCH FOUNDATION 32-006766

Part VII | Supplemental Information.

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

12/31/17

## 2017 FEDERAL BOOK SUMMARY DEPRECIATION SCHEDULE

PAGE 1

**CLIENT 3745** 

### CYSTINOSIS RESEARCH FOUNDATION

32-0067668

10	DESCRIPTION	DATE <u>ACQUIRED</u>	DATE SOLD	COST/ BASIS	BUS. PCT.	CUR 179/ SDA	PRIOR 179/ SDA/ DEPR.	_METHOD_	LIFE.	CURRENT DEPR.
ORM	990/990-PF									
MAC	CHINERY 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
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	TOTAL DEPRECIATION			56,838		0	56,821		8	0
	GRAND TOTAL DEPRECIATION	,		56,838		0	56,821			0

12/31/17	8	017 F	EDER,	AL B	00 X	DEP	2017 FEDERAL BOOK DEPRECIATION SCHEDULE	TION	SCHE	DULE				PAGE 1
CLIENT 3745			٥	YSTIN	IOSIS F	RESEAF	CYSTINOSIS RESEARCH FOUNDATION	NDATIO	Z					32-0067668
NO. DESCRIPTION	DATE ACQUIRED	DATE SOLD	COST/ BASIS	BUS.	CUR 179 BONUS	SPECIAL DEPR. ALLOW.	PRIOR 179/ BONUS/ SP. DFPR.	PRIOR DEC. BAL DEPR.	SALVAG /BASIS REDUCT	DEPR. BASIS	PRIOR DEPR.	METHOD	METHOD LIEE RÅTE	CURRENT DEPR.
FORM 990/990-PF MACHINERY AND EQUIPMENT							<u>.</u>					,		
1 SOFTWARE	4/30/08		12,038				•			12.038	12.038	5	_	C
2 WEBSITE	9/01/08		27,275							27,275	27,275		. 10	0
	6/30/08		7,875							7,875	7,875		5	0
4 WEBSITE	10/01/10	30	9,650	1						9,650	9,633	S/L	rs.	0
TOTAL MACHINERY AND EQUIPME			56,838		0	0	0	0	0	56,838	56,821			0
7. TOTAL DEPRECIATION		c #	56,838	1		0		0		56,838	56,821			0
GRAND TOTAL DEPRECIATION		а	56,838	I	0	0	0	0	0	56,838	56,821			0

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## FEDERAL SUPPLEMENTAL INFORMATION

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**CLIENT 3745** 

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

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

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

NOTE (1) - SCHEDULE L - PART IV

NOTE (1)
DIRECTOR DONALD SOLSBY'S WIFE, ZOE SOLSBY, IS A CONSULTANT TO THE FOUNDATION. MRS.
SOLSBY RECEIVED COMPENSATION OF APPROXIMATELY \$27,000 FOR THE SIX MONTHS ENDED JUNE
30,2017.

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.