Form	99	0
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F	m 9 9	90	I		Ĩ	OMB No. 1545-0047
FOR			Return of Organization Exempt From Inc			2020
Depa Inter	artment mal Rev	t of the Treasury venue Service	Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except ► Do not enter social security numbers on this form as it may be ma ► Go to www.irs.gov/Form990 for instructions and the latest in	de public.		Open to Public Inspection
Α	For t	he 2020 calendar	year, or tax year beginning $7/01$, 2020, and endin		,	20 2021
В	Check	if applicable: C		D Employ	er identi	fication number
	A		STINOSIS RESEARCH FOUNDATION	32-	0067	668
	N		200 VON KARMAN AVENUE #920	E Telepho	one numb	ber
	Ir	hitial return	VINE, CA 92612	949	-223	-7610
	Fi	nal return/terminated				
	_	mended return		G Gross r		
	A	pp in the provide s	Name and address of principal officer:	H(a) Is this a group retur		103 110
<u> </u>	Так		ME AS C ABOVE 501(c)(3) 501(c) () ◄ (insert no.) 4947(a)(1) or 527	H(b) Are all subordinates If "No," attach a list	See ins	tructions
<u> </u>]			501(c)(3) 501(c) () ◄ (insert no.) 4947(a)(1) or 527 CYSTINOSISRESEARCH.ORG	H(c) Group exemption nu	imbor 🕨	
ĸ			Corporation Trust Association Other ► L Year of format			egal domicile: CA
_	art I	Summary		2003		
	1	Briefly describe t	the organization's mission or most significant activities: SEE SCHEI	DULE O		
a						
anc						
Governance	_	Check this box	if the organization discontinued its operations or disposed of mo			
g	2		g members of the governing body (Part VI, line 1a)		1 as:	21
ి ర			endent voting members of the governing body (Part VI, line 1b)		4	21
Activities &	5		individuals employed in calendar year 2020 (Part V, line 2a)		5	1
ctiv	6		volunteers (estimate if necessary)ousiness revenue from Part VIII, column (C), line 12		6 7a	5
A			siness taxable income from Form 990-T, Part I, line 11		7a 7b	0.
				Prior Year	/5	Current Year
	8	Contributions an	d grants (Part VIII, line 1h)		320.	3,658,065.
Revenue	9	0	revenue (Part VIII, line 2g)			-,,
eve	10		ne (Part VIII, column (A), lines 3, 4, and 7d)		504.	151,448.
œ	11		Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		0.4	2 000 512
	12 13		add lines 8 through 11 (must equal Part VIII, column (A), line 12) ar amounts paid (Part IX, column (A), lines 1-3)	=, = = = ;		3,809,513.
	14		or for members (Part IX, column (A), line 4)	=/===/=	.25.	2,791,861.
	15		ompensation, employee benefits (Part IX, column (A), lines 5-10)		35	67,912.
ses	16.2		draising fees (Part IX, column (A), line 11e)			57, 512.
Expenses	.0a					
Ĕ	17		expenses (Part IX, column (D), line 25)		30	611 067
	18	•	Add lines 13-17 (must equal Part IX, column (A), line 25)			<u>611,067.</u> 3,470,840.
	19	•	penses. Subtract line 18 from line 12	0/002/0		338,673.
r Se	-		······································	Beginning of Currer		End of Year
iets i lanc	20		rt X, line 16)	9,847,6		10,349,578.
Net Assets Fund Balanc	21	Total liabilities (F	Part X, line 26)	2,297,9		1,867,136.
Pet	22	Net assets or fur	nd balances. Subtract line 21 from line 20	7,549,7	24.	8,482,442.
Pa	art II	Signature E	Block			
Unde	er pena	Ities of perjury, I declare	e that I have examined this return, including accompanying schedules and statements, and to other than officer) is based on all information of which preparer has any knowledge.	the best of my knowledge	and belie	ef, it is true, correct, and
COIII	picie. L		earch and oncer is based on an information of which preparel has any knowledge.			

	Circuit we of officer			N=4-			
Sign Here	Signature of officer		Date				
Here	GEOFFREY STACK		TRUSTEE				
	Type or print name and title						
	Print/Type preparer's name	Preparer's signature	Date	Check	if PTIN		
Paid	PETER MONTGOMERY			self-employed		209820	
Preparer Use Only	Firm's name MONTGOMERY, (
Use Only	Firm's address > 23801 CALABA	Firm's EIN ► 954489850					
	CALABASAS, CA	Phone no. 8	318-999	9-6967			
May the IRS	discuss this return with the preparer	shown above? See instructions			Х	Yes	No
BAA For Paperwork Reduction Act Notice, see the separate instructions. TEEA0101L 01/19/21 F						Form 990	(2020)

			ESEARCH FOUNDA			32-006766	58	Ρ	age 2
Pa			1 Service Accomp		: 111				Х
1		be the organization's							<u>A</u>
	<u>SEE_SCHE</u>	DULE 0							
2	-	-			h were not listed on the pric			_	
							Yes	Х	No
3		ibe these new services		ant changes in how it o	onducts, any program ser	vices?	Yes	Х	No
5		ibe these changes on			onducts, any program ser		103	Λ	no
4	Describe the	organization's progra	m service accomplish	ments for each of its th	ree largest program servi	ces, as measure	ed by e	expen	ses.
	and revenue,	if any, for each prog	ram service reported.	red to report the arriour	t of grants and allocation	s to others, the	total e	kpens	ses,
	<i>(</i>)					<u> </u>			
4 8	a (Code:		2,980,093.	including grants of \$	2,791,881.)(R	evenue >)
	<u>SEE_SCHEI</u>								·
							:		
									·
									·
41	o (Code:) (Expenses 💲	5	including grants of \$) (R	evenue \$)
							:		
									· -
							:		
	(Q			· · · · · · · · · · · · · · · · · · ·		<u> </u>			
40	c (Code:) (Expenses \$		including grants of \$) (R	evenue Ş)
									·
									·
							·		
4 0		n services (Describe							
	(Expenses	\$	including gran) (Revenue \$)	
40	e Total program	n service expenses	► 2,980	,093.			F a 11/10	000	(2020)

Pa	rt IV Checklist of Required Schedules			
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If 'Yes,' complete Schedule A.	1	Yes X	No
2	Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> See instructions?	2	X	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If 'Yes,' complete Schedule C, Part I.	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? <i>If 'Yes,'</i> 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? <i>If 'Yes,' complete Schedule D, Part IV</i> .	9		Х
10	Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi endowments? If 'Yes,' complete Schedule D, Part V.	10		Х
11	If the organization's answer to any of the following questions is 'Yes', then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.			
ä	a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If 'Yes,' complete Schedule D. Part VI	11 a	х	
I	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
(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
	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
(e Did the organization report an amount for other liabilities in Part X, line 25? If 'Yes,' complete Schedule D, Part X	11 e		Х
1	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
I	b Was the organization included in consolidated, independent audited financial statements for the tax year? If 'Yes,' and if the organization answered 'No' to line 12a, then completing Schedule D, Parts XI and XII is optional	12b		Х
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If 'Yes,' complete Schedule E	13		Х
14 a	a Did the organization maintain an office, employees, or agents outside of the United States?	14a		Х
I	b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If 'Yes,' complete Schedule F, Parts I and IV</i>	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? <i>If 'Yes,' complete Schedule F, Parts II and IV</i>	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 (A), lines 6 and 11e? <i>If 'Yes,' complete Schedule G, Part I</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
20a	Did the organization operate one or more hospital facilities? If 'Yes,' complete Schedule H	20a		Х
Ł	If 'Yes' to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b		
21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If 'Yes,' complete Schedule I, Parts I and II.</i>	21	Х	

Form 990 (2020)

Form 990 (2020)	CYSTINOSIS	RESEARCH	FOUNDATION

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Form 990 (2020) CYSTINOSIS RESEARCH FOUNDATION

Pa	rt IV	Checklist of Required Schedules (continued)			
				Yes	No
22	Did ti colur	he organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, nn (A), line 2? If 'Yes,' complete Schedule I, Parts I and III	22		Х
23	and f	ne organization answer 'Yes' to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current ormer officers, directors, trustees, key employees, and highest compensated employees? <i>If 'Yes,' complete edule J</i>	23		Х
24	the la	ne organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of ast day of the year, that was issued after December 31, 2002? <i>If 'Yes,' answer lines 24b through 24d and</i> olete Schedule K. If 'No, 'go to line 25a	24a		Х
I	,	he organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
		ne organization maintain an escrow account other than a refunding escrow at any time during the year to defease tax-exempt bonds?	24c		
	,	he organization act as an 'on behalf of' issuer for bonds outstanding at any time during the year?	24d		
25	a Secti	ion 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit			
	trans	action with a disqualified person during the year? If 'Yes,' complete Schedule L, Part I	25a		Х
l	that t	e organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If 'Yes,' complete edule L, Part I	25b		Х
26	Did t forme or fai	he organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current or er officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity mily member of any of these persons? <i>If 'Yes,' complete Schedule L, Part II</i>	26		Х
27	empl mem	he organization provide a grant or other assistance to any current or former officer, director, trustee, key loyee, creator or founder, substantial contributor or employee thereof, a grant selection committee uber, or to a 35% controlled entity (including an employee thereof) or family member of any of these ons? If 'Yes,' complete Schedule L, Part III.	27		Х
28	Was f instru	the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV uctions, for applicable filing thresholds, conditions, and exceptions):			
i		rrent or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If ,' complete Schedule L, Part IV	28a		Х
I	b A far	nily member of any individual described in line 28a? If 'Yes,' complete Schedule L, Part IV	28b		Х
	c A 35 Yes,	% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? <i>If</i> ' <i>complete Schedule L, Part IV</i>	28c		Х
29	Did t	he organization receive more than \$25,000 in non-cash contributions? If 'Yes,' complete Schedule M	29		Х
30	Did t contr	he organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation 'ibutions? <i>If 'Yes,' complete Schedule M</i>	30		Х
31	Did t	he organization liquidate, terminate, or dissolve and cease operations? If 'Yes,' complete Schedule N, Part I	31		Х
32	Did th Sche	ne organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If 'Yes,' complete edule N, Part II.	32		Х
33		ne organization own 100% of an entity disregarded as separate from the organization under Regulations sections 7701-2 and 301.7701-3? <i>If 'Yes,' complete Schedule R, Part L</i>	33		Х
	and I	the organization related to any tax-exempt or taxable entity? If 'Yes,' complete Schedule R, Part II, III, or IV, Part V, line 1	34	Х	
35	a Did t	he organization have a controlled entity within the meaning of section 512(b)(13)?	35a	Х	
	b If 'Ye entity	es' to line 35a, did the organization receive any payment from or engage in any transaction with a controlled y within the meaning of section 512(b)(13)? If 'Yes,' complete Schedule R, Part V, line 2	35b		Х
36	Secti orgar	ion 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related nization? If 'Yes,' complete Schedule R, Part V, line 2	36		Х
37	Did th treate	he organization conduct more than 5% of its activities through an entity that is not a related organization and that is ed as a partnership for federal income tax purposes? <i>If 'Yes,' complete Schedule R, Part VI</i>	37		Х
38	Note	ne organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? : All Form 990 filers are required to complete Schedule O	38	Х	
Pa		Statements Regarding Other IRS Filings and Tax Compliance			
	(Check if Schedule O contains a response or note to any line in this Part V			
1	a Ento	r the number reported in Box 3 of Form 1096. Enter -0- if not applicable 1a 8		Yes	No
		r the number of Forms W-2G included in line 1a. Enter -0- if not applicable			
		he organization comply with backup withholding rules for reportable payments to vendors and reportable gaming bling) winnings to prize winners?	1 c		
BAA	1	TEEA0104L 10/07/20	Form	990 ((2020)

Form 990 (2020)

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Form 990 (2020) CYSTINOSIS RESEARCH FOUNDATION 32-0067668	}	F	Page 5
Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)			
		Yes	No
2a Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return 2a			
b If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b	Х	
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		Х
b If 'Yes,' has it filed a Form 990-T for this year? If 'No' to line 3b, provide an explanation on Schedule 0	3b		
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)?	4a		Х
b If 'Yes,' enter the name of the foreign country►			
See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).			
5 a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5 a		Х
b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5 b		Х
c If 'Yes,' to line 5a or 5b, did the organization file Form 8886-T?	5 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?	6 a		Х
b If 'Yes,' did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6 b		
7 Organizations that may receive deductible contributions under section 170(c).			
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?	7 a		X
b If 'Yes,' did the organization notify the donor of the value of the goods or services provided?	7 b		
c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7 c		Х
d If 'Yes,' indicate the number of Forms 8282 filed during the year 7d			
e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7 e		Х
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7 f		Х
g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7 g		
h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7 h		
8 Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?	8		
9 Sponsoring organizations maintaining donor advised funds.			
a Did the sponsoring organization make any taxable distributions under section 4966?	9 a		
b Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9 b		
10 Section 501(c)(7) organizations. Enter:			
a Initiation fees and capital contributions included on Part VIII, line 12 10a			
b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities 10 b			
11 Section 501(c)(12) organizations. Enter:			
a Gross income from members or shareholders 11 a			
b Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.).			
12 a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a		
b If 'Yes,' enter the amount of tax-exempt interest received or accrued during the year 12b			
13 Section 501(c)(29) qualified nonprofit health insurance issuers.	10		
 a Is the organization licensed to issue qualified health plans in more than one state? Note: See the instructions for additional information the organization must report on Schedule O. 	13a		
 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. 13b 			
c Enter the amount of reserves on hand			-
14a Did the organization receive any payments for indoor tanning services during the tax year?	14a		Х
b If 'Yes,' has it filed a Form 720 to report these payments? <i>If 'No,' provide an explanation on Schedule O</i>	14b		
15 Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year?	15		Х
If 'Yes,' see instructions and file Form 4720, Schedule N.			-
16 Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If 'Yes,' complete Form 4720, Schedule O.	16		X
	-		(2020)

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Part VI	Governance, Management, and Disclosure For each 'Yes' response to lines 2 through 7b below, and for
	a 'No' response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on
	Schedule O. See instructions.
	Check if Schedule O contains a response or note to any line in this Part VI
Section /	A. Governing Body and Management

					Yes	No
1	a Enter the number of voting members of the governing body at the end of the tax year If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain on Schedule O.	1a	21			
	b Enter the number of voting members included on line 1a, above, who are independent	1 b	21			
	Did any officer, director, trustee, or key employee have a family relationship or a business relationship	nip with		2	Х	
3		e direct	supervision	3		х
4	Did the organization make any significant changes to its governing documents			<u> </u>		
	since the prior Form 990 was filed?			4		Х
5	Did the organization become aware during the year of a significant diversion of the organizat	ion's as	sets?	5		Х
6	Did the organization have members or stockholders?			6		Х
7	a Did the organization have members, stockholders, or other persons who had the power to elect or ap members of the governing body?			7 a		Х
	b Are any governance decisions of the organization reserved to (or subject to approval by) mer stockholders, or persons other than the governing body?			7 b		Х
8	the following:	0				
	a The governing body?			8 a	Х	
	b Each committee with authority to act on behalf of the governing body?			8 b	Х	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cann organization's mailing address? <i>If 'Yes,' provide the names and addresses on Schedule Q</i>			9		Х
Se	ction B. Policies (This Section B requests information about policies not requ	uired i	by the Internal Re	evenu	e Cc	ode.)
			<i>,</i>		Yes	No
10	a Did the organization have local chapters, branches, or affiliates?			10 a		Х
	b If 'Yes,' did the organization have written policies and procedures governing the activities of such chapters, affiliates, a					
	operations are consistent with the organization's exempt purposes?			10 b		
	a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the f			11 a	Х	
	b Describe in Schedule O the process, if any, used by the organization to review this Form 990	· SE	E SCHEDULE O			
12	a Did the organization have a written conflict of interest policy? If 'No,' go to line 13			12a	Х	
	b Were officers, directors, or trustees, and key employees required to disclose annually interests that of to conflicts?					
	• Did the organization regularly and consistently monitor and enforce compliance with the policy? If 'V			12 b	Х	
	c Did the organization regularly and consistently monitor and enforce compliance with the policy? <i>If 'Y Schedule O how this was done</i> SEE. SCHEDULE . Q		cribe in	12b 12c	Х	
	Did the organization have a written whistleblower policy?	′es,' des 			X X	
	Did the organization have a written whistleblower policy?	′es,' des 		12c	Х	
13 14 15	 Did the organization have a written whistleblower policy? Did the organization have a written document retention and destruction policy? Did the process for determining compensation of the following persons include a review and approval persons, comparability data, and contemporaneous substantiation of the deliberation and destruction and destruction of the deliberation and destruction of the deliberation and destruction and destruction of the deliberation and destruction destructi	es,' des	ependent	12c 13	X X	
13 14 15	 Did the organization have a written whistleblower policy? Did the organization have a written document retention and destruction policy? Did the process for determining compensation of the following persons include a review and approva persons, comparability data, and contemporaneous substantiation of the deliberation and decarbox a The organization's CEO, Executive Director, or top management official 	es,' des	ependent	12c 13	X X	
13 14 15	 Did the organization have a written whistleblower policy? Did the organization have a written document retention and destruction policy? Did the process for determining compensation of the following persons include a review and approval persons, comparability data, and contemporaneous substantiation of the deliberation and destruction and destruction of the deliberation and destruction of the deliberation and destruction and destruction of the deliberation and destruction destructi	es,' des	ependent	12c 13 14	X X	X X X
13 14 15	 Did the organization have a written whistleblower policy? Did the organization have a written document retention and destruction policy? Did the process for determining compensation of the following persons include a review and approva persons, comparability data, and contemporaneous substantiation of the deliberation and decarbox a The organization's CEO, Executive Director, or top management official 	es,' des	ependent	12c 13 14 15a	X X	
13 14 15	 Did the organization have a written whistleblower policy? Did the organization have a written document retention and destruction policy? Did the process for determining compensation of the following persons include a review and approva persons, comparability data, and contemporaneous substantiation of the deliberation and dec a The organization's CEO, Executive Director, or top management official	és,' des	ependent ement with a	12c 13 14 15a	X X	
13 14 15 16	 Did the organization have a written whistleblower policy? Did the organization have a written document retention and destruction policy? Did the process for determining compensation of the following persons include a review and approvations, comparability data, and contemporaneous substantiation of the deliberation and decemporaneous substantiation of the deliberation and decemporaneous substantiation of the deliberation and decemporaneous for the organization's CEO, Executive Director, or top management official	'es,' des	ependent ement with a uard the	12c 13 14 15a 15b 16a	X X	Х
13 14 15 16	 Did the organization have a written whistleblower policy? Did the organization have a written document retention and destruction policy? Did the process for determining compensation of the following persons include a review and approval persons, comparability data, and contemporaneous substantiation of the deliberation and decompensation's CEO, Executive Director, or top management official	'es,' des	ependent ement with a uard the	12c 13 14 15a 15b	X X	Х
13 14 15 16 <u>Sec</u>	 Did the organization have a written whistleblower policy? Did the organization have a written document retention and destruction policy? Did the process for determining compensation of the following persons include a review and approval persons, comparability data, and contemporaneous substantiation of the deliberation and decompensation's CEO, Executive Director, or top management official	'es,' des	ependent ement with a uard the	12c 13 14 15a 15b 16a	X X	Х
13 14 15 16 <u>Sec</u> 17	 Did the organization have a written whistleblower policy? Did the organization have a written document retention and destruction policy? Did the process for determining compensation of the following persons include a review and approvations, comparability data, and contemporaneous substantiation of the deliberation and deciberation and deciberation's CEO, Executive Director, or top management official	es,' des'	ependent ement with a uard the	12c 13 14 15a 15b 16a 16b	X X	X
13 14 15 16 <u>Sec</u>	 Did the organization have a written whistleblower policy? Did the organization have a written document retention and destruction policy? Did the process for determining compensation of the following persons include a review and approvations, comparability data, and contemporaneous substantiation of the deliberation and deciberations, comparability data, and contemporaneous substantiation of the deliberation and deciberation's CEO, Executive Director, or top management official	es,' des'	ement with a uard the and 990-T (Section 50	12c 13 14 15a 15b 16a 16b	X X	X
13 14 15 16 <u>Sec</u> 17	 Did the organization have a written whistleblower policy? Did the organization have a written document retention and destruction policy? Did the process for determining compensation of the following persons include a review and approvations, comparability data, and contemporaneous substantiation of the deliberation and deciberations, comparability data, and contemporaneous substantiation of the deliberation and deciberation's CEO, Executive Director, or top management official	es,' des'	ependent ement with a uard the	12c 13 14 15a 15b 16a 16b	X X	X
13 14 15 16 <u>See</u> 17 18	 Did the organization have a written whistleblower policy? Did the organization have a written document retention and destruction policy? Did the process for determining compensation of the following persons include a review and approvate persons, comparability data, and contemporaneous substantiation of the deliberation and decemporaneous substantiation	er (expla	ependent ement with a uard the and 990-T (Section 50 ain on Schedule O) financial statements availa	12 c 13 14 15 a 15 b 16 a 16 b	X X	X

20 State the name, address, and telephone number of the person who possesses the organization's books and records ►

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Er Independent Contractors	nnlovees 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 an endine of the organization of the orga								

ons), reg ga compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.

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

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

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

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

See instructions for the order in which to list the persons above.

ſ

Х 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	Pos thar is	s both	an o	officer truste	eck more ss persor and a ee)	Reportable compensation from	(E) Reportable compensation from	(F) Estimated amount of other
		per week (list any hours for related organiza- tions below dotted line)	Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated	the organization (W-2/1099-MISC)	related organizations (W-2/1099-MISC)	compensation from the organization and related organizations
(1)	NANCY J. STACK	40								
	CHAIR - TRUSTEE	0	Х		Х			0.	0.	0.
_(2)	GEOFFREY_STACK	0								
	VICE CHAIR-TTEE	0	Х		Х			0.	0.	0.
(3)	DONALD L. SOLSBY TREASURER - TTE	<u>2_</u>	Х		Х			0.	0.	0.
(4)	MARCU ALEXANDER	0								<u>.</u>
`'_	TRUSTEE		Х					0.	0.	0.
(5)	STEPHANIE CHERQUI, PHD	0								
`'_	TRUSTEE		Х					0.	0.	0.
(6)	BRUCE CRAIR	0								
	TRUSTEE	0	Х					0.	0.	0.
_(7)	JILL EMERSON, CPA	0								
	TRUSTEE	0	Х					0.	0.	0.
(8)	DENICE FLERCHINGER	0								
	TRUSTEE	0	Х					0.	0.	0.
(9)	THOMAS A GENDRON	0								
	TRUSTEE	0	Х					0.	0.	0.
(10)	TRACI GENDRON	0								
	TRUSTEE	0	Х					0.	0.	0.
(11)	JOHN S HAGESTAD	0								
	TRUSTEE	0	Х					0.	0.	0.
(12)	LAUREN HARTZ	0								
	TRUSTEE	0	Х					0.	0.	0.
(13)	MICHAEL K HAYDE	0								
	TRUSTEE	0	Х					0.	0.	0.
(14)	STEPHEN L. JENKINS	0								
	TRUSTEE	0	Х					0.	0.	0.
BAA		TEEA0	107L	10/07	/20					Form 990 (2020)

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Part VII Section A. Officers, Directors, Tru	istees,	Key	Em	plo	bye	es,	and	d Highest Com	pensated Emp	loyees	(continued)
	(B)			(C	•						
(A) Name and title	Average hours per week	box offic	not ch , unles cer and	ss pe d a d	erson directe	is botl pr/trus	h an tee)	(D) Reportable compensation from the organization	(E) Reportable compensation from related organizations	C	(F) ated amount of other
	(list any hours for related	Individual trustee or director	Institutional trustee	Officer	Key employee	Highest Imploye	Former	(W-2/1099-MISC)	(W-2/1099-MISC)	the o	nsation from rganization d related anizations
	organiza - tions	otor	onalt		ploye	e e				orge	
	below dotted line)	istee	rustee		ð	Highest compensated employee					
(15) ERIN_LITTLE		v							0		0
TRUSTEE (16) DAVID W. MOSSMAN	0	Х						0.	0.		0.
TRUSTEE	0	Х						0.	0.		0.
(17) KEVIN PARTINGTON TRUSTEE	0	х						0.	0.		0.
(18) TERESA PARTINGTON	0	Λ						0.	0.		0.
TRUSTEE	0	Х						0.	0.		0.
(19) NATALIE STACK TRUSTEE	0 0	х						0.	0.		
(20) BRIAN STURGIS	0	Λ					-	0.	0.		0.
TRUSTEE	0	Х						0.	0.		0.
(21) BARBARA KULYK	0										
TRUSTEE	0	Х						0.	0.		0.
(23)											
(24)											
(25)											
1 b Subtotal	<u> </u>	<u> </u>					•	0.	0.		0.
c Total from continuation sheets to Part VII, Section	on A							0.	0.		0.
d Total (add lines 1b and 1c).							►	0.	0.		0.
2 Total number of individuals (including but not limited	to those I	isted	abov	ve) v	vho	recei	ved	more than \$100,00	0 of reportable comp	ensatio	n
from the organization ► 0											
											Yes No
3 Did the organization list any former officer, direc on line 1a? If 'Yes,' complete Schedule J for suc										. 3	X
4 For any individual listed on line 1a, is the sum of	f reportab	le co	mper	nsa	tion	and	oth	er compensation	from		
the organization and related organizations greate such individual										. 4	Х
5 Did any person listed on line 1a receive or accru for services rendered to the organization? If 'Yes	e comper s,' comple	nsatio ete So	n fro chedu	om a ule	any <i>J fo</i>	unre <i>r suc</i>	late ch p	ed organization or	individual	. 5	X
Section B. Independent Contractors											
1 Complete this table for your five highest compen compensation from the organization. Report compen											
(A) Name and business add	ress							(B) Description (of services	(Compe	C) Insation
								,			
2 Total number of independent contractors (including b	out not lim	ited t/	h tho	ا م	istor	laho		who received more	than		
\$100,000 of compensation from the organization			2 0103	30 II	13100	4 UUU	ve)				

Form 990 (2020) CYSTINOSIS RESEARCH FOUNDATION

Part VIII Statement of Revenue

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	Check if Schedule O contains a response or note to any	line in this Part VI	11		
		(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514
nts nts	1 a Federated campaigns 1 a				
Gra	b Membership dues 1b				
Contributions, Gifts, Grants and Other Similar Amounts	c Fundraising events1c1,557,259.d Related organizations1d				
nilar nilar	e Government grants (contributions) 1e				
Sins,	f All other contributions, gifts, grants, and				
iti e	similar amounts not included above 1f 2,100,806.				
₫₽	g Noncash contributions included in lines 1a-1f				
Con	h Total. Add lines 1a-1f.	3,658,065.			
	Business Code	0,000,0001			
Program Service Revenue	2a				
Å	b				
vice	¢				
Sei	d				
ram	f All other program service revenue				
rog	g Total. Add lines 2a-2f				
<u> </u>	3 Investment income (including dividends, interest, and				
	other similar amounts)	123,546.	123,546.		
	4 Income from investment of tax-exempt bond proceeds ►				
	5 Royalties				
	(i) Real (ii) Personal				
	6a 6a b Less: rental expenses 6b				
	c Rental income or (loss) 6c				
	d Net rental income or (loss)				
	7 a Gross amount from (i) Securities (ii) Other				
	sales of assets				
	other than inventory 7a 27,902. b Less: cost or other basis				
	and sales expenses 7b				
	c Gain or (loss) 7c 27,902.				
	d Net gain or (loss)►	27,902.	27,902.		
ne	8 a Gross income from fundraising events (not including \$ 1,557,259.				
Ven	of contributions reported on line 1c).				
Be	See Part IV, line 18				
Other Revenue	b Less: direct expenses 8b				
₹	c Net income or (loss) from fundraising events►				
	9 a Gross income from gaming activities.				
	See Part IV, line 19				
	b Less: direct expenses 9b c Net income or (loss) from gaming activities ►				
	10a Gross sales of inventory, less returns and allowances				
	b Less: cost of goods sold				
	c Net income or (loss) from sales of inventory►				
S	Business Code				
ରୁ ଶ	11a				
lan ent	b				
es cel					
Miscellaneous Revenue	d All other revenue				
	12 Total revenue. See instructions.	3,809,513	151,448	0	0

Form 990 (2020) 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 re	1	(B)	(C)	(D)
Do I 6b,	not include amounts reported on lines 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	Program service expenses	Management and general expenses	Fundraising expenses
1	Grants and other assistance to domestic				
	organizations and domestic governments. See Part IV, line 21	1,836,012.	1,836,012.		
2	Grants and other assistance to domestic	1,050,012.	1,030,012.		
-	individuals. See Part IV, line 22				
3	Grants and other assistance to foreign organizations, foreign governments, and for- eign individuals. See Part IV, lines 15 and 16	955,849.	955,849.		
4	Benefits paid to or for members				
5	Compensation of current officers, directors, trustees, and key employees	0.	0.	0.	
6	Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	0.	0.	0.	
7	Other salaries and wages	63,207.	1,540.	58,652.	3,01
, 8	Pension plan accruals and contributions (include section 401(k) and 403(b)	03,207.	1,540.	56,052.	5,01
~	èmployer contributions)				
9	Other employee benefits	4 505			
0 1	Payroll taxes Fees for services (nonemployees):	4,705.		4,474.	23
	ı Management				
	Accounting	04 207	2 000	70 (74	01
		84,387.	3,900.	79,674.	81
	Professional fundraising services. See Part IV, line 17				
	Investment management fees				
g	Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule 0.)				
2	Advertising and promotion.	121,753.	10,315.		111,43
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				
0	Interest				
1	Payments to affiliates				
2	Depreciation, depletion, and amortization	17,888.		17,888.	
3	Insurance	11,027.		11,027.	
1	Other expenses. Itemize expenses not covered above (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
ā	MAGAZINE	137,697.	68,343.		69,35
	OUTSIDE SERVICES	92,275.	66,825.	16,500.	8,95
	PRINTING AND PUBLICATIONS	44,725.		835.	43,89
	RENTAL EXPENSE	38,542.	8,817.	24,143.	5,58
	All other expenses	62,773.	28,492.	21,268.	13,01
5	Total functional expenses. Add lines 1 through 24e	3,470,840.	2,980,093.	234,461.	256,28
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 ► if following				
٩A	SOP 98-2 (ASC 958-720)	TEEA01101 10	107.000		Form 990 (202
. –		TEE A01101 10	(1) (2) (2)		

Form 990 (2020) CYSTINOSIS RESEARCH FOUNDATION Part X Balance Sheet

		Check if Schedule O contains a response or note to any line in this Part X			
			(A) Beginning of year		(B) End of year
	1	Cash – non-interest-bearing		1	
	2	Savings and temporary cash investments.	5,984,805.	2	5,968,759.
	3	Pledges and grants receivable, net	912,433.	3	600,684.
	4	Accounts receivable, net		4	
	5	Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		5	
	6	Loans and other receivables from other disqualified persons (as defined under		5	
	0	section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7	Notes and loans receivable, net.		7	
S	8	Inventories for sale or use.		8	
Assets	9	Prepaid expenses and deferred charges	49,556.	9	89,502.
As	-		49,000.		05,502.
	IUa	Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D			
	b	Less: accumulated depreciation 10b 91,409.	88,677.	10 c	70,788.
	11	Investments – publicly traded securities.	2,812,223.	11	3,619,845.
	12	Investments – other securities. See Part IV, line 11		12	, ,
	13	Investments – program-related. See Part IV, line 11		13	
	14	Intangible assets.		14	
	15	Other assets. See Part IV, line 11		15	
	16	Total assets. Add lines 1 through 15 (must equal line 33)	9,847,694.	16	10,349,578.
	17	Accounts payable and accrued expenses	16,405.	17	17,794.
	18	Grants payable	2,281,565.	18	1,849,342.
	19	Deferred revenue		19	
	20	Tax-exempt bond liabilities		20	
es	21	Escrow or custodial account liability. Complete Part IV of Schedule D		21	
Liabilities	22	Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		22	
	23	Secured mortgages and notes payable to unrelated third parties		23	
	24	Unsecured notes and loans payable to unrelated third parties		24	
	25	Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D.		25	
	26	Total liabilities. Add lines 17 through 25	2,297,970.	26	1,867,136.
ces		Organizations that follow FASB ASC 958, check here ► X and complete lines 27, 28, 32, and 33.			
an	27	Net assets without donor restrictions	7,549,724.	27	8,482,442.
Bal	28	Net assets with donor restrictions	1,345,124.	28	0,402,442.
Net Assets or Fund Balance		Organizations that do not follow FASB ASC 958, check here ►			
Т.	20	Capital stock or trust principal, or current funds		29	
ম	29 20	Paid-in or capital surplus, or land, building, or equipment fund.		29 30	
8	30 21	Retained earnings, endowment, accumulated income, or other funds			
As	31	Total net assets or fund balances		31	0 400 440
let	32 33	Total liabilities and net assets/fund balances.	7,549,724.	32	8,482,442.
BA			9,847,694.	33	10,349,578. Form 990 (2020)
DA	-				FUITI 990 (2020)

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Form 990 (20	20) CYSTINOSIS RESEARCH FOUNDATION 32-	00676	68	Pa	age 12
Part XI F	econciliation of Net Assets				
C	neck if Schedule O contains a response or note to any line in this Part XI.				. 🗌
1 Total re	venue (must equal Part VIII, column (A), line 12)	1	3,8	09.5	513.
2 Total ex	penses (must equal Part IX, column (A), line 25)	2			340.
3 Revenu	eless expenses. Subtract line 2 from line 1	3			573.
4 Net ass	ets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4			724.
5 Net unr	alized gains (losses) on investments.	5		-)45.
6 Donated	services and use of facilities	6		<u> </u>	
7 Investm	ent expenses	7			
8 Prior pe	riod adjustments	8			
9 Other c	anges in net assets or fund balances (explain on Schedule O)	9			0.
	ts or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32,	-			0.
	(B))	10	8,4	82,4	442.
Part XII F	inancial Statements and Reporting				
	neck if Schedule O contains a response or note to any line in this Part XII				
				Yes	
1 Accoun	ing method used to prepare the Form 990: Cash X Accrual Other		_	105	
If the or in Sche	panization changed its method of accounting from a prior year or checked 'Other,' explain Jule O.				
2 a Were th	e organization's financial statements compiled or reviewed by an independent accountant?		2a		Х
s <u>ep</u> arat	check a box below to indicate whether the financial statements for the year were compiled or reviewe basis, consolidated basis, or both: parate basis Consolidated basis Both consolidated and separate basis	ed on a			
b Were th	e organization's financial statements audited by an independent accountant?		2b	Х	
lf 'Yes,' basis, c	check a box below to indicate whether the financial statements for the year were audited on a separatonsolidated basis, or both:				
review,	b line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit or compilation of its financial statements and selection of an independent accountant?	, 	2c	Х	
on Sche					
	It of a federal award, was the organization required to undergo an audit or audits as set forth in the Single t and OMB Circular A-133?		3a		Х
	lid the organization undergo the required audit or audits? If the organization did not undergo the required auc s, explain why on Schedule O and describe any steps taken to undergo such audits		3b		
BAA	TEEA0112L 10/19/20		Form	990	(2020)

SCHEDULE A (Form 990 or 990-EZ)

Department of the Treasury

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.

2020
Open to Public Inspection

OMB No. 1545-0047

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

Internal													
	f the organization						Employer identifica						
Part	TINOSIS RESE			organizations must	comple	ote thi	32-006766 s.part.) See instruc						
				(For lines 1 through 12,									
1	<u> </u>	•		churches described in sec		-	•						
2				n Schedule E (Form 990 or									
3	A hospital or a	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												
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 in section 170												
8	A community	trust described	l in section 170(b)(1)	(A)(vi). (Complete Part	II.)								
9				ection 170(b)(1)(A)(ix) oper									
	or university or university:		0 0	re (see instructions). Enter		ne, city,	and state of the college of	pr					
10	An organizatio	on that normall	y receives (1) more	than 33-1/3% of its supp	oort from	n contrib	outions, membership fee	es, and gross receipts					
	from activities investment inc	related to its e ome and unre	exempt functions, su	bject to certain exception ble income (less section	ons; and	(2) no r	nore than 33-1/3% of it	s support from gross					
11				velv to test for public saf	etv. See	section	n 509(a)(4).						
12		5	· · [· · · · · · · · · ·	vely for the benefit of, to	,			it the nurnoses of one					
	or more public	lv supported o	rganizations describ	bed in section 509(a)(1) of supporting organization	or sectio	n 509(a)(2). See section 509(a)	(3). Check the box in					
а	Type I. A support organization(s) complete Part	the power to re	equiarly appoint or ele	ed, or controlled by its sup ct a majority of the directo	oported o rs or trus	rganizat tees of	ion(s), typically by giving the supporting organization	the supported on. You must					
b				controlled in connection	with its	support	ed organization(s), by	having control or					
	management of must complet	f the supporting e Part IV, Sect	organization vested i ions A and C.	n the same persons that c	ontrol or	manage	the supported organizati	on(s). You					
с				ation operated in connectio plete Part IV, Sections									
d	functionally initiation instructions).	nctionally integ tegrated. The o You must com	rated. A supporting or organization general plete Part IV, Section	ganization operated in con ly must satisfy a distribu ns A and D, and Part V.	nnection Ition req	with its s uiremen	supported organization(s) t and an attentiveness	that is not requirement (see					
е	Check this box	if the organiz	ation received a wri	tten determination from	the IRS	that it is	a Type I, Type II, Type	e III functionally					
				supporting organization									
			n about the support										
) Name of supported or	-	(ii) EIN	(iii) Type of organization	(iv)	s the	(v) Amount of monetary	(vi) Amount of other					
				(described on lines 1-10 above (see instructions))	organizat	ion listed overning	support (see instructions)	support (see instructions)					
					docur	nent?							
					Yes	No							
(A)													
(B)													
(C)													
<u>(D)</u>													
<u>(E)</u>													
Total													
	Fau Damanuaula Da		atter and the boots	ations for Form 000 or (00 57			m 000 or 000 EZ 2020					

Schedule A (Form 990 or 990-EZ) 2020 C	YSTINOSIS	RESEARCH	FOUNDATION
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Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi) (Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

	ndar year (or fiscal year nning in) ►	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
1	Gifts, grants, contributions, and membership fees received. (Do not include any 'unusual grants.)	4,818,959.	4,095,889.	5,347,869.	4,064,820.	3,658,065.	21,985,602.
2	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						0.
3	The value of services or facilities furnished by a governmental unit to the organization without charge						0.
4	Total. Add lines 1 through 3	4,818,959.	4,095,889.	5,347,869.	4,064,820.	3,658,065.	21,985,602.
5	The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						0.
6	Public support. Subtract line 5 from line 4						21,985,602.
Sec	tion B. Total Support						
	ndar year (or fiscal year nning in) ►	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
7	Amounts from line 4	4,818,959.	4,095,889.	5,347,869.	4,064,820.	3,658,065.	21,985,602.
8	Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	38,599.	86,549.	54,850.	243,604.	151,448.	575,050.
9	Net income from unrelated business activities, whether or not the business is regularly carried on						0.
10	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						0.
	Total support. Add lines 7 through 10						22,560,652.
12	Gross receipts from related activ	vities, etc. (see ins	structions)			12	0.
13	First 5 years. If the Form 990 is organization, check this box and						► 🗌
Sec	tion C. Computation of Pu	blic Support P	ercentage				
	Public support percentage for 20 Public support percentage from						97.45%
							97.76%
	33-1/3% support test–2020. If t and stop here. The organization	qualifies as a pul	olicly supported o	rganization			····· • X
b	33-1/3% support test-2019. If the and stop here. The organization	ne organization die I qualifies as a pu	d not check a box blicly supported o	on line 13 or 16a	a, and line 15 is 3	3-1/3% or more, o	check this box ·····►
17a	10%-facts-and-circumstances te or more, and if the organization the organization meets the facts	meets the facts-a	nd-circumstances	test, check this I	box and stop here	. Explain in Part	VI how
	10%-facts-and-circumstances te or more, and if the organization organization meets the 'facts-an	meets the facts-a d-circumstances'	nd-circumstances test. The organization	test, check this lation qualifies as	box and stop here a publicly support	Explain in Part ed organization.	VI how the
18	Private foundation. If the organi	zation did not che	ck a box on line	13, 16a, 16b, 17a	, or 17b, check th	is box and see in	structions 🕨
BAA					Sc	hedule A (Form 9	90 or 990-EZ) 2020

Schedule A (Form 990 or 990-EZ) 2020

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Part III Support Schedule for Organizations Described in Section 509(a)(2) (Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Sec	tion A. Public Support						
	lar year (or fiscal year beginning in) ►	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
1	Gifts, grants, contributions, and membership fees received. (Do not include any 'unusual grants.)						
2	Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3	Gross receipts from activities that are not an unrelated trade or business under section 513.						
4	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5	The value of services or facilities furnished by a governmental unit to the organization without charge						
	Total. Add lines 1 through 5 Amounts included on lines 1, 2, and 3 received from disqualified persons						
b	Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
с	Add lines 7a and 7b						
8	Public support. (Subtract line 7c from line 6.)						
Sec	tion B. Total Support				•		
Calen	dar year (or fiscal year beginning in) 🕨	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
	Amounts from line 6						
	Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
b	Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
с 11	Add lines 10a and 10b Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
	Total support. (Add lines 9, 10c, 11, and 12.)						
	First 5 years. If the Form 990 is organization, check this box and	stop here		third, fourth, or f	ifth tax year as a	section 501(c)(3)	►
-	tion C. Computation of Pu			10 1 (0	、		0
	Public support percentage for 20	•					00
-	Public support percentage from					16	0/0
	tion D. Computation of Inv					I I	
17	Investment income percentage f						00
18	Investment income percentage f						00
	33-1/3% support tests—2020. If is not more than 33-1/3%, check	this box and sto	p here. The orgar	nization qualifies a	as a publicly supp	orted organization	▶
	33-1/3% support tests - 2019. If i line 18 is not more than 33-1/3%	, check this box a	and stop here. Th	e organization qu	alifies as a public	ly supported organ	nization 🕨 🔄
20	Private foundation. If the organi	zation did not che	eck a box on line	14, 19a, or 19b, c	check this box and	I see instructions	••••••

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Part IV Supporting Organizations

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

Section A. All Supporting Organizations

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

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Part IV	Supporting Organizations (continued)			
			Yes	No
11 Has t	ne organization accepted a gift or contribution from any of the following persons?			
a A pers	a A person who directly or indirectly controls, either alone or together with persons described in lines 11b and 11c below,			
the g	overning body of a supported organization?	11a		
b A fan	ily member of a person described in line 11a above?	11b		

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

Section B. Type I Supporting Organizations

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

Section C. Type II Supporting Organizations

 Yes
 No

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

Section D. All Type III Supporting Organizations

th of the		
ing the prior tax		
y provided? 1		
supported		
zation(s). 2		
ve a significant e or assets at		
3		
y snzi ve	copies of the provided? 1 upported Part VI how ration(s). 2	copies of the provided? 1 upported Part VI how ration(s). 2 e a significant or assets at 1

Section E. Type III Functionally Integrated Supporting Organizations

- 1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).
 - a 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 governmental entity (see instructions).

2 Activities Test. Answer lines 2a and 2b below.

- a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? If 'Yes,' then in **Part VI identify those supported** organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.
- b Did the activities described in line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? If 'Yes,' explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.
- 3 Parent of Supported Organizations. Answer lines 3a and 3b 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? *If 'Yes' or 'No,' provide details in Part VI.*
- **b** Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If 'Yes,' describe in **Part VI** the role played by the organization in this regard.

Yes

2a

2b

3a

3h

No

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11c

1

2

Yes

No

Page 5

Schedule A (Form 990 or 990-EZ) 2020 CYSTINOSIS RESEARCH FOUNDATION Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

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Page 6

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

 Section A – Adjusted Net Income
 (A) Prior Year

 (B) Current Year (optional)

Section A – Adjusted Net Income		(A) Prior Year	(optional)
1 Net short-term capital gain	1		
2 Recoveries of prior-year distributions	2		
3 Other gross income (see instructions)	3		
4 Add lines 1 through 3.	4		
5 Depreciation and depletion	5		
6 Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6		
7 Other expenses (see instructions)	7		
8 Adjusted Net Income (subtract lines 5, 6, and 7 from line 4)	8		
ection B — Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1 Aggregate fair market value of all non-exempt-use assets (see instructions for sho tax year or assets held for part of year):	rt		
a Average monthly value of securities	1a		
b Average monthly cash balances	1b		
c Fair market value of other non-exempt-use assets	1c		
d Total (add lines 1a, 1b, and 1c)	1d		
e Discount claimed for blockage or other factors (explain in detail in Part VI):			
2 Acquisition indebtedness applicable to non-exempt-use assets	2		
3 Subtract line 2 from line 1d.	3		
4 Cash deemed held for exempt use. Enter 0.015 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 0.035.	6		
7 Recoveries of prior-year distributions	7		
8 Minimum Asset Amount (add line 7 to line 6)	8		
ection C – Distributable Amount			Current Year
1 Adjusted net income for prior year (from Section A, line 8, column A)	1		
2 Enter 0.85 of line 1.	2		
3 Minimum asset amount for prior year (from Section B, line 8, column A)	3		
4 Enter greater of line 2 or line 3.	4		
5 Income tax imposed in prior year	5		
6 Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6		
		T III I:	

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

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Schedule A (Form 990 or 990-EZ) 2020

Schedule A (Form 990 or 990-EZ) 2020	CYSTINOSIS	RESEARCH	FOUNDATION
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Pa	rt V Type III Non-Functionally Integrated 509(a)(3) Su			d)	
	tion D – Distributions		•		Current Year
1	Amounts paid to supported organizations to accomplish exempt pu	rposes		1	
2	Amounts paid to perform activity that directly furthers exempt purposes of in excess of income from activity	IS,	2		
3	Administrative expenses paid to accomplish exempt purposes of su		3		
4	Amounts paid to acquire exempt-use assets			4	
5	Qualified set-aside amounts (prior IRS approval required - provide	e details in Part VI)		5	
6	Other distributions (describe in Part VI). See instructions.			6	
	Total annual distributions. Add lines 1 through 6.			7	
8	Distributions to attentive supported organizations to which the organizati in Part VI). See instructions.	on is responsive (provide	details	8	
9	Distributable amount for 2020 from Section C, line 6			9	
10	Line 8 amount divided by line 9 amount			10	
Sec	tion E – Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributio Pre-2020	ons	(iii) Distributable Amount for 2020
1	Distributable amount for 2020 from Section C, line 6				
2	Underdistributions, if any, for years prior to 2020 (reasonable cause required – <i>explain in Part VI</i>). See instructions.				
3	Excess distributions carryover, if any, to 2020				
á	a From 2015				
	• From 2016				
	C From 2017				
	From 2018				
	e From 2019				
	f Total of lines 3a through 3e				
	g Applied to underdistributions of prior years				
	n Applied to 2020 distributable amount				
	i Carryover from 2015 not applied (see instructions)				
	j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.				
4	Distributions for 2020 from Section D, line 7: \$				
ć	a Applied to underdistributions of prior years				
-	Applied to 2020 distributable amount				
	Remainder. Subtract lines 4a and 4b from line 4.				
5	Remaining underdistributions for years prior to 2020, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, <i>explain in Part VI</i> . See instructions.				
6	Remaining underdistributions for 2020. Subtract lines 3h and 4b from line 1. For result greater than zero, <i>explain in Part VI</i> . See instructions.				
7	Excess distributions carryover to 2021. Add lines 3j and 4c.				
8	Breakdown of line 7:				
ć	Excess from 2016				
	Excess from 2017				
	Excess from 2018				
(Excess from 2019				
(Excess from 2020				

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Schedule A (Form 990 or 990-EZ) 2020

Schedule I	3
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or 990-PF)

(Form 990, 990-EZ,

Schedule	of	Contributors
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OMB No. 1545-0047

2020

► A	ttach to	Form 990,	Form 9	990-EZ,	or For	m 99 0- P	F.
Go	to www.	.irs.gov/Fo	rm990 ⁻	for the I	latest i	nformati	ion.

Department of the Treasury Internal Revenue Service Employer identification number Name of the organization CYSTINOSIS RESEARCH FOUNDATION 32-0067668 Organization type (check one): Filers of: Section: X 501(c)(3) Form 990 or 990-EZ (enter number) organization 4947(a)(1) nonexempt charitable trust not 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 private foundation 501(c)(3) taxable private foundation

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

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

General Rule

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

Special Rules

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

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

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

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

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

Schedule B (Form 990, 990-EZ, or 990-PF) (2020)	1 1	Page 2
Name of organization	Employer identification number	
CYSTINOSIS RESEARCH FOUNDATION	32-0067668	
Part I Contributors (see instructions). Use duplicate copies of Part Lif additional space is needed		

Farti	Contributors (see instructions). Use duplicate copies of Part 1 if additional s	pace is needed.	
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	GEOFFREY AND NANCY STACK		Person X
		\$ 600,000.	Payroll Noncash
		\$600,000.	(Complete Part II for
	NEWPORT BEACH, CA 92660	-	noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
2	THE ROBERT LA LOGGIA CHARITABLE FUN	_	Person X
	PO_BOX_9509	\$ 250,000.	Payroll Noncash
			(Complete Part II for
	WARWICK , RI 02889	-	noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
3	MAGISTRO FOUNDATION	_	Person X
	1480 E. SUNNY DUNES ROAD	\$ 315,000.	Payroll Noncash
	PALM SPRINGS, CA 92264		(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
			Person
		Ś	Payroll Noncash
		·	(Complete Part II for
		-	noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		_	Person
		\$	Payroll Noncash
			(Complete Part II for
		-	noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		_	Person
		\$	Payroll Noncash
			(Complete Part II for
		-	noncash contributions.)

Schedule B (Form 990, 990-EZ, or 990-PF) (2020)	1	1	Page 3
Name of organization		ification nur	nber
CYSTINOSIS RESEARCH FOUNDATION	32-0067668		

Part II Noncash Property (see instructions). Use duplicate copies of Part II if additional space is needed.

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

	B (Form 990, 990-EZ, or 990-PF) (2020)			1 1 Page 4						
Name of organ				Employer identification number						
	or (10) that total more than \$1,000 for t the following line entry. For organizations c contributions of \$1,000 or less for the year.	he year from any one contributo ompleting Part III, enter the total of (Enter this information once. See in	r. Complete	e columns (a) through (e) and v religious, charitable, etc						
(a) No. from	Use duplicate copies of Part III if additional (b) Purpose of gift	space is needed. (c) Use of gift		(d) Description of how gift is held						
No. from Part I		(0) 000 01 g		(4)						
	<u>N/A</u>		+							
			+							
		(e) Transfer of gift								
	Transferee's name, addres	s, and ZIP + 4	Relati	onship of transferor to transferee						
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift		(d) Description of how gift is held						
		e) Transfer of gift								
	Transferee's name, addres	Relationship of transferor to transferee								
(a) No. from Part I		(c) Use of gift		(d) Description of how gift is held						
		(e) Transfer of gift	+·							
	Transferee's name, addres	s, and ZIP + 4	Relati	onship of transferor to transferee						
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift		(d) Description of how gift is held						
			+							
	/a) Tuanafau af wift									
	(e) Transfer of gift Transferee's name, address, and ZIP + 4			onship of transferor to transferee						
BAA			Sched	ule B (Form 990, 990-EZ, or 990-PF) (2020)						

				OMB No. 1545-0047			
	HEDULE D rm 990)	► Complet	plemental Financial Statemer te if the organization answered 'Yes' on For	m 990.		2020	
•		Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b. ► Attach to Form 990.					
Interr	rtment of the Treasury al Revenue Service	► Go to www.irs	.gov/Form990 for instructions and the lates	t information.		Open to Public Inspection	ł
Name	of the organization				Employer id	dentification number	
CV	TUTNOCTO DEC	EADOU FOINDATTON			22 006	7669	
		EARCH FOUNDATION	or Advised Funds or Other Similar F	unds or Acc	32-006	1008	
I al	Complete	if the organization ans	wered 'Yes' on Form 990, Part IV, li	ne 6.	ountor		
			(a) Donor advised funds	(b) F	unds and	other accounts	
1		end of year					
2		ntributions to (during year)					
-	3 Aggregate value of grants from (during year)						
4	00 0	at end of year					
5	are the organizat	ion's property, subject to the	nor advisors in writing that the assets held ir organization's exclusive legal control?		· · · · · · · ·	Yes No	
6	for charitable pur	poses and not for the benefit	ors, and donor advisors in writing that grant t t of the donor or donor advisor, or for any ot	her purpose cor	nferring _]Yes □No	
Der	1 1		······		· · · · · · · L		
Pa		tion Easements.	wered 'Yes' on Form 990, Part IV, li	ne 7.			
1			y the organization (check all that apply).	-			
	Preservation of	of land for public use (for exam	ple, recreation or education)	vation of a histo	rically imp	ortant land area	
		natural habitat	Preser	vation of a certif	fied histori	c structure	
		of open space					
2	Complete lines 2a last day of the ta		held a qualified conservation contribution in the	form of a conserv	vation ease	ment on the	
	5	,		F	leld at the	End of the Tax Yea	ar
	-	-	ments.				
			fied historic structure included in (a)				
	structure listed in	the National Register	n (c) acquired after 7/25/06, and not on a hi	2 d			
3	Number of conserv tax year ►	vation easements modified, tran	nsferred, released, extinguished, or terminated l	by the organization	n during th	e	
4	Number of states v	where property subject to conse	ervation easement is located ►				
5	Does the organiz	ation have a written policy re	garding the periodic monitoring, inspection, nts it holds?	handling of viol	ations,	Yes No	
6			inspecting, handling of violations, and enforcing				
7	Amount of expens ►\$	es incurred in monitoring, inspe	ecting, handling of violations, and enforcing con	servation easeme	ents during	the year	
8	Does each conse and section 170(I	rvation easement reported on h)(4)(B)(ii)?	n line 2(d) above satisfy the requirements of	section 170(h)((4)(B)(i)	Yes No	
9	In Part XIII, desc include, if applica conservation eas	able, the text of the footnote	oorts conservation easements in its revenue to the organization's financial statements the	and expense states and expense states and expenses and the second states and the second states and the states a	atement a organizati	nd balance sheet, a on's accounting for	and r
Pa	t III Organiza Complete	tions Maintaining Colle	ections of Art, Historical Treasures, wered 'Yes' on Form 990, Part IV, li	or Other Sin ne 8.	ıilar Ass	ets.	
1:	historical treasure	es, or other similar assets he	r FASB ASC 958, not to report in its revenue Id for public exhibition, education, or resear al statements that describes these items.	e statement and ch in furtherance	balance s e of public	heet works of art, service, provide in	ı
l	historical treasures	n elected, as permitted unde s, or other similar assets held fo s relating to these items:	r FASB ASC 958, to report in its revenue sta or public exhibition, education, or research in fu	atement and bal rtherance of publ	ance shee ic service,	t works of art, provide the	
	••		line 1				
-	· ·				-		
2	amounts required	to be reported under FASB	nistorical treasures, or other similar assets for fi ASC 958 relating to these items: 1			lowing	
		n Form 990, Part VIII, line	· L		►\$		

BAA For Paperwork Reduction Act Notice, see the Instructions for Form 990.
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TEEA3301L 08/18/20

Schedule D (Form 990) 2020 CYST				32-006	
Part III Organizations Mainta	ining Collect	ions of Art, Histo	rical Treasures, or	Other Similar Ass	ets (continued)
3 Using the organization's acquisition items (check all that apply):	n, accession, and	other records, check ar	ny of the following that ma	ake significant use of its	collection
a Public exhibition		d 🗌 Loan d	or exchange program		
b Scholarly research		e Other			
c Preservation for future gene					
4 Provide a description of the organiz Part XIII.					
5 During the year, did the organiza to be sold to raise funds rather t					Yes No
Part IV Escrow and Custodia line 9, or reported an	amount on F	nts. Complete if tl orm 990, Part X, I	ne organization ans line 21.	swered 'Yes' on For	rm 990, Part IV,
1 a Is the organization an agent, tru on Form 990, Part X?	stee, custodian	or other intermediary	for contributions or othe	r assets not included	Yes No
b If 'Yes,' explain the arrangement				[
			5		Amount
c Beginning balance				1c	
d Additions during the year				1d	
e Distributions during the year				1e	
f Ending balance					
2 a Did the organization include an a	amount on Form	990, Part X, line 21,	for escrow or custodial a	account liability?	Yes No
b If 'Yes,' explain the arrangemen	t in Part XIII. Ch	eck here if the explan	ation has been provided	d on Part XIII	
Part V Endowment Funds.					
1 - Designing of year belongs	(a) Current yea	ar (b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1 a Beginning of year balance					
b Contributions					
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					
2 Provide the estimated percentag			e Ig, column (a)) held a	as:	
a Board designated or quasi-endown	ient 🕨 📃	ō			
b Permanent endowment ►					
c Term endowment ►	·0	al 100%			
The percentages on lines 2a, 2b, a	ina 2c snoula equ	al 100%.			
3 a Are there endowment funds not in	the possession of	the organization that a	re held and administered	for the	Vec No
organization by: (i) Unrelated organizations					Yes No 3a(i)
(ii) Related organizations					3a(ii)
b If 'Yes' on line 3a(ii), are the relation					3b
4 Describe in Part XIII the intende	-				50
Part VI Land, Buildings, and					
Complete if the organ		ered 'Yes' on Forn	n 990 Part IV line	11a See Form 99	0 Part X line 10
Description of property			1		
		Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1 a Land.					
b Buildings			0.07/	0.055	
c Leasehold improvements			8,874.	2,357.	6,517.
d Equipment			106,488.	75,871.	30,617.
e Other			46,835.	13,181.	33,654.
Total. Add lines 1a through 1e. (Colum	nn (d) must equa	ai ⊢orm 990, Part X, c	oiumn (B), line 10c.)		70,788.
BAA				Schedu	ule D (Form 990) 2020

Part VII	Investments – Other Securities.			
(-) D	Complete if the organization answered			
	iption of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of	-year market value
	al derivatives held equity interests			
(3) Other				
				<u> </u>
(A) (B)				
(<u>C)</u>				
(D)				
(E)				
(F)				
(G)				
(H)				
()				
Total. (Colum	n (b) must equal Form 990, Part X, column (B) line 12.) 🕨			
Part VIII	Investments – Program Related. Complete if the organization answered			
	(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end-	of-year market value
(1)				
(2)				
(3)				
(4)				
(5)				
(6)				
(7)				
(8) (9)				
(10)				
· ·	n (b) must equal Form 990, Part X, column (B) line 13.) 🕨			
Part IX	Other Assets. Complete if the organization answered			
), Part IV, line 11d. See Form 9	
(1)	(a) De	scription		(b) Book value
(1)				
(3)				,
(4)				
(5)				
(6)				
(7) (8)				
(9)				
(10)				
	umn (b) must equal Form 990, Part X, column (i	B) line 15.)	· · · · · · · · · · · · · · · · · · ·	
Part X	Other Liabilities.			
	Complete if the organization answered 'Yes' on F	form 990, Part IV, line 1	1e or 11f. See Form 990, Part X, line 25.	
1.		iption of liability		(b) Book value
(1) Feder (2)	al income taxes			
(3)				
(4)				
(5)				
(6)				
(7)				
(8)				
(9)				
(10)				
	n (b) must equal Form 990, Part X, column (B) line 25.)		▶	
· Jun (UUIUIII	(1, 1, 2) $(1, 1, 2)$ $(1, 1, 2)$ $(1, 1, 1)$ (2) $(1, 1)$ (2) $(1, 1)$ (2) $(1, 1)$ (2) $($			

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

Schedule D (Form 990) 2020 CYSTINOSIS RESEARCH FOUNDATION	32-0067668	Page 4
Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per	Return. N/A	
Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.		
1 Total revenue, gains, and other support per audited financial statements	1	
2 Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
a Net unrealized gains (losses) on investments 2a		
b Donated services and use of facilities		
c Recoveries of prior year grants		
d Other (Describe in Part XIII.)		
e Add lines 2a through 2d	2e	
3 Subtract line 2e from line 1	3	
4 Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
a Investment expenses not included on Form 990, Part VIII, line 7b 4a		
b Other (Describe in Part XIII.)		
c Add lines 4a and 4b		
5 Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.).	-	
Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses p		
Complete if the organization answered 'Yes' on Form 990, Part IV, line 12a.		
1 Total expenses and losses per audited financial statements		
2 Amounts included on line 1 but not on Form 990, Part IX, line 25:		
a Donated services and use of facilities		
b Prior year adjustments.		
c Other losses.		
d Other (Describe in Part XIII.)		
e Add lines 2a through 2d .	2e	
3 Subtract line 2e from line 1.		
Amounts included on Form 990, Part IX, line 25, but not on line 1:		
a Investment expenses not included on Form 990, Part VIII, line 75		
b Other (Describe in Part XIII.)		
c Add lines 4a and 4b	4c	
5 Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)		
Part XIII Supplemental Information.		

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

SCHEDULE	F
(Form 990)	

(9) FRANCE

(10) ITALY

(11)

(12)

(13)

(14)

(15)

(16)

(17)

3a Subtotal.

b Total from continuation sheets to Part I..... c Totals (add lines 3a and 3b).

SCHEDULE F Statement of Activities Outside the United States						OMB No. 1545-0047
(Form 990)	 Complete if the or 	rganization answer	red 'Yes' on Form 990, Part IV, lin ach to Form 990.	e 14b, 15, or 16.		2020
Department of the Treasury Internal Revenue Service	► Go to www.i		for instructions and the latest	information.		Open to Public Inspection
Name of the organization				Emp	oloyer identif	ication number
CYSTINOSIS RESEA	RCH FOUNDATION			32	-00676	68
Part I General Info	rmation on Activiti , Part IV, line 14b.	es Outside th	e United States. Comple	te if the org	anizatio	n answered 'Yes'
1 For grantmakers. Do the grantees' eligibili	es the organization ma ty for the grants or assi	intain records to stance, and the s	substantiate the amount of its selection criteria used to award	grants and oth the grants or	ier assista assistanci	nce, e?XYes No
2 For grantmakers. Des United States.	cribe in Part V the organi	zation's procedure	s for monitoring the use of its gra	ants and other a	ssistance	outside the
3 Activities per Region	. (The following Part I,	line 3 table can b	e duplicated if additional space	e is needed.)F	ART V	
(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity (d) is a pr service, de specific ty service(the reg	ogram escribe ype of s) in	(f) Total expenditures for and investments in the region
(1) BELGIUM			GRANTS	MEDICAL RE	SEARCH	5,500.
(2) BELGIUM			GRANTS	MEDICAL RE	SEARCH	46,174.
(3) ITALY			GRANTS	MEDICAL RE	SEARCH	75,000.
(4) SWITZERLAND			GRANTS	MEDICAL RE	SEARCH	290,000.
(5) NEW ZEALAND			GRANTS	MEDICAL RE	SEARCH	200,530.
(6) FRANCE			GRANT	MEDICAL RE	SEARCH	31,306.
(7) ITALY			GRANTS	MEDICAL RE	SEARCH	119,339.
(8) FRANCE			GRANTS	MEDICAL RE	SEARCH	108,000.

0

5,000.

75,000.

955,849.

MEDICAL RESEARCH

MEDICAL RESEARCH

0

GRANTS

GRANTS

32-0067668

Page 2

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

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book FMV, appraisal other)
				MEDICAL					
			FRANCE	RESEARCH	108,000.	CHECK			
				MEDICAL					
			FRANCE	RESEARCH	31,306.	CHECK			
				MEDICAL					
			FRANCE	RESEARCH	46,174.	CHECK			
				MEDICAL					
			FRANCE	RESEARCH	5,000.	CHECK			
				MEDICAL					
			FRANCE	RESEARCH	5,500.	CHECK			
				MEDICAL					
			ITALY	RESEARCH	119,339.	CHECK			
				MEDICAL	,				
			ITALY	RESEARCH	75,000.	CHECK			
				MEDICAL					
			ITALY	RESEARCH	75,000.	CHECK			
				MEDICAL	,				
			NEW ZEALAND	RESEARCH	200,530.	CHECK			
				MEDICAL	,				
			SWITZERLAND	RESEARCH	290,000.	CHECK			
				1202000	200,0001				
				+					
	Enter total number of recipient orga organization by the IRS, or for which								
3 E	Enter total number of other organiza	ations or entities						•••••••••••••••••	ŗ

Schedule F (Form 990) 2020 CYSTINOSIS RESEARCH FOUNDATION

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

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of noncash assistance	(g) Description of noncash assistance	(h) Method of valuation (book FMV, appraisal other)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							
BAA	•			·	·	Schedule F	(Form 990) 2020

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Page	4
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1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? If 'Yes,' the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926). □ Yes ▼ No 2 Did the organization have an interest in a foreign trust during the tax year? If 'Yes,' the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trusts with a U.S. Owner (see Instructions for Form 3520 and 3520-A; don't file with Form 990). □ Yes ▼ No 3 Did the organization have an ownership interest in a foreign corporation during the tax year? If 'Yes,' the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Corporations (see Instructions for Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Trust by a 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 5471, Information may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see		5		
 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; don't file with Form 990)	1	organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign	Yes	X No
 organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Corporations (see Instructions for Form 5471). Yes X No Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? If 'Yes,' the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621). Did the organization have an ownership interest in a foreign partnership during the tax year? If 'Yes,' the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865). Did the organization have any operations in or related to any boycotting countries during the tax year? If 'Yes,' the organization may be required to separately file Form 5713. International Boycott Report (see	2	required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S.	Yes	X No
 electing fund during the tax year? If 'Yes,' the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621). 5 Did the organization have an ownership interest in a foreign partnership during the tax year? If 'Yes,' the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865). 6 Did the organization have any operations in or related to any boycotting countries during the tax year? If 'Yes,' the organization may be required to separately file Form 5713. International Boycott Report (see	3	organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain	Yes	X No
 organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865)	4	electing fund during the tax year? If 'Yes,' the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see	Yes	X No
If 'Yes,' the organization may be required to separately file Form 5713. International Boycott Report (see	5	organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign	Yes	X No
	6	If 'Yes,' the organization may be required to separately file Form 5713, International Boycott Report (see	Yes	X No

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Schedule F (Form 990) 2020

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) HOSPICE CIVILS DE LYON, 3 QUAI DES CELESTINS, 69002 LYON, FRANCE
- (2) IMAGINE INSTITUTE GENETIC DISEASES, 24 BLVD DU MONTPARNASSE, 75015 PARIS, FRANCE
- (3) UNIVERSITY HOSPITAL, KUNSTLERGASSE 17, 8001 ZURICH, SWITZERLAND
- (4) BAMBINO GESU HOSPITAL, PIAZZA S. ONOFRIA 4, 00165 ROME, ITALY
- (5) INSTITUTE DE DUVE, 75 AVENUE HIPPOCRATE, BOX B1.75.20, BRUSSELS B-1200, BELGIUM
- (6) UNIVERSITY OF AUCKLAND, AUCKLAND 1010, NEW ZEALAND

32-0067668

	Suppleme	ental Informa	ition Reg	jarding F	undraising or Gami	ng Activities	OMB No. 1545-0047
SCHEDULE G (Form 990 or 990-EZ)	Comple	, or 19, or if the a.	2020				
Department of the Treasury Internal Revenue Service	► G	-	 Attach 	to Form 990	,000 on Form 990-EZ, line 6a or Form 990-EZ. ructions and the latest		Open to Public Inspection
Name of the organization						Employer identifie	
CYSTINOSIS RES			tion anow	arad 'Vac' a	on Form 990, Part IV, line	32-006766	58
Form 990-E2	Z filers are not re	quired to comp	lete this p	oart.			
	-	raised funds thi	rough any		owing activities. Check		
a Mail solicitatio				e			
	email solicitations	5		f	Solicitation of gove X Special fundraising	0	
c Phone solicita d In-person soli				y	A opecial fundraising		
		r oral agreement	t with any i	ndividual (i	including officers, directo	rs, trustees, or key	
employees listed	in Form 990, Par	t VII) or entity i	in connect	tion with p	rofessional fundraising	services?	
b If 'Yes,' list the To compensated at h	east \$5,000 by th	ividuals or enti- ne organization.	ties (fund	raisers) pl	ursuant to agreements u	under which the fundra	aiser is to be
(i) Name and addres	s of individual		(iii) Did	fundraiser	(iv) Gross receipts	(v) Amount paid to (or retained by)	(vi) Amount paid to
or entity (fundr		(ii) Activity	have custo	dy or control ributions?	from activity	fundraiser listed in	(or retained by) organization
			Yes	No		column (i)	
1							
							·
2							
3							
5							
_							
4							
5							
							·
6							
7							
7							
8							
9							
10							
Total							
Total3 List all states in wh					ontributions or has been	notified it is exempt from	n registration
or licensing.				50.000			
<u>CA</u>							

	•				FOUNDATION
Part II	Fundraisin	g Events. Co	mplete if the	organization	answered 'Ye

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

		Elst events with gross receipts gro				
Revenue			(a) Event #1 ANNUAL FUNDRAI	(b) Event #2	(c) Other events NONE	(d) Total events (add column (a) through column (c))
			(event type)	(event type)	(total number)	5 (#
	1	Gross receipts	1,557,259.			1,557,259.
	2	Less: Contributions	1,557,259.			1,557,259.
	3	Gross income (line 1 minus line 2)				
enses	4	Cash prizes				
	5	Noncash prizes				
	6	Rent/facility costs				
ž	7	Food and beverages				
Direct Expenses	8	Entertainment				
	9	Other direct expenses				
	10	Direct expense summary. Add lines 4 thr				
11 Net income summary. Subtract line 10 from line 3, column (d) Part III Gaming. Complete if the organization answered 'Yes' on Form 990, Part IV, line 19, or reported more						
Par	τm	\$15,000 on Form 990-EZ, line 6a.	allon answered res	s on Form 990, Pa	rt iv, line 19, or re	ported more than
		<u>+,</u> ,,,,,		(b) Pull tabs/instant		(d) Total gaming
Revenue			(a) Bingo	bingo/progressive bingo	(c) Other gaming	(add column (a) through column (c))
Re	1	Gross revenue				
Direct Expenses	2	Cash prizes				
	3	Noncash prizes				
irect	4	Rent/facility costs				
	5	Other direct expenses				
	6	Volunteer labor	Yes%	Yes%	Yes% No	
	7	Direct expense summary. Add lines 2 thr	ough 5 in column (d).			
	8	Net gaming income summary. Subtract li	ine 7 from line 1, colum	n (d)	•	
	U	Net guning meene summary. Oubtract in		in (u):		
	i Is th	er the state(s) in which the organization co ne organization licensed to conduct gaming lo,' explain:	g activities in each of th			
		e any of the organization's gaming license 'es,' explain:		or terminated during th		

Schedule G (Form 990 or 990-EZ) 2020

Schedule G (Form 990 or 990-EZ) 2020 CYSTINOSIS RESEARCH FOUNDATION	32-0067668	Page 3
11 Does the organization conduct gaming activities with nonmembers?	Yes	No
12 Is the organization a grantor, beneficiary or trustee of a trust, or a member of a partnership or other entity formed to administer charitable gaming?		No
13 Indicate the percentage of gaming activity conducted in:a The organization's facility	. 13a	0 0
b An outside facility.	. 13b	olo
14 Enter the name and address of the person who prepares the organization's gaming/special events books and record	ls:	
Name ►		
Address ►		
of gaming revenue retained by the third party ► \$ c If 'Yes,' enter name and address of the third party:	the amount	No
Name ►		
Address ►		ا ا
16 Gaming manager information:		
Name ►		
Gaming manager compensation ► \$		
Description of services provided		
Director/officer Employee Independent contractor		
17 Mandatory distributions:		
a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license?	Yes	No
b Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in	n the	
organization's own exempt activities during the tax year ► \$ Part IV Supplemental Information. Provide the explanations required by Part I, line 2b, co	lumna (iii) and (<u></u>
and Part IV Supplemental information. Provide the explanations required by Part 1, line 2b, co and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide an information. See instructions.	ny additional	v),

SCHEDULE I	Grants and Other Assistance to Organizations,
(Form 990)	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.
Department of the Treasury Internal Revenue Service	► Go to www.irs.gov/Form990 for the latest information.

Open to Public Inspection

Employer identification number 32-0067668

OMB No. 1545-0047

Name of the organization

CYSTINOSIS RESEARCH FOUNDATION

Part I General Information on Grants and 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.

	, 5 1		• /	1		1	
1 (a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1) UNIVERSITY OF CALIFORNIA SD							
9500 GILMAN DRIVE, DEPT 0935							MEDICAL
LA JOLLA, CA 92093	95-6006144		110,621.	0.			RESEARCH
(2) THE SCRIPPS INSTITUTE							
10550 N. TORREY PINES ROAD							MEDICAL
LA JOLLA, CA 92037	33-0435954		300,000.	0.			RESEARCH
(3) STANFORD UNIVERSITY							
326 GALVEZ_STREET							MEDICAL
STANFORD, CA 94305	94-1156365		150,000.	0.			RESEARCH
(4) UNIVERSITY OF PITTSBURGH							
3550_TERRACE_ST							MEDICAL
PITTSBURGH, PA 15213	11-3708851		410,810.	0.			RESEARCH
(5) MASSACHUSETTS GENERAL HOSPITA							
55_FRUIT_ST							MEDICAL
BOSTON, MA 02114	04-1564655		67,109.	0.			RESEARCH
(6) ALBERT EINSTEIN COLLEGE OF ME							
1300 MORRIS PARK AVE							MEDICAL
BRONX, NY 10461			333,164.	0.			RESEARCH
(7) TRUSTEES OF PRINCETON UNIVERS							
NEW_SOUTH							MEDICAL
PRINCETON, NJ 08544			160,244.	0.			RESEARCH
(8) AMMA THERAPEUTICS, INC.							
							MEDICAL
HAYWARD, CA 94544			304,064.	0.			RESEARCH
2 Enter total number of section 501(c)((3) and government or	ganizations listed	in the line 1 table			•••••••••••••••••••••••••••••••••••••••	
3 Enter total number of other organization	tions listed in the line	1 table				••••••	<u> </u>
BAA For Paperwork Reduction Act Notice	e, see the Instructions	for Form 990.		TEEA3901L	07/15/20	Schee	dule I (Form 990) 2020

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Schedule I (Form 990) 2020 CYSTINOSIS RESEARCH FOUNDATION

32-0067668

Page 2

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

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
1					
2					
3					
4					
5					
6					
7					
Part IV Supplemental Information. F	Provide the informatio	n required in Part I	, line 2; Part III, co	lumn (b); and any othe	er additional information.

SCH	EDU	JLI	ΕL	
(Form	99 0	or	990	-E2

Transactions With Interested Persons

OMB No. 1545-0047

►	Complete if the organization answered 'Yes' on Form 990, Part IV, line 25a, 25b, 2	26, 27	7. 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.

2020 Open To Public Inspection

Employer identification number

►\$

Department of the Treasury Internal Revenue Service Name of the organization

CYSTI	NOSIS RESEARCH FOUND	ATION	:	32-0067668									
Part I	Part I Excess Benefit Transactions (section 501(c)(3), section 501(c)(4), and section 501(c)(29) organizations only). Complete if the organization answered 'Yes' on Form 990, Part IV, line 25a or 25b, or Form 990-EZ, Part V, line 40b.												
1	(a) Name of disqualified person	(b) Relationship between disqualified person and	(c) Descripti	on of transaction	(d) Cor	rected?							
	(a) Name of disqualified person	organization	(c) Descripti		Yes	No							
(1)													
(2)													
(3)													
(4)													
(5)													
(6)													
		y the organization managers or disqualified pe											

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

Part II Loans to and/or From Interested Persons.

Complete if the organization answered 'Yes' on Form 990-EZ, Part V, line 38a or Form 990, Part IV, line 26; or if the organization reported an amount on Form 990, Part X, line 5, 6, or 22.

(a) Name of interested person	(b) Relationship with organization	(c) Purpose of Ioan	(d) Loa fron organi	an to or n the zation?	(e) Original principal amount	(f) Balance due	(g) In default?		(h) Approved by board or committee?		(i) Written agreement?	
			То	From			Yes	No	Yes	No	Yes	No
(1)												
(2)												
(3)												
(4)												
(5)												
(6)												
(7)												
(8)												
(9)												
(10)												
Total					▶\$							

Part III Grants or Assistance Benefiting Interested Persons.

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

	(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of assistance	(d) Type of assistance	(e) Purpose of assistance
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					

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

Schedule L (Form 990 or 990-EZ) 2020

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

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of transaction	(d) Description of transaction	(e) Sha organiz rever	aring of zation's nues?
				Yes	No
(1) ZOE SOLSBY	WIFE OF OFFICE	78,000.	COMPENSATION		Х
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					

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

SUPPLEMENTAL INFORMATION

SEE NOTE 1 TO SCHEDULE L

32-0067668

Page 2

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.

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

OMB No. 1545-0047
2020
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 I, LINE 1 - ORGANIZATION MISSION OR SIGNIFICANT ACTIVITIES

CRF'S MISSION IS TO SUPPORT BENCH, CLINICAL AND TRANSLATIONAL RESEARCH TO FIND BETTER TREATMENTS AND A CURE FOR CYSTINOSIS. CRF IS DEDICATED TO FUNDING RESEARCH THAT WILL INPROVE THE QUALITY OF LIFE FOR THOSE WITH CYSTINOSIS AND ULTIMATELY FIND A CURE FOR THIS DEVASTATING DISEASE.

FORM 990, PART III, LINE 1 - ORGANIZATION MISSION

CRF'S MISSION IS TO SUPPORT BENCH, CLINICAL AND TRANSLATIONAL RESEARCH TO FIND BETTER TREATMENTS AND A CURE FOR CYSTINOSIS.CRF IS DEDICATED TO FUNDING RESEARCH THAT WILL INPROVE THE QUALITY OF LIFE FOR THOSE WITH CYSTINOSIS AND ULTIMATELY FIND A CURE FOR THIS DEVASTATING DISEASE.

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

"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 WISH OF OTHERS WITH CYSTINOSIS - A REALITY.

MISSION STATEMENT

CRF'S MISSION IS TO SUPPORT BENCH, CLINICAL AND TRANSLATIONAL RESEARCH TO FIND BETTER TREATMENTS AND CURE FOR CYSTINOSIS. CRF IS DEDICATED TO FUNDING RESEARCH THAT WILL IMPROVE THE QUALITY OF LIFE FOR THOSE WITH CYSTINOSIS AND TO ULTIMATELY FIND A CURE FOR THIS DEVASTATING DISEASE.

RESEARCH

CRF IS COMMITED TO FINDING A CURE THROUGH AN AGGRESSIVELY FUNDED RESEARCH AGENDA. CRF <u>AWARDS RESEARCH GRANTS BI-ANNUALLY TO ACCELERATE THE RESEARCH PROCESS AND TO ENSURE</u> **BAA** For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ. TEEA4901L 07/28/20 Schedule O (Form 990 or 990-EZ) (2020)

THAT THERE IS NEVER A GAP IN FUNDING NEW CUTTING-EDGE RESEARCH PROJECTS. CRF IS DEDICATED TO IMPROVING THE QUALITY OF LIFE FOR CYSTINOSIS PATIENTS AND TO FINDING BETTER TREATMENTS, INCLUDING A CURE, FOR OUR ADULTS AND CHILDREN LIVING WITH CYSTINOSIS.

EDUCATION

THE CYSTINOSIS RESEARCH FOUNDATION IS DEDICATED TO EDUCATING THE CYSTINOSIS COMMUNITY, THE PUBLIC AND THE MEDICAL COMMUNITY ABOUT CYSTINOSIS TO ENSURE EARLY DIAGNOSIS AND IMMEDIATE AND PROPER TREAMENT.

HISTORY AND RESEARCH

CYSTINOSIS IS A RARE, METABOLIC, GENETIC DISEASE THAT AFFLICTS APPROXIMATELY 2,000 CHILDREN AND ADULTS WORLDWIDE. CRF IS INCREASINGLY FOCUSED ON FUNDING CLINICAL AND TRANSLATIONAL RESEARCH WHICH IS CRUCIAL TO FINDING NEW TREATMENTS AND A CURE FOR CYSTINOSIS. CRF IS COMMITTED TO PRIORITIZING AND AGGRESSIVELY SUPPORTING RESEARCH THAT HAS THE POTENTIAL TO SIGNIFICANTLY IMPROVE THE QUALITY OF LIFE FOR CHILDREN AND ADULTS WITH CYSTINOSIS.

RESEARCH GIVES US HOPE

WE FIRMLY BELIEVE THAT FUNDING AND SUPPORTING RESEARCH GIVES US HOPE FOR A BRIGHTER FUTURE FOR THOSE LIVING WITH CYSTINOSIS.HOPE ALLOWS US TO LIVE WITH CYSTINOSIS UNTIL THE DAY A CURE IS FOUND.

SINCE 2003, THE CYSTINOSIS RESEARCH FOUNDATION (CRF) HAS RAISED ALMOST \$62 MILLION AND HAS BECOME THE LEADING PROVIDER OF FUNDS FOR CYSTINOSIS RESEARCH THROUGHOUT THE WORLD. CRF HAS STRATEGICALLY AND AGGRESSIVELY INVESTED MILLIONS OF DOLARS INTO

CYSTINOSIS RESEARCH, AND HAS CREATED A THRIVING AND COLLABORATIVE RESEARCH COMMUNITY, AND AS A RESULT, HAS CHANGED THE COURSE OF CYSTINOSIS. FROM THE START OF THE FOUNDATION ALL CRF OPERATING COSTS HAVE BEEN PRIVATELY UNDERWRITTEN SO THAT 100 PERCENT OF THE FUNDS DONATED TO CRF ARE USED TO SUPPORT CYSTINOSIS RESEARCH.

WE ARE PLEASED TO ANNOUNCE THAT DURING THE 12 MONTHS PERIOD ENDING JUNE 30,2021, CRF AWARDED 11 NEW AND EXTENSION GRANTS, AND ONE EQUIPMENT GRANT TOTALING MORE THAN \$1,133,667 FOR CYSTINOSIS RESEARCH. THE NEW GRANTS BRING US THAT MUCH CLOSER TO BETTER TREATMENTS AND A CURE.

CRF AWARDS GRANTS TO THE BEST AND BRIGHTEST RESEARCHERS IN THE WORLD. TO DATE, CRF HAS FUNDED 207 STUDIES AT LEADING RESEARCH INSTITUTIONS IN 12 COUNTRIES. CRF-FUNDED RESEARCHERS HAVE PUBLISHED 91 ARTICLES IN PRESTIGIOUS, TOP-RATED JOURNALS. THOSE ARTICLES, AVAILABLE TO EVERYONE IN THE WORLD, HAVE CONTRIBUTED TO THE UNDERSTANDING OF THE PATHOGENESIS AND TREATMENT OF CYSTINOSIS.

RESEARCH PROGRESS

FROM THE START OF THE FOUNDATION, 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.

OUR STRATEGY OF PROVIDING SEED MONEY TO TALENTED RESEARCHERS HAS BEEN SUCCESSFUL. OUR FIRST PROJECT INVOLVED FUNDING RESEARCHERS WHO WERE FOCUSED ON A NEW TREATMENT. CRF PROVIDED GRANTS THAT FUNDED EVERY BENCH AND CLINICAL TRIAL THAT LED TO THE DISCOVERY OF A DELAYED-RELEASE FORM OF THE LIFE-SAVING MEDICATION FOR CYSTINOSIS. THAT

MEDICATION, PROCYSBI WAS APPROVED BY THE FDA ON APRIL 30, 2013, AND IS CONSIDERED THE MOST SIGNIFICANT ADVANCEMENT IN THE TREATMENT OF CYSTINOSIS IN 30 YEARS.

IN 2007, CRF BEGAN FUNDING DR. STEPHANIE CHERQUI, AT UC SAN DIEGO WHO WAS FOCUSED ON STEM CELL AND GENE THERAPY RESEARCH. AS A DIRECT RESULT OF CRF'S EARLY AND CONTINUOUS FUNDING, IN DECEMBER 2018, THE FDA APPROVED A CLINICAL TRIAL TO TEST THE EFFICACY AND SAFETY OF A STEM CELL AND GENE THERAPY TREATMENT FOR CYSTINOSIS PATIENTS. IN OCTOBER 2019, THE FIRST CYSTINOSIS PATIENT WAS TRANSPLANTED AND IN JUNE, 2020, TWO MORE PATIENTS WERE TRANSPLANTED WITH THE STEM CELL THERAPY. CRF'S GRANTS TO DR. CHERQUI HAVE BEEN LEVERAGED BY MULTI-MILLION-DOLLAR GRANTS FROM OTHER FUNDING AGENCIES. IF THIS TREATMENT WORKS, IT COULD STOP THE PROGRESSION OF CYSTINOSIS OR BE THE CURE FOR CYSTINOSIS.

SINCE CYSTINOSIS IS A SYSTEMIC DISEASE AND EVERY TISSUE IS AFFECTED, CRF HAS TARGETED MULTIPLE AREAS OF RESEARCH TO FUND 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.

CYSTINOSIS RESEARCH HELPS OTHERS

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

CRF FAMILIES AND PARTNERS

THE CYSTINOSIS REASEARCH FOUNDATION HAS WITNESSED TREMENDOUS GROWTH OVER THE YEARS AS CYSTINOSIS FAMILIES HAVE JOINED OUR FUNDRAISING EFFORTS. PEOPLE FROM ALL OVER THE WORLD HAVE EMBRACED THE CYSTINOSIS CAUSE AND ENTHUSIASTICALLY RAISED FUND 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 2019, 66 FAMILIES FROM AROUNT THE WORLD GATHERED TO SHARE STORIES, HOPES AND DREAMS, AND TO BUILD LIFE-LONG FRIENDSHIPS. LEADING CRF FUNDED RESEARCHERS ATTENDED THE CONFERENCE AND UPDATED THE CYSTINOSIS COMMUNITY ON THEIR RESEARCH PROGRESS INCLUDING UPDATES ON GENE AND STEM CELL THERAPIES, NOVEL EYE REASEARCH AND NEUROLOGICAL RESEARCH. THE CONFERENCE EDUCATES CYSTINOSIS FAMILIES ABOUT THE CURRENT AND ONGOING RESEARCH AND OFFERS THEM HOPE THAT BRIGHTER DAYS ARE AHEAD FOR CYSTINOSIS PATIENTS. THE 2020 AND 2021 CONFERENCES WERE CANCELLED BECAUSE OF THE PANDEMIC BUT WE RESUME THE CONFERENCE IN 2022.

CURE CYSTINOSIS INTERNATIONAL REGISTRY

THE CYSTINOSIS RESEARCH FOUNDATION IS EXCITED TO ANNOUNCE THAT A NEW, UPDATED REGISTRY, THE CURE CYSTINOSIS INTERNATIONAL REGISTRY (CCIR) WAS LAUNCHED IN APRIL 2021. THE NEW REGISTRY WILL TRACK PATIENTS' NATURAL HISTORY DATA, COLLECT DATA ABOUT CURRENT TREATMENTS, IDENTIFY KNOWN AND UNKNOWN MEDICAL COMPLICATIONS AND COLLECT INFORMATION ABOUT QUALITY OF LIFE ISSUES. THE CCIR WILL BE A CENTRAL HUB OF INFORMATION FOR THE GLOBAL COMMUNITY. THE DEIDENTIFIED PATIENT DATA FROM THE REGISTRY CAN BE SHARED WITH CYSTINOSIS CLINICIANS, RESEARCHERS AND SCIENTISTS WHO ARE PURSUING

RESEARCH FOCUSED ON BETTER TREATMENTS AND A CURE FOR CYSTINOSIS.

CRF INTERNATIONAL RESEARCH SYMPOSIUM

CRF'S INTERNATIONAL RESEARCH SYMPOSIUM IS HELD EVERY TWO YEARS AND IS A HIGHLIGHT FOR CYSTINOSIS RESEARCHERS. ATTENDEES ARE CRF FUNDED RESEARCHERS AND SCIENTISTS FROM AROUND THE WORLD.APPROXIMATELY 65 CYSTINOSIS EXPERTS FROM LEADING INTERNATIONAL UNIVERSITIES AND RESEARCH INSTITUTIONS ARE INVITED TO GIVE PRESENTATIONS ABOUT THEIR WORK. ATTENDEES SHARE THEIR RESEARCH PROGRESS AND ARE ENCOURAGED TO FORM COLLABORATIONS IN AN EFFORT TO ACCELERATE THE RESEARCH PROGRESS. 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 AN AS NEEDED BASIS AND DISCUSSES RESOLUTIONS 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)

Related Organizations and Unrelated Partnerships

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

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

OMB No. 1545-0047

Open to Public Inspection

Department of the Treasury Internal Revenue Service

Name of the organization CYSTINOSIS RESEARCH FOUNDATION

Employer identification number 32-0067668

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

	(a) Name, address, and EIN (if applicable) of disregarded entity		(b) Primary ac	ctivity	(c Legal dom or foreign	:) icile (state country)	То	(d) tal income	End-c	(e) of-year assets	Dire	(f) ct contro entity	lling
<u>(1)</u>													
(2)													
(3)													
Par	t II Identification of Related Tax-Exempt Or had one or more related tax-exempt orga	ganizatio	ons. Complete s during the ta	if the org	ganization	answered	d 'Yes'	on Form 990), Pari	t IV, line 34,	becau	se it	
	(a) Name, address, and EIN of related organization		(b) ary activity	(e Legal dom	c) iicile (state ii country)	(d) Exempt (sectio	Code	(e) Public charity (if section 501	status	(f) Direct contro entity		(g Sec 512 controlled Yes) (b)(13) d entity? No
<u>(1)</u>												163	NO
(2)													
(3)													
(4)													
				1						1			

Schedule R (Form 990) 2020 CYSTINOSIS RESEARCH FOUNDATION

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

		5						3	,							
(a) Name, address, and EIN of related organization	(b) Primary activity	(c) Legal domicile (state or foreign	(d) Direct controllin entity	ng	(e) Predominant i (related, unre excluded frou under secti	elated, m tax ions	(f) Share o incoi	f total	Sha end-c	g) re of of-year sets	Dispi tior	h) ropor- nate ations?	K-1 (Form	ox Gene le part	(j) eral or aging tner?	(k) Percentage ownership
		country)			512-514)					Yes	No	10`65)	Yes	No	
<u>(1)</u>																
(2)	-															
	-															
Part IV Identification of line 34, because	of Related Organ se it had one or	nizations more rela	Taxable a ated organ	as a (nizati	Corporation	on or d as a	Trust. Co a corpora	omplete ation or	if the o trust du	organiza uring the	tion a tax y	nswe /ear.	red 'Yes' on	Form 9	90, P	art IV,
(a) Name, address, and EIN	of related organizat	ion Prim	(b) ary activity	(sta	(c) gal domicile te or foreign country)	COI	(d) Direct ntrolling	(C corp	e) of entity , S corp, rust)	(f) Share total in	e of	Sh	(g) hare of end-of- year assets	(h) Percentag ownershi	je Se p con	(i) c 512(b)(13) trolled entity?
					country)		entity	ort	rusi)						Y	es No
(1) NANOWAFER, INC 3501 JAMBOREE RD NEWPORT BEACH, CA 81-1666461			EDICAL SEARCH		TX		N/A	сс	ORP		C		0.	100.0	0	x
(2)																
(3)																
BAA					TEEA	5002L	07/15/20						5	Schedule I	₹ (Form	990) 2020

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

Note: Complete line 1 if any entity is listed in Parts II, III, or IV of this schedule.				Yes	No
1 During the tax year, did the organization engage in any of the following transactions with one or more related organizations li	isted in Parts II-IV?				
a Receipt of (i) interest, (ii) annuities, (iii) royalties, or (iv) rent from a controlled entity			1a		Х
b Gift, grant, or capital contribution to related organization(s)			1b		Х
c Gift, grant, or capital contribution from related organization(s).			1c		Х
d Loans or loan guarantees to or for related organization(s).			1d		Х
e Loans or loan guarantees by related organization(s)			1e		Х
f Dividends from related organization(s).					Х
g Sale of assets to related organization(s).					Х
h Purchase of assets from related organization(s).					Х
i Exchange of assets with related organization(s)					Х
j Lease of facilities, equipment, or other assets to related organization(s)			1j		Х
k Lease of facilities, equipment, or other assets from related organization(s).					Х
I Performance of services or membership or fundraising solicitations for related organization(s)					Х
m Performance of services or membership or fundraising solicitations by related organization(s).					Х
n Sharing of facilities, equipment, mailing lists, or other assets with related organization(s)					Х
o Sharing of paid employees with related organization(s)			10		Х
p Reimbursement paid to related organization(s) for expenses					Х
q Reimbursement paid by related organization(s) for expenses.			1q		Х
r Other transfer of cash or property to related organization(s).				-	Х
s Other transfer of cash or property from related organization(s)			1s		Х
2 If the answer to any of the above is 'Yes,' see the instructions for information on who must complete this line, including cove	1			/_IN	
(a) Name of related organization	(b) Transaction type (a-s)	(c) Amount involved	Nethod of amoun	determ t involv	nining ed
(1)					
(2)					
(3)					
(4)					
(5)					
					0000
BAA TEEA5003L 07/15/20		Schedu	ile R (For	m 990)	2020

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

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

(a) Name, address, and EIN of entity	(b) Primary activity	(c) Legal domicile (state or foreign country)	income (related, unre- lated, excluded	Are all sec 501(organiz	tion	(f) Share of total income	(g) Share of end-of-year assets	tior	h) ropor- nate itions?	(i) Code V-UBI amount in box 20 of Schedule K-1 (Form 1065)	(Gene mana parti) ral or aging her?	(k) Percentage ownership
			from tax under sections 512-514)	Yes	No			Yes	No	. ,	Yes	No	
(1)													
	-												
	-												
(2)													
	-												
	-												
(3)													
	-												
	-												
(4)													
	4												
	-												
(5)	_												
	4												
(6)													
	-												
<u>(7)</u>													
	-												
	-												
(8)													
	4												
	-												
PAA													90) 2020

BAA

Part VII Supplemental Information

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

CLIENT 3745FYE

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

FEBRUARY 14, 2022

GEOFFREY STACK CYSTINOSIS RESEARCH FOUNDATION 19200 VON KARMAN AVENUE SUITE 920 IRVINE, CA 92612

DEAR JEFF:

YOUR 2020 FEDERAL RETURN OF ORGANIZATION EXEMPT FROM INCOME TAX WILL BE ELECTRONICALLY FILED WITH THE INTERNAL REVENUE SERVICE UPON RECEIPT OF A SIGNED FORM 8879-EO - IRS E-FILE SIGNATURE AUTHORIZATION. NO TAX IS PAYABLE WITH THE FILING OF THIS RETURN.

YOUR 2020 CALIFORNIA EXEMPT ORGANIZATION ANNUAL INFORMATION RETURN WILL BE ELECTRONICALLY FILED WITH THE STATE OF CALIFORNIA UPON RECEIPT OF A SIGNED FORM 8453-EO. NO TAX IS PAYABLE WITH THE FILING OF THIS RETURN.

ENCLOSED IS YOUR CALIFORNIA REGISTRATION/RENEWAL FEE REPORT TO THE ATTORNEY GENERAL. THE ORIGINAL SHOULD BE SIGNED AT THE BOTTOM OF PAGE ONE. THERE IS A FEE DUE OF \$150 PAYABLE BY MAY 16, 2022. MAKE THE CHECK OR MONEY ORDER PAYABLE TO "DEPARTMENT OF JUSTICE" AND MAIL YOUR CALIFORNIA REPORT ON OR BEFORE MAY 16, 2022 TO:

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

PLEASE CALL ME IF YOU HAVE ANY QUESTIONS.

YOURS SINCERELY,

PETER MONTGOMERY

6/30/21

2020 FEDERAL BOOK SUMMARY DEPRECIATION SCHEDULE

PAGE 1

CLIENT 3745FYE

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

<u>NO.</u>	DESCRIPTION	DATE ACQUIRED	DATE SOLD	COST/ BASIS	BUS. PCT.	CUR 179/ SDA	PRIOR 179/ SDA/ DEPR.	METHOD 1	IFE.	CURRENT DEPR.
FORM	√ 990/990-PF									
FU	RNITURE AND FIXTURES									
5	FURNITURE & FIXTURE	6/30/19		30,000			4,486	S/L	7	4,286
9	FURNITURE & FIXTURES	8/30/19		12,061			1,436	S/L	7	1,723
10	FURNITURE & FIXTURES	9/13/19		4,774			568	S/L	7	682
	TOTAL FURNITURE AND FIXTURE			46,835		0	6,490			6,691
IM	PROVEMENTS									
6	LEASEHOLD IMPROVEMENTS	6/30/19		3,864			552	S/L	7	552
11	LEASEHOLD IMPROVEMENTS	10/01/19		5,010			537	S/L	7	716
	TOTAL IMPROVEMENTS			8,874		0	1,089			1,268
MA	ACHINERY AND EQUIPMENT									
1	SOFTWARE	4/30/08		12,038			12,038	S/L	7	0
2	WEBSITE	9/01/08		27,275			27,275	S/L	5	0
3	WEBSITE	6/30/09		7,875			7,875	S/L	5	0
4	WEBSITE	10/01/10		9,650			9,650	S/L	5	0
7	WEBSITE DEVELOPMENT	9/02/19		24,825			4,138	S/L	5	4,965
8	WEBSITE DEVELOPMENT	3/24/19		24,825			4,965	S/L	5	4,965
12	OFFICE EQUIPMENT	6/30/20		24,825				S/L	_	0
	TOTAL MACHINERY AND EQUIPME			131,313		0	65,941			9,930
	TOTAL DEPRECIATION			187,022		0	73,520		-	17,889
	GRAND TOTAL DEPRECIATION			187,022		0	73,520		=	17,889

6/30/21

2020 FEDERAL BOOK DEPRECIATION SCHEDULE

PAGE 1

CLIENT 3745FYE

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

NO	DESCRIPTION	DATE <u>ACQUIRED</u>	DATE SOLD	COST/ BASIS	BUS. PCT.	CUR 179 BONUS	SPECIAL DEPR. ALLOW.	PRIOR 179/ BONUS/ SP. DEPR.	PRIOR DEC. BAL DEPR.	SALVAG /BASIS REDUCT	DEPR. BASIS	PRIOR DEPR.	METHOD J	LIFE <u>RATE</u>	CURRENT DEPR.
ORM	1 990/990-PF														
FUF	RNITURE AND FIXTURES														
5	FURNITURE & FIXTURE	6/30/19		30,000							30,000	4,486	S/L	7	4,2
9	FURNITURE & FIXTURES	8/30/19		12,061							12,061	1,436	S/L	7	1,72
10	FURNITURE & FIXTURES	9/13/19		4,774							4,774	568	S/L	7	68
	TOTAL FURNITURE AND FIXTURE			46,835		0	0	C) () (46,835	6,490			6,69
IMF	PROVEMENTS														
6	LEASEHOLD IMPROVEMENTS	6/30/19		3,864							3,864	552	S/L	7	5
11	LEASEHOLD IMPROVEMENTS	10/01/19		5,010					. <u> </u>		5,010	537	S/L	7	7
	TOTAL IMPROVEMENTS			8,874		0	0	C) () (8,874	1,089			1,2
MA	CHINERY AND EQUIPMENT														
1	SOFTWARE	4/30/08		12,038							12,038	12,038	S/L	7	
2	WEBSITE	9/01/08		27,275							27,275	27,275	S/L	5	
3	WEBSITE	6/30/09		7,875							7,875	7,875	S/L	5	
4	WEBSITE	10/01/10		9,650							9,650	9,650	S/L	5	
7	WEBSITE DEVELOPMENT	9/02/19		24,825							24,825	4,138	S/L	5	4,96
8	WEBSITE DEVELOPMENT	3/24/19		24,825							24,825	4,965	S/L	5	4,96
12	OFFICE EQUIPMENT	6/30/20		24,825							24,825		S/L		
	TOTAL MACHINERY AND EQUIPME			131,313		0	0	C) () (131,313	65,941			9,93
	TOTAL DEPRECIATION			187,022		0	0	() ()	187,022	73,520			17,88

6/30/21

2020 FEDERAL BOOK DEPRECIATION SCHEDULE

PAGE 2

CLIENT 3745FYE

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

CLIENT 3743FTE				5151	110515	NESLA		MDATIC					32-000/000
NO DESCRIPTION	DATE <u>ACQUIRED</u>	DATE SOLD	COST/ BASIS	BUS. PCT.	CUR 179 BONUS	SPECIAL DEPR. ALLOW.	PRIOR 179/ BONUS/ SP. DEPR.	PRIOR DEC. BAL DEPR.	SALVAG /BASIS REDUCT	DEPR. BASIS	PRIOR DEPR.	METHODLIFERAT	CURRENT EDEPR
GRAND TOTAL DEPRECIATION			187,022)	0	0	0	<u>)</u> 0	0	187,022	73,520		17,889
			i										<u> </u>

Form 8879-EO			nature Authorization npt Organization		ON	1B No. 1545-0047
Department of the Treasury Internal Revenue Service	For calenda	r year 2020, or fiscal year beginning _ ► Do not send to th ► Go to www.irs.gov/Forr	, 20 <u>2021</u>		2020	
Name of exempt organization or p	erson subject to	tax		Taxpayer	identificatio	n number
CYSTINOSIS RESEA		NDATION		32-00	67668	
Name and title of officer or persor	n subject to tax					
GEOFFREY STACK	um and D	eturn Information (Whol				
Check the box for the retucted the box on line 1a, leave line 1b, 2b, 3b, 4b,	urn for which 2a, 3a, 4a, 5 5b, 6b, or 7b	you are using this Form 8879 a. 6a. or 7a below, and the ar	9-EO and enter the applicable amou mount on that line for the return beir nk (do not enter -0-). But, if you ent	na filed with t	his form v	was blank, then
1 a Form 990 check her	re ► X	b Total revenue, if any (Fo	rm 990, Part VIII, column (A), line 1	2)	1 b	3,809,513.
2 a Form 990-EZ check	here	b Total revenue, if any	(Form 990-EZ, line 9)		2 b	0,000,0101
3 a Form 1120-POL che	eck here	b Total tax (Form 1	120-POL, line 22)		3 b	
4 a Form 990-PF check	here	b Tax based on investr	ment income (Form 990-PF, Part VI,	line 5)	4 b	
5 a Form 8868 check he		•	, line 3c)		5 b	
6 a Form 990-T check h			art III, line 4)		6 b	
7 a Form 4720 check he	ere ►	b Total tax (Form 4720, Pa	rt III, line 1)		7b	
Part II Declaration	and Signa	ture Authorization of O	fficer or Person Subject to T	ax		
IRS and to receive from t processing the return or ref initiate an electronic funds of the federal taxes owed U.S. Treasury Financial A financial institutions invol inquiries and resolve issue	he IRS (a) ar und, and (c) th withdrawal (di on this retur gent at 1-88 ved in the pr es related to	n acknowledgement of receipt he date of any refund. If applica rect debit) entry to the financial n, and the financial institution 8-353-4537 no later than 2 bu ocessing of the electronic pay	er, transmitter, or electronic return of cor reason for rejection of the transmible, I authorize the U.S. Treasury and institution account indicated in the tax in to debit the entry to this account. This is a count of the payment of the second of the payment (Figure 1).	nišsion, (b) th its designated preparation so Fo revoke a p ettlement) da al information	ne reason Financial oftware fo payment, te. I also necessa	for any delay in Agent to r payment I must contact the authorize the ry to answer
	OMERY, O	GLICK & COMPANY	to enter my PIN	374	56	as my signature
<u></u>		ERO firm name		Enter five nu do not enter	mbers, but	
on the tax year 2020 el (ies) regulating charit disclosure consent sc	ies as part o	led return. If I have indicated wi f the IRS Fed/State program,	thin this return that a copy of the return I also authorize the aforementioned	is being filed	with a sta	te agency on the return's
electronically filed ret	urn. If I have	indicated within this return the	zation, I will enter my PIN as my sig nat a copy of the return is being filed PIN on the return's disclosure conser	l with a state	e tax year agency(i	^r 2020 es) regulating
Signature of officer or person subj	ect to tax 🕨		Date	• •		
Part III Certification	and Auth					
ERO's EFIN/PIN. Enter yo	our six-digit e	electronic filing identification				
number (EFIN) followed b	by your five-c	ligit self-selected PIN			50	285068720 not enter all zeros
I certify that the above num I am submitting this return in Providers for Business Re	n accordance	ny PIN, which is my signature o with the requirements of Pub. 41 0	n the 2020 electronically filed return in 63, Modernized e-File (MeF) Information	dicated above. for Authorized	. I confirm IRS <i>e-file</i>	that
ERO's signature			Date ►			
		FRO Must Retain 1	This Form – See Instructions			

ERO Must Retain This Form – See Instructions Do Not Submit This Form to the IRS Unless Requested To Do So 2020

FEDERAL SUPPLEMENTAL INFORMATION

CLIENT 3745FYE

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

PAGE 1

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.

TAXABLE	YEAR	California Exampt Organization				I	FORM	
202	20	California Exempt Organization Annual Information Return					199	
Calendar Ye	ear 2020	or fiscal year beginning (mm/dd/yyyy) 7/01/2020, a	ind ending (mm/dd/yyyy) 6/30/	202	1 ·		
Corporation/Or	rganization					California corporation nu	umber	
		RESEARCH FOUNDATION				9801377		
Additional info	rmation. Se	e instructions.				EIN 32-0067668		
Street address	-	•				PMB no.		
19200 V City	VON KA	ARMAN AVENUE #920		State	7	Zip code		
IRVINE				CA		92612		
Foreign country	y name			Foreign province/state/county	F	Foreign postal code		
 B Amended C IRC Secti D Final info ● □ D Enter date E Check acc 1 □ C F Federal re 4 □ Oth 	I return ion 4947(a) prmation re issolved e: (mm/dd counting m Cash 2 eturn filed? her 990 ser	$ \begin{array}{c} & & & & & & & & & & & & & & & & & & &$	t reported to the exempt under ganization eng- e instructions the organization "Yes," enter the nonember sour the organization d the organization	tion have any changes to its g he FTB? See instructions R&TC Section 23701d, has the aged in political activities? on exempt under R&TC Sectio e gross receipts from 'ces	n 2370 \$	● Yes ● Yes 1g? ● Yes ● Yes port	X No X No X No X No X No	
H Is this org If "Yes," v	ganization what is the	in a group exemption	the organizatio dited in a prio federal Form i te filed with IF		as the	IRS	X No	
Part I	Comple	te Part I unless not required to file this form. See General I	nformation	B and C.				
		oss sales or receipts from other sources. From Side 2, Part			1	151	,448.	
Receipts		oss dues and assessments from members and affiliates			2	2 (50	0.65	
and Revenues		oss contributions, gifts, grants, and similar amounts receive			3	3,658	,065.	
Revenues		tal gross receipts for filing requirement test. Add line 1 thro is line must be completed. If the result is less than \$50,000		eral Information B •	4	3,809	,513.	
		ost of goods sold	· · · · · · · · · · · · · · · · · · ·				/ 0 2 0 1	
	6 Co	ost or other basis, and sales expenses of assets sold	• 6					
	7 To	tal costs. Add line 5 and line 6			7			
	8 To	tal gross income. Subtract line 7 from line 4		• • • • • • • • • • • • • • • • • •	8	3,809	,513.	
Expenses	9 To	tal expenses and disbursements. From Side 2, Part II, line	18	• • • • • • • • • • • • • • • • • • • •	9	3,470	,840.	
	10 E>	cess of receipts over expenses and disbursements. Subtrac	ct line 9 fro	m line 8 •	10	338	,673.	
		tal payments		•	11			
		e tax. See General Information K.		•	12			
		ayments balance. If line 11 is more than line 12, subtract lin			13			
Filing		se tax balance. If line 12 is more than line 11, subtract line 1			14			
Fee	15 P€	enalties and Interest. See General Information J.		-	15			
	16 Ba	lance due. Add line 12 and line 15. Then subtract line 11 from the result \dots		•••••••••••••••••••••••••••••••••••••••	16		0.	
Sign Here	Under pen correct, ar Signature of officer	alties of perjury, I declare that I have examined this return, including accompany d complete. Declaration of preparer (other than taxpayer) is based on all inform Title TRUSTEE		Date		 Telephone 949-223-761 		
_	Preparer's		Date	Check if self-				
Paid Preparer's	signature	MONTCOMEDY OF TOY & CONDANY	employed		P01209820 ● Firm's FEIN			
Use Only	Firm's nar (or yours,							
	self-emplo and addre	yed) 23001 CALABASAS AD SIE 105			954489850 ● Telephone			
		CALABASAS, CA 91302				818-999-696	7	
	May th	e FTB discuss this return with the preparer shown above? S	see instruct	ions		X Yes	No	

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32-0067668

CYSTINOSIS RESEARCH FOUNDATION

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

	rega	rdless of amount of gross receipts	 complete Part II or furnis 	in substitute information	-		
	1	Gross sales or receipts from all	business activities. See	instructions	•	1	
	2	Interest			•	2	
	3	Dividends				3	123,546.
Receipt	s 4	Gross rents				4	
from Other	5	Gross royalties				5	
Sources	s	Gross amount received from sa				6	27,902.
	6					7	27,902.
	7	Other income. Attach schedule.				-	151 440
	8	Total gross sales or receipts from other				8	151,448.
	9	Contributions, gifts, grants, and similar				9	2,791,861.
	10	Disbursements to or for member	ers		•	10	
	11	Compensation of officers, direc				11	0.
Evnana	12	Other salaries and wages				12	63,207.
Expense and	^{es} 13	Interest			• • • • • • • • • • • • • •	13	
Disburs	se- 14	Taxes			• • • • • • • • • • • • •	14	4,705.
ments	15	Rents			• • • • • • • • • • • • • •	15	
	16	Depreciation and depletion (Se	e instructions)		•	16	17,888.
	17	Other expenses and disbursem	ents. Attach schedule	SEE ST.	ATEMENT 3 🖕	17	593,179.
	18	Total expenses and disbursements. Add				18	3,470,840.
Sched	-	Balance Sheet	Beginning of			of taxab	
Assets		Balance Sheet	(a)	(b)	(c)		(d)
	ch			5,984,805.	(0)	•	5,968,759.
		receivable		912,433.		•	600,684.
_		eivable		J12,4JJ.		•	000,004.
						•	
-		state government obligations				•	
		in other bonds					
-		in stock		2,812,223.		•	2 610 945
-				2,812,223.			3,619,845.
		ns				•	
		nents. Attach schedule				•	
		assets			162,1		
		lated depreciation		88 , 677.	91,4		70,788.
		·····				•	
12 Oth	her assets.	Attach scheduleSTM	4	49,556.		•	89,502.
13 To	tal assets			9,847,694.			10,349,578.
Liabiliti	es and r	net worth					
14 Acc	counts pay	able		16,405.		•	17,794.
15 Cor	ntributions	, gifts, or grants payable		2,281,565.		•	1,849,342.
		otes payable				•	· · ·
		ayable				•	
		es. Attach schedule.					
		or principal fund		7,549,724.		•	8,482,442.
		pital surplus. Attach reconciliation		,,010,,21.		•	0,102,112.
		nings or income fund.				•	
		ies and net worth		9,847,694.			10,349,578.
Sched							
Seneu		Do not complete this schedule			less than \$50,000		
1 Ne	t income r	er books			books this year not incl	uded	
		ne tax.	•		h schedule		
		bital losses over capital gains	•	8 Deductions in this r			
		ecorded on books this year.		against book incom	5		
		ule	•				
		orded on books this year not deducted			d line 8		
		. Attach schedule	•	10 Net income per			
		ne 1 through line 5	338,673.	-	from line 6		338,673.
U 101	ui. Auu III	io i anougn mio o	550,075.				550,075.

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Schedule B

(Form	990,	990-EZ
·		

or 990-PF) Department of the Treasury

Internal	Revenue	Service

CALIFORNIA COPY Schedule of Contributors

► Attach to Form 990, Form 990-EZ, or Form 990-PF.

|--|

Internal Revenue Service	Go to www.irs.gov/Form990 for the latest inform	nation.
Name of the organization		Employer identification number
CYSTINOSIS RESE	EARCH FOUNDATION	32-0067668
Organization type (cheo	ck one):	
Filers of:	Section:	
Form 990 or 990-EZ	X 501(c)(3) (enter number) organization	
	4947(a)(1) nonexempt charitable trust not treated as a p	ivate foundation
	527 political organization	
Form 990-PF	501(c)(3) exempt private foundation	
	4947(a)(1) nonexempt charitable trust treated as a privat	e foundation
	501(c)(3) taxable private foundation	

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

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

General Rule

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

Special Rules

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

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

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

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

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

Schedule B (Form 990, 990-EZ, or 990-PF) (2020)	1 1	Page 2
Name of organization	Employer identification number	
CYSTINOSIS RESEARCH FOUNDATION	32-0067668	
Part I Contributors (see instructions). Use duplicate copies of Part Lif additional space is needed		

Farti	Contributors (see instructions). Use duplicate copies of Part 1 if additional s	pace is needed.	
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	GEOFFREY AND NANCY STACK		Person X
	[\$ 600,000.	Payroll Noncash
		\$600,000.	(Complete Part II for
	NEWPORT BEACH, CA 92660	-	noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
2	THE ROBERT LA LOGGIA CHARITABLE FUN	_	Person X
	PO_BOX_9509	\$ 250,000.	Payroll Noncash
			(Complete Part II for
	WARWICK , RI 02889	-	noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
3	MAGISTRO FOUNDATION	_	Person X
	1480 E. SUNNY DUNES ROAD	\$ 315,000.	Payroll Noncash
	PALM SPRINGS, CA 92264		(Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
			Person
		Ś	Payroll Noncash
		·	(Complete Part II for
		-	noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		_	Person
		\$	Payroll Noncash
			(Complete Part II for
		-	noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		_	Person
		\$	Payroll Noncash
			(Complete Part II for
		-	noncash contributions.)

Schedule B (Form 990, 990-EZ, or 990-PF) (2020)	1	1	Page 3
Name of organization	Employer ident	ification nur	nber
CYSTINOSIS RESEARCH FOUNDATION	32-0067	668	

Part II Noncash Property (see instructions). Use duplicate copies of Part II if additional space is needed.

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

	B (Form 990, 990-EZ, or 990-PF) (2020)			1 1 Page 4				
Name of organ				Employer identification number				
	or (10) that total more than \$1,000 for t the following line entry. For organizations c contributions of \$1,000 or less for the year.	he year from any one contributo ompleting Part III, enter the total of (Enter this information once. See in	r. Complete	e columns (a) through (e) and v religious, charitable, etc				
(a) No. from	Use duplicate copies of Part III if additional (b) Purpose of gift	space is needed. (c) Use of gift		(d) Description of how gift is held				
No. from Part I		(0) 000 01 g		(4) - coolip lion of home give ione -				
	<u>N/A</u>		+					
			+					
		(e) Transfer of gift	L					
	Transferee's name, addres	s, and ZIP + 4	Relati	onship of transferor to transferee				
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift		(d) Description of how gift is held				
		e) Transfer of gift						
	Transferee's name, addres	Relati	onship of transferor to transferee					
(a) No. from Part I		(c) Use of gift		(d) Description of how gift is held				
		(e) Transfer of gift	+·					
	Transferee's name, addres	s, and ZIP + 4	Relati	onship of transferor to transferee				
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift		(d) Description of how gift is held				
			+					
	(e) Transfer of gift							
	Transferee's name, addres		Relati	onship of transferor to transferee				
BAA			Sched	ule B (Form 990, 990-EZ, or 990-PF) (2020)				

TAXABLE YEAR

2020 Corporation Depreciation and Amortization

3885

	ch to Form 100 or For	m 100W. FORM	4 199							
Corpo	ration name						Californ	nia corp	oratior	n number
CYS	STINOSIS RESEA	ARCH FOUNDAT	ION				9801	1377		
Par	t I Election To Ex	pense Certain Pro	perty Under IRC S	ection 179						
1	Maximum deduction	under IRC Section	179 for California.					1		\$25 , 000
2	Total cost of IRC Se		•					2		
3	Threshold cost of IR		•				-	3		\$200 , 000
4	Reduction in limitation			'			-	4		
	Dollar limitation for t		act line 4 from line					5		
6	(a)	Description of property		(b) Cost (business	use only)	(c) Electe	d cost			
7	Listed property (elec							- 1		
8	Total elected cost of						-	8		
9	Tentative deduction.							9		
10	Carryover of disallov						-	10 11		
11 12	Business income lim IRC Section 179 exp			•			-	12		
13	Carryover of disallov					1		12		
Par				reciation Deduction			356			
14	(a)	(b)	(c)	(d)	(e)	(f)	(g	<u>،</u>		(h)
14	Description	Date acquired	Cost or	Depreciation	Depreciation		Deprecia		or	Additional first
	of property	(mm/dd/yyyy)	other basis	allowed or	method	rate	this y	/ear		year
				allowable in earlier years						depreciation
SOF	TWARE	4/30/2008	12,038.	12,038.	S/L	7				
-	BSITE	9/01/2008	27,275.	27,275.	<u>S/L</u>	5				
	BSITE	6/30/2009	7,875.	7,875.	S/L	5				
	BSITE	10/01/2010	9,650.	9,650.	S/L	5				
	RNITURE & FIX	6/30/2019	30,000.	4,486.	S/L	7	4	,28	6.	
	Add the amounts in		•			· · ·		, 20	<u>.</u>	
15	\$2,000. See instruct	ions for line 14 co	lumn (n). The lotai lumn (h)	or column (n) may	not exceed	15	17	,88	9.	
Par							/	/00		
16	Total: If the corporat	tion is electina:								
	IRC Section 179 exp	ense, add the amo	unt on line 12 and	line 15, column (g) or					
	Additional first year Depreciation (if no e	depreciation under	R&IC Section 243	om line 15 column	(a)	5, columns ((g) and (h)	or 1	6	
17	Total depreciation cl								7	
	Depreciation adjustn		•						-	
	Form 100W, Side 1,	line 6. If line 17 is	less than line 16,	enter the difference	e here and o	on Form 100	or			
	Form 100W, Side 2, state adjustments or							1	8	
Par									-	
19	(a)	(b)	(c)	(d)	(e)	(f)			(g)
	Description	Date acquire	d Cost o	or Amort	ization	R&TC	Period			Amortization
	of property	(mm/dd/yyyy	y) other bas		r allowable er years	Section (see instr)	percenta	ige		for this year
					. ,	(
20	Total. Add the amou	ints in column (a)	L	I		1		20		
21	Total amortization cl						-	21		
22							-			
~~	Amortization adjustn Form 100W, Side 1,	line 6. If line 21 is g	less than line 20,	enter the difference	e here and o	on Form 100	or			
	Form 100W, Side 2,							22		



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TAXABLE YEAR

2020 Corporation Depreciation and Amortization

3885

	ch to Form 100 or Forr	m 100W. FORM	1 199						
Corpo	ration name						Californ	nia corporati	ion number
CYS	STINOSIS RESEA	RCH FOUNDAT	ION				9801	L377	
Par	t I Election To Ex	pense Certain Pro	perty Under IRC S	ection 179					
1	Maximum deduction	under IRC Section	179 for California.					1	\$25,000
2	Total cost of IRC Sec	ction 179 property	placed in service					2	
3	Threshold cost of IRC	C Section 179 prop	erty before reducti	on in limitation				3	\$200 , 000
4	Reduction in limitation	on. Subtract line 3	from line 2. If zero	or less, enter -0				4	
5	Dollar limitation for ta	axable year. Subtr	act line 4 from line	1. If zero or less, e	enter -0			5	
6	(a)	Description of property		(b) Cost (business)	use only)	(c) Elected	d cost		
7	Listed property (elect				· · · · · · · · · · · · · · · · · · ·			T	
8	Total elected cost of							8	
9	Tentative deduction.						L L	9	
10	Carryover of disallow							10	
11 12	Business income lim IRC Section 179 exp			•			-	11 12	
12	Carryover of disallow							12	
Par				reciation Deduction			356		
14	(a)	(b)	(c)	(d)	(e)	(f)	(g)	(h)
14	Description	Date acquired	Cost or	Depreciation	Depreciation		Deprecia		Additional first
	of property	(mm/dd/yyyy)	other basis	allowed or allowable in	method	rate	this y	/ear	year depreciation
				earlier years					uepreciation
LEA	ASEHOLD IMPRO	6/30/2019	3,864.	552.	S/L	7		552.	
-	SITE DEVELOP	9/02/2019	24,825.	4,138.	S/L	5	4	,965.	
-	SITE DEVELOP	3/24/2019	24,825.	4,965.	S/L	5		,965.	
-	RNITURE & FIX	8/30/2019	12,061.	1,436.	S/L	7		,723.	
	RNITURE & FIX	9/13/2019	4,774.	568.	S/L	7		682.	
	Add the amounts in o	· · ·		•		4			
15	\$2,000. See instructi								
Par		,,							I
16	Total: If the corporation	ion is electing:							
	IRC Section 179 expe Additional first year of	ense, add the amo	unt on line 12 and	line 15, column (g)) or	E columno ((a) and (b)		
	Depreciation (if no el								
17	Total depreciation cla								
	Depreciation adjustm	nent. If line 17 is a	reater than line 16.	. enter the difference	e here and	on Form 10	0 or		
	Form 100W, Side 1, Form 100W, Side 2,	line 6. If line 17 is line 12 (If Californ	less than line 16, e	enter the difference	e here and o	on Form 100 Det income b	Or efore		
	state adjustments on							18	
Par	t IV Amortization								
19	(a)	(b)	(c)		d)	(e)	(f)		(g)
	Description of property	Date acquire (mm/dd/yyyy	d Cost o) other bas		ization allowable	R&TC Section	Period percenta		Amortization
	or property	(mm/dd/yyyy		in earlie		(see instr)	percente	ige	for this year
_									
_									
_									
_									
20	Total. Add the amou	nts in column (a)		· · · · · · · · · · · · · · · · · · ·				20	
21	Total amortization cla	(0)					F	21	
22	Amortization adjustm	nent. If line 21 is g	reater than line 20.	, enter the difference	ce here and	on Form 10	0 or		
-	Form 100W, Side 1,	line 6. If line 21 is	less than line 20, 6	enter the difference	e here and o	on Form 100	or	~	
	Form 100W, Side 2,	line 12						22	

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TAXABLE YEAR

2020 Corporation Depreciation and Amortization

3885

	ch to Form 100 or For	m 100W. FOR	M 199						
Corpo	ration name						Califor	nia corpora	ation number
CYS	STINOSIS RESEA	ARCH FOUNDAT	ION				980	1377	
Par	t I Election To Ex	pense Certain Pro	perty Under IRC S	ection 179					
1	Maximum deduction							1	\$25 , 000
2	Total cost of IRC Se		•					2	
3	Threshold cost of IR		-					3	\$200 , 000
4	Reduction in limitation			,				4	
5	Dollar limitation for t		act line 4 from line					5	
6	(a)	Description of property		(b) Cost (business	s use only)	(c) Elected	1 COST		
-7	Listed property (also	ted IDC Cention 1	70		7				
7 8	Listed property (elector) Total elected cost of					ino 7		8	
9	Tentative deduction.							9	
10	Carryover of disallow							10	
11	Business income lim							11	
12	IRC Section 179 exp			•				12	
13	Carryover of disallow	ved deduction to 20	021. Add line 9 and	d line 10, less line	12	13			
Par	t II Depreciation ar	nd Election of Addit	ional First Year Dep	reciation Deduction	n Under R&T	C Section 243	56		
14	(a)	(b)	(c)	(d)	(e)	(f)	(((h)
	Description of property	Date acquired (mm/dd/yyyy)	Cost or other basis	Depreciation allowed or	Depreciation method	n Life or rate	Deprecia this		Additional first year
				allowable in				<i>J</i> = =	depreciation
		10/01/0010	F 010	earlier years				84.6	
-	ASEHOLD IMPRO		5,010.	537.	. S/L	7		716	•
OFT	FICE EQUIPMEN	6/30/2020	24,825.			0			
15	Add the amounts in \$2,000. See instruct								
Par									
16	Total: If the corporat	tion is electina:							
	IRC Section 179 exp	ense, add the amo	ount on line 12 and	l line 15, column (g) or				
	Additional first year Depreciation (if no e	depreciation under	nter the amount fr	om line 15 colum	nts on line i n (a)	15, columns (g) and (n) or	
17	Total depreciation cl								
18	Depreciation adjustn	nent. If line 17 is g	reater than line 16	, enter the differen	ice here and	l on Form 10	0 or		
	Form 100W, Side 1, Form 100W, Side 2,	line 6. If line 17 is line 12 (If Californ	less than line 16, his depreciation ar	enter the differenc	e here and determine r	on Form 100 het income b	or efore		
	state adjustments or							18	
Par	t IV Amortization								
19	(a)	(b)	(c)		(d)	(e)	(f)		(g)
	Description of property	Date acquire (mm/dd/yyyy			tization or allowable	R&TC Section	Period percent		Amortization for this year
	5. p. sp 5. 9	(,		ier years	(see instr)	1	- 9 -	for this year
20	Total. Add the amou	(5)						20	
21	Total amortization cl	aimed for federal p	ourposes from fede	eral Form 4562, lin	e 44			21	
22	Amortization adjustn	nent. If line 21 is g	reater than line 20	, enter the differen	ice here and	d on Form 10	0 or		
	Form 100W, Side 1, Form 100W, Side 2,							22	

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2020

CALIFORNIA STATEMENTS

CLIENT 3745FYE

STATEMENT 1

CYSTINOSIS RESEARCH FOUNDATION

FORM 199, PART II, LINE 9 CONTRIBUTIONS, GIFTS, GRANTS, AND SIMILAR AMOUNTS PAID DONEE'S NAME: DONEE'S STREET ADDRESS: DONEE'S CITY, STATE, ZIP: UNIVERSITY OF CALIFORNIA SD 9500 GILMAN DRIVE, DEPT 0935 LA JOLLA, CA 92093 AMOUNT GIVEN: 110,621. DONEE'S NAME:THE SCRIPPS INSTITUTEDONEE'S STREET ADDRESS:10550 N. TORREY PINES ROADDONEE'S CITY, STATE, ZIP:LA JOLLA, CA 92037 AMOUNT GIVEN: 300,000. DONEE'S NAME:STANFORD UNIVERSITYDONEE'S STREET ADDRESS:326 GALVEZ STREETDONEE'S CITY, STATE, ZIP:STANFORD, CA 94305AMOUNT CLVEN.STANFORD, CA 94305 AMOUNT GIVEN: 150,000. DONEE'S NAME:UNIVERSITY OF PITTSBURGHDONEE'S STREET ADDRESS:3550 TERRACE STDONEE'S CITY, STATE, ZIP:PITTSBURGH, PA 15213 AMOUNT GIVEN: 410,810. DONEE'S NAME:MASSACHUSETTS GENERAL HOSPITADONEE'S STREET ADDRESS:55 FRUIT ST.DONEE'S CITY, STATE, ZIP:BOSTON, MA 02114 AMOUNT GIVEN: 67,109. DONEE'S STREET ADDRESS: DONEE'S CITY, STATE, ZIP: AMOUNT GIVEN: ALBERT EINSTEIN COLLEGE OF ME 1300 MORRIS PARK AVE BRONX, NY 10461 333,164. DONEE'S NAME: DONEE'S STREET ADDRESS: DONEE'S CITY, STATE, ZIP: MOUNT CIVEN. TRUSTEES OF PRINCETON UNIVERS NEW SOUTH PRINCETON, NJ 08544 AMOUNT GIVEN: 160,244. DONEE'S NAME:AMMA THERAPEUTICS, INC.DONEE'S STREET ADDRESS:31162 SAN CLEMENTE ST STE 100DONEE'S CITY, STATE, ZIP:HAYWARD, CA 94544 AMOUNT GIVEN: 304,064. AMOUNT GIVEN: 5,500. AMOUNT GIVEN: 46,174. AMOUNT GIVEN: 75,000. AMOUNT GIVEN: 290,000. AMOUNT GIVEN: 200,530. AMOUNT GIVEN: 31,306. AMOUNT GIVEN:

AMOUNT GIVEN:

PAGE 1

32-0067668

119,339.

108,000.

2020	CALIFORNIA STATEMENTS							
CLIENT 3745FYE	CYSTINOSIS RESEARCH FOUNDATION	32-0067668						
STATEMENT 1 (CONTINUED) FORM 199, PART II, LINE 9 CONTRIBUTIONS, GIFTS, GRAN AMOUNT GIVEN: AMOUNT GIVEN:	TS, AND SIMILAR AMOUNTS PAID	5,000. 75,000. 3 <u>2,791,861.</u>						
STATEMENT 2 FORM 199, PART II, LINE 11 COMPENSATION OF OFFICERS, D CURRENT OFFICERS:	DIRECTORS, TRUSTEES AND KEY EMPLOYEES TITLE AND TOTAL CONTRI- AVERAGE HOURS COMPEN- BUTION TO							
NAME AND ADDRESS	AVERAGE HOURS COMPEN- BUTION TO <u>PER WEEK DEVOTED</u> SATION EBP & DC							
NANCY J. STACK 219 EVENING CANYON ROAD CORONA DEL MAR, CA 92625	CHAIR - TRUSTEE \$ 0.\$ 0 40.00	.\$0.						
GEOFFREY STACK 3501 JAMBOREE ROAD, SUITE NEWPORT BEACH, CA 92660	VICE CHAIR-TTEE 0. 0 6100 0	. 0.						
DONALD L. SOLSBY 24 RISA STREET RANCHO MISSION VIEJO, CA 9	TREASURER - TTE 0. 0 2.00 2694	. 0.						
MARCU ALEXANDER 3010 N ALAMO ROAD BOISE, ID 83704	TRUSTEE 0. 0 0	. 0.						
STEPHANIE CHERQUI, PHD 9500 GILMAN DRIVE, MC 0734 LA JOLLA, CA 92093	TRUSTEE 0. 0	. 0.						
BRUCE CRAIR 20634 CIRCULO LOMA YORBA LINDA, CA 92887	TRUSTEE 0. 0 0	. 0.						
JILL EMERSON, CPA 2020 SKY DAUGTHER TRAIL HAMMONTON, NJ 08037	TRUSTEE 0. 0 0	. 0.						
DENICE FLERCHINGER P.O. BOX 754 CLARKSTON, WA 99403	TRUSTEE 0. 0	. 0.						
THOMAS A GENDRON 1081 WOODWARD WAY FORT COLLINS, CO 80524	TRUSTEE 0. 0	. 0.						

CALIFORNIA STATEMENTS

PAGE 3

CLIENT 3745FYE

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

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

CURRENT OFFICERS: NAME AND ADDRESS	TITLE AND AVERAGE HOUI PER WEEK DEVC	TOTAL RS COMPEI TED SATIC	L N- H N	CONTRI- BUTION TO EBP & DC	EXPENSE ACCOUNT/ OTHER
TRACI GENDRON 3825 HARBOR WALK LANE FORT COLLINS, CO 80525	TRUSTEE 0	\$		0.	
JOHN S HAGESTAD 3501 JAMBOREE ROAD SUITE 6100 NEWPORT BEACH, CA 92660	TRUSTEE 0		0.	0.	0.
LAUREN HARTZ 1138 MEADOWLARK DRIVE PITTSBURGH, PA 15243	TRUSTEE 0		0.	0.	0.
MICHAEL K HAYDE 8 EXECUTIVE CIRCLE IRVINE, CA 92614	TRUSTEE 0		0.	0.	0.
STEPHEN L. JENKINS 2211 C 1800 E SALT LAKE CITY, UT 84106	TRUSTEE 0		0.	0.	0.
ERIN LITTLE 5244 BRUCE RD 3 PORT ELGIN, ONTARIO NOH2C6 CANAD	TRUSTEE 0		0.	0.	0.
DAVID W. MOSSMAN 12 PINEHURST LANE NEWPORT BEACH, CA 92660	TRUSTEE 0		0.	0.	0.
KEVIN PARTINGTON 400 CAPITOL MALL SUITE 1800 SACRAMENTO, CA 95814	TRUSTEE 0		0.	0.	0.
TERESA PARTINGTON 1315 TENEIGHTH WAY SACRAMENTO, CA 95818	TRUSTEE 0		0.	0.	0.
NATALIE STACK 3395 MICHELSON DRIVE APT 3439 IRVINE, CA 92612	TRUSTEE 0		0.	0.	0.
BRIAN STURGIS 520 WHISKEY JACK CIRCLE SANDPOINT, ID 83864	TRUSTEE 0		0.	0.	0.
BARBARA KULYK BOX 34 CONSORT, ALBERTA AB TOC 1BO CANA	TRUSTEE 0		0.	0.	0.
	T	DTAL <u>\$</u>	0.\$	0.	\$0.

2020

CLIENT 3745FYE

CALIFORNIA STATEMENTS

CYSTINOSIS RESEARCH FOUNDATION

PAGE 4 32-0067668

STATEMENT 3 FORM 199, PART II, LINE 17 OTHER EXPENSES

ACCOUNTING FEES	\$	84,387.
ADVERTISING AND PROMOTION		121,753.
AUCTION ITEMS		1,080.
CREDIT CARD FEES		10,217.
EDUCATION		25,843.
INSURANCE		11,027.
MAGAZINE		137,697.
OTHER EXPENSES		5,770.
		92,275.
		1,274.
POSTAGE AND SHIPPING		3,516.
PRINTING AND PUBLICATIONS		44,725.
RENTAL EXPENSE		38,542.
SUPPLIES		1,079.
TELEPHONE		5,628.
WEBSITE		8,366.
ΤΟΤΑΙ	Ś	593,179.
10111	<u> </u>	000,1101

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

PREPAID EXPENSES AND DEFERRED	CHARGES	89,502.
	TOTAL	\$ 89,502.

Date Accept	ed				DO NOT MAIL	THIS FOR	RM TO THE FTB
TAXABLE YEAR Califo		rnia e-file Retu	urn Autho	rization fo	r		FORM
2020	Exem	pt Organizatio	ns				8453-EO
Exempt Organiz		j - j	_			Identifying nu	Imber
CYSTINO	SIS RESEARCH	FOUNDATION				32-006	7668
Part I I	Electronic Return	Information (whole doll	ars only)				
-		199, line 4)					3,809,513.
	•	199, line 8)					3,809,513.
3 Total e	expenses and disburs	sements (Form 199, line	9)			3	3,470,840.
Part II S	Settle Your Acco	unt Electronically for	or Taxable Yea	nr 2020			
4 Ele	ectronic funds withdra	awal 4a Amount		4b Withdra	awal date (mm/dd/)	ууу)	
Part III I	Banking Informa	tion (Have you verified	the exempt organ	ization's banking i	nformation?)		
5 Routin	g number						
	nt number			7 Type of account	t: Checking	Savi	ngs
	Declaration of Of						
	he exempt organizati or the amount listed	ion's account to be settle on line 4a.	ed as designated i	n Part II. If I chec	k Part II, Box 4, I a	uthorize an	electronic funds
correspondir organization's Tax Board (I for the fee Ii statements b	ng lines of the exemp s return is true, correct FTB) does not receiv ability and all applica e transmitted to the FT	ter, or intermediate servi- ot organization's 2020 Ca t, and complete. If the exer- e full and timely paymen able interest and penaltie B by the ERO, transmitter thorize the FTB to disclo	alifornia electronic mpt organization is it of the exempt o es. I authorize the , or intermediate se	return. To the be filing a balance du rganization's fee I exempt organizat ervice provider. If th	st of my knowledge e return, I understan ability, the exempt ion return and acco e processing of the	e and belief, d that if the F organizatior ompanying s exempt orga	the exempt ranchise n will remain liable chedules and nization's
Sign	•			TRUST	EE		
Here	Signature of officer		Date	Title			
Part V I	Declaration of El	ectronic Return Ori	ninator (FPO)	and Paid Pron	arer Soo instruct	000	
the best of r organization officer's sign forms and in Authorized e exempt organ under penals statements,	ny knowledge. (If I a 's return. I declare, F nature on form FTB 8 oformation that I will e-file Providers. I will nization return is filed, ties of perjury, I decla	e above exempt organiza am only an intermediate however, that form FTB 8 453-EO before transmitt file with the FTB, and I h keep form FTB 8453-EC whichever is later, and I w are that I have examined y knowledge and belief,	service provider, 453-EO accuratel ing this return to t ave followed all c o on file for four y rill make a copy ava I the above exempt	understand that y reflects the data he FTB; I have pr ther requirements ears from the due ailable to the FTB u ot organization's re	am not responsib on the return.) I h ovided the organize described in FTB date of the return pon request. If I am eturn and accompa	le for review ave obtained ation officer Pub. 1345, 2 or four years also the paid nying sched	ing the exempt d the organization with a copy of all 020 Handbook for s from the date the preparer, ules and
	ERO's			Date	also paid y self		O's PTIN
ERO	signature	MONTGOMERY, GL	TCK C COMDA	NV	preparer A emp	Firm's FEIN	01209820
Must	Firm's name (or yours if self-employed)	23801 CALABASA					54489850
Sign	and address	CALABASAS		5	CA		1302
		have examined the above organiz					
are true, correct	t, and complete. I make thi	is declaration based on all infor	mation of which I have			ı	
Paid	Paid preparer's signature			Date	Check if self-employe		id preparer's PTIN
Preparer				I		Firm's FEIN	
Must Sign	Firm's name (or yours if self- employed) and address					ZIP code	

For Privacy Notice, get FTB 1131 ENG/SP.

FTB 8453-EO 2020

STATE OF CALIFORNIA RRF-1 (Rev. 09/2017)	I					DEPARTMENT OF JU PAGE	JSTICE 1 of 5	Æ
IN MAIL TO: Registry of Charitable Trusts P.O. Box 903447 Sacramento, CA 94203-4470 (For Registry Use Or TO ATTORNEY GENERAL OF CALIFORNIA						Only)		
Street Sections 12586 and 12587, California Government Code 1300 I Street 11 Cal. Code Regs. sections 301-306, 309, 311, and 312 Sacramento, CA 95814 Failure to submit this report annually no later than four months and fifteen after the end of the organization's accounting period may result in the loss of tax exemption and the assessment of a minimum tax of \$800, plus interest, and/or fines or filing penalties. Revenue & Taxation Code								
WEBSITE ADDRESS: www.ag.ca.gov/charities/		3703; Government Code s						
CYSTINOSIS RESEARCH Name of Organization	FOUNDATION	N		Check if: Change of				
List all DBAs and names the organization u	uses or has used							
19200 VON KARMAN AVE Address (Number and Street)	NUE #920			State Charity F	Registration Num	nber <u>CT123183</u>		
IRVINE, CA 92612 City or Town, State and ZIP Code				Corporation or	Organization No	p. <u>9801377</u>		
949-223-7610 Telephone Number		CYSTINOSISRE	SEARCH.	Federal Emplo	oyer ID No. 32	-0067668		
		RENEWAL FEE SCHE		. Code Regs. se	ctions 301-307, 3			
Gross Annual Revenue	Fee	Make Check Paya Gross Annual Rev		Fee	Gross Annual	Revenue	F	ee
Less than \$25,000	<u>1 ee</u> 0	Between \$100,001				0,001 and \$10 millior		<u>ce</u> 150
Between \$25,000 and \$100,000	\$25	Between \$250,001				00,001 and \$50 millio	on \$	225 300
PART A – ACTIVITIES		•						
For your most recent full a	accounting peri	od (beginning	7/01/20	ending	6/30/21) list:		
Gross Annual Revenue \$	3 809 513	Noncash Cont	tributions \$		0. Total A	ssets \$ 10,34	9 57	18
			-			·	<i>9</i> , <i>3</i>	0.
Program Ex	penses \$	0.		l otal Expenses	\$ \$ <u>3,47</u>	0,840.		
PART B – STATEMENTS	REGARDIN	G ORGANIZATIO		G THE PERIC	DD OF THIS F	REPORT		
Note: All questions must be an providing an explanation	swered. If you and details for	answer "yes" to any r each "yes" respons	v of the quest se. Please rev	ions below, you view RRF-1 inst	u must attach a tructions for info	separate page ormation required.	Yes	No
1 During this reporting period, w officer, director or trustee thereof, o	vere there any o either directly of	contracts, loans, leases c r with an entity in w	or other financial hich any such	transactions betw n officer, director of	reen the organiza r trustee had any t	ation and any financial interest?		Х
2 During this reporting period, v	was there any th	neft, embezzlement,	, diversion or	misuse of the o	organization's charita	ble property or funds?		Х
3 During this reporting period, were any organization funds used to pay any penalty, fine or judgment?						Χ		
4 During this reporting period, were the services of a commercial fundraiser, fundraising counsel for charitable purposes, or commercial coventurer used?					Х			
5 During this reporting period, did the organization receive any governmental funding?					Х			
6 During this reporting period, did the organization hold a raffle for charitable purposes?						Х		
7 Does the organization conduct a vehicle donation program?						Х		
8 Did the organization conduct an independent audit and prepare audited financial statements in accordance with generally accepted accounting principles for this reporting period?				Х				
9 At the end of this reporting period, did the organization hold restricted net assets, while reporting negative unrestricted net assets?					Х			
	I declare under penalty of perjury that I have examined this report, including accompanying documents, and to the best of my knowledge and belief, the content is true, correct and complete, and I am authorized to sign.							ge
	GEOI	FFREY STACK		TRUSTEE				
Signature of Authorized Agent	Printed			Title		Date		