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Department of the Treasury Internal Revenue Service

# STANNED JUN 3 0 2011

# **Return of Organization Exempt From Income Tax**

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except black lung benefit trust or private foundation)

► The organization may have to use a copy of this return to satisfy state reporting requirements

OMB No 1545 0047

2010

Open to Public Inspection

Α	For the 2	2010 calen	dar year, or tax year beginning , 2010, and endin	g			,
В	Check if ap	plicable		] 1	D Employe	r Iden	itification Number
	Addres	ss change	CYSTINOSIS RESEARCH FOUNDATION		32-0	06	7668
	Name	change	18802 BARDEEN AVE.	Ţī	E Telephon	е пип	nber
	Initial	return	IRVINE, CA 92612		949-	223	3-7610
	Termii						
	H	ded return		1,	G Gross red		\$ 2,322,910.
	$\vdash$		F Name and address of principal officer GEOFFREY STACK	H(a) Is this a			
	Аррііс	ation pending	SAME AS C ABOVE	H(b) Are all at	-		filiates? Yes X No
_	T		<u> </u>		ttach a list (		istructions)
<u>ٺ</u>		mpt status	X 501(c)(3) 501(c) ( ) ◀ (insert no ) 4947(a)(1) or 527				_
<u>J</u>	Websi		W.CYSTINOSISRESEARCH.ORG	H(c) Group ex			
K		organization	X         Corporation         Trust         Association         Other ►         L Year of Format	ion 2003	<b>M</b> _Sta	ate of	legal domicile CA
Pa	rt I	Summai					
			be the organization's mission or most significant activities $\ \underline{ t THE}\ \underline{ t CYST}$				
çe			IS_TO_SUPPORT_CLINICAL_RESEARCH_INTO_BETTER_TR				
Jan	_F.	IND A_C	URE FOR CYSTINOSIS. CRE HAS BEEN INSTRUMENTAL	IN ESTA	ABLISH:	ING	_A WORLD-WIDE_
/er	l		REGISTRY TO BRING TOGETHER_ALL_THOSE WHO SUFFE				
ő	!	eck this bo		ore than 25	% of its n	_	1
প্র	1		oting members of the governing body (Part VI, line 1a) dependent voting members of the governing body (Part VI, line 1b)		}	<u>3</u>	13
ties	1		of individuals employed in calendar year 2010 (Part V, line 2a)		-	5	13
Activities & Governance			of volunteers (estimate if necessary)		-	6	0
Ac	1		ed business revenue from Part VIII, column (C), line 12		}-	_ <u>-</u> 7a	
	<b>b</b> Ne	et unrelated	business taxable income from Form 800 1 me 34			7 b	
				Pri	or Year		Current Year
	8 Cc	ntributions	and grants (Part VIII, line 1h)	3,	223,62	27.	2,220,084.
Revenue	<b>9</b> Pr	ogram serv	rice revenue (Part VIII, In 29) JUN 2 0 2011 🖓				
Ver	10 inv	vestment ir	ncome (Part VIII, column (A) lines 3, 4, and 7d)		-33,05	50.	39,172.
å	11 Ot	her revenu	e (Part VIII, column (A), lines 5 64 8c 9c 10c, and fe				
	<b>12</b> To	tal revenue	e – add lines 8 through 1 (must equal Early III Jobiumn (A), line 12)	3,	190,5	<u> 17 .</u>	2,259,256.
	<b>13</b> Gr	ants and s	ımılar amounts paid (Part IX, column (A), lines 1-3)	2,	079,85	<u> 33.</u>	2,572,395.
	14 Be	enefits paid	to or for members (Part IX, column (A), line 4)				
	<b>15</b> Sa	laries, othe	er compensation, employee benefits (Part IX, column (A), lines 5-10)				
ses	<b>16a</b> Pr	ofessional	fundraising fees (Part IX, column (A), line 11e)				
Expenses	İ		sing expenses (Part IX, column (D), line 25) ► 237, 686.				
X			ses (Part IX, column (A), lines 11a-11d, 11f-24f)		510,03	20	520,998.
			es Add lines 13-17 (must equal Part IX, column (A), line 25)	2	589,88		3,093,393.
	i		s expenses Subtract line 18 from line 12	4,	600,69		
		veriue less	s expenses Subtract line to nont line 12	Pogunana			-834,137.
		tal accete	(Part X, line 16)		of Current		End of Year 3, 469, 901.
Asse	i		es (Part X, line 26)		107,67		2,325,223.
Net Assets Fund Baland							
	<u>22 Ne</u>   Ne		re Block Subtract line 21 from line 20 re Block	_ ⊥,	902,71	<u>. o .</u>	1,144,678.
con	ler penalties iplete Deck	s of perjury 1 d aration of prep	leclare that I have examined this return, including accompanying schedules and statements and to are return than officer) is based on all information of which preparer has any knowledge	the best of my	knowledge a	and be	elief, it is true, correct, and
			Derthers I Stale	<del></del>	6/1	<del>-</del>	2011
Sig	ın.	Signatu	ire of porcer	Date	-//-	<u>'</u>	
He	re	GEO:	FFREY STACK	TRUSTI	FF	-	
			print name and title	11(0511			<del></del>
		Print/Type p	preparer's name Preparer's name Date	1	Check	.6	PTIN
<b>D</b> -	id	1	MONTGOMERY (1) A 7 6/10	/1.		l if	P01209820
Pa	ıa eparer			<del>//   s</del>	elf-employed		11 01203020
	e Only	Firm s name				٥٦	4400000
J	Conny	Firm's addre					-4489850
	15 . 150	<del></del>	WOODLAND HILLS, CA 91367	P	Phone no	(81	<del></del>
			nis return with the preparer shown above? (see instructions)				X Yes No
BA	A For Pa	aperwork R	Reduction Act Notice, see the separate instructions.	A0113L 12/2	1/10		Form <b>990</b> (2010)

	990 (2010) CYSTINOSIS RESEARCH FOUNDATION	32-0067668	Page 2
Par	t III Statement of Program Service Accomplishments		
	Check if Schedule O contains a response to any question in this Part III		X
1	Briefly describe the organization's mission		
	SEE SCHEDULE O		
			<b>-</b>
	Del the control of th		
2	Did the organization undertake any significant program services during the year which were not listed of Form 990 or 990-EZ?		7] No
	If 'Yes,' describe these new services on Schedule O	Yes 2	∐ No
3	Did the organization cease conducting, or make significant changes in how it conducts, any program si	ervices? Yes	No No
3	If 'Yes,' describe these changes on Schedule O	ervices.	110
4	Describe the exempt purpose achievements for each of the organization's three largest program service	es by expenses. Section 5	01(c)(3)
	and 501(c)(4) organizations and section 4947(a)(1) trusts are required to report the amount of grants a expenses, and revenue, if any, for each program service reported	nd allocations to others, the	ne total
4 a	(Code $(2,572,395)$ ) (Expenses $(2,572,395)$ ) (Expenses $(2,572,395)$ ) (		)
	WHEN THE CYSTINOSIS RESEARCH FOUNDATION WAS ESTABLISHED, ONE OF		
	IMPROVE THE QUALITY OF LIFE FOR CHILDREN WITH CYSTINOSIS. FINDIN		
	TREATMENTS FOR CYSTINOSIS WAS THE KEY TO THAT GOAL. WE HAVE AGGR		
	AND CUTTING-EDGE RESEARCH BY PURSUING THE BEST AND THE BRIGHTEST	<b></b> -	CRF
	APPROACH TO RESEARCH IS INTERDISCIPLINARY AND MULTI-FACETED. WE COLLABORATIONS AND CYSTINOSIS RESEARCH STUDIES THAT RESULT IN HU	<del></del>	AT C
	WE ARE INCREASINGLY FOCUSED ON THE CLINICAL AND TRANSLATIONAL RE		
	MAKING THE NECESSARY STRIDES TOWARD A CURE FOR CYSTINOSIS.	PERIOR CROCIAL I	
		- <b>-</b>	
41	Code (Code (Schedule O)) (Expenses \$ 90,549. Including grants of \$ ) (SEE SCHEDULE O	Revenue \$	)
		- <b></b>	
		- <b></b>	
		- <b></b>	
4	c (Code (Cod	Revenue \$	١
71	FUNDING QUALITY CYSTINOSIS RESEARCH STUDIES REMAINS A PRIORITY A		/
	PROCESS. TO DATE, THE CRF HAS FUNDED AND COMMITTED OVER \$11.8 MI		
	RESEARCH AND HAS FUNDED MORE THAN 78 RESEARCH STUDIES AND FELLOW		
	THE SUPPORT OF OUR FRIENDS AND COMMUNITY WE HAVE SIGNIFICANTLY O		
	CYSTINOSIS RESEARCH. OUR FUNDING EFFORTS HAVE ALLOWED TALENTED D		
	RESEARCHERS IN THE AREA OF CYSTINOSIS TO INITIATE NOVEL RESEARCH	<del></del> -	
	ADVANCE THEIR RESEARCH EFFORTS. THE VIDEO CAMPAIGN HAS BEEN INST	- <i>-</i>	EYING
	THIS MESSAGE TO THE PUBLIC AND THE RESEARCH COMMUNITY THROUGH OU	R WEB SITE, YOU	TUBE
	AND VARIOUS INTERNET SITES.		
4	d Other program services (Describe in Schedule O )  SEE SCHEDULE O		
	(Expenses \$ 21,643. including grants of \$ ) (Revenue \$	)	
4	e Total program service expenses ► 2,725,508.		

Pai	rt IV Checklist of Required Schedules			
•			Yes	No
1	Is the organization described in section $501(c)(3)$ or $4947(a)(1)$ (other than a private foundation)? If 'Yes,' complete Schedule A	1	X	
2	Is the organization required to complete Schedule B, Schedule of Contributors? (see instructions)	2		Х
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If 'Yes,' complete Schedule C, Part I	3		х
4	Section 501(c)(3) organizations Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the lax 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		
6	Did the organization maintain any donor advised funds or any similar funds or accounts where donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If 'Yes,' complete Schedule D, Part I	6		Х
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas or historic structures? If 'Yes,' complete Schedule D, Part II	7		Х
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If 'Yes,' complete Schedule D, Part III	8		X
9	Did the organization report an amount in Part X, line 21, serve as a custodian for amounts not listed in Part X, or provide credit counseling, debt management, credit repair, or debt negotiation services? If 'Yes,' complete Schedule D, Part IV	9		Х
10	Did the organization, directly or through a related organization, hold assets in term, permanent, or 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, VIII, IX, or X as applicable			
i	a Did the organization report an amount for land, buildings and equipment in Part X, line 10? If 'Yes.' complete Schedule D, Part VI	11a	Х	
ŧ	<b>b</b> Did the organization report an amount for investments— other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? <i>If 'Yes,' complete Schedule D, Part VII</i>	11b		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
•	<b>d</b> 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		_ X
1	f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If 'Yes,' complete Schedule D, Part X	11 f		Х
12	a Did the organization obtain separate, independent audited financial statements for the tax year? If 'Yes,' complete Schedule D, Parts XI, XII, and XIII	12a	Х	
	b Was the organization included in consolidated, independent audited financial statements for the tax year? If 'Yes,' and if the organization answered 'No' to line 12a, then completing Schedule D, Parts XI, XII, and XIII is optional	12b		_x
	Is the organization a school described in section 170(b)(1)(A)(ii)? If 'Yes,' complete Schedule E	13	-	X
	a Did the organization maintain an office, employees, or agents outside of the United States?	14a		X
	<b>b</b> Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, and program service activities outside the United States? If 'Yes,' complete Schedule F, Parts I and IV	14b		X
	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization or entity located outside the United States? If 'Yes,' complete Schedule F, Parts II and IV	15	X	
	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or assistance to individuals located outside the United States? If 'Yes,' complete Schedule F, Parts III and IV	16		Х
	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If 'Yes,' complete Schedule G, Part I (see instructions)	17		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	
	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
20	aDid the organization operate one or more hospitals? If 'Yes,' complete Schedule H	20		X
	<b>b</b> If 'Yes' to line 20a, did the organization attach its audited financial statements to this return? <b>Note.</b> Some Form 990 filers that operate one or more hospitals must attach audited financial statements (see instructions)	20 b		

Par	Checklist of Required Schedules (Continued)			
`			Yes	No
21	Did the organization report more than \$5,000 of grants and other assistance to governments and organizations in the United States on Part IX, column (A), line 1? If 'Yes,' complete Schedule I, Parts I and II	21	X	
22	Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 27 If 'Yes.' complete Schedule I, Parts I and III	22		Χ
23	Did the organization answer 'Yes' to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If 'Yes,' complete Schedule J</i>	23		Х
24 a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of	23		Λ_
	the last day of the year, and that was issued after December 31, 2002 If 'Yes,' answer lines 24b through 24d and complete Schedule K. If 'No,' go to line 25	24a		Х
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
C	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		
d	Did the organization act as an 'on behalf of' issuer for bonds outstanding at any time during the year?	24d		
25 a	Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If 'Yes,' complete Schedule L, Part I	25a		Х
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If 'Yes,' complete Schedule L, Part I	25b		X
26	Was a loan to or by a current or former officer, director, trustee, key employee, highly compensated employee, or disqualified person outstanding as of the end of the organization's tax year? If 'Yes,' complete Schedule L, Part II	26		_X_
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor, or a grant selection committee member, or to a person related to such an individual? If 'Yes.' complete Schedule L. Part III	27		Х
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)			1
а	A current or former officer, director, trustee, or key employee? If 'Yes,' complete Schedule L. Part IV	28a		_X_
b	A family member of a current or former officer, director, trustee, or key employee? If 'Yes,' complete Schedule L. Part IV	28b		Х
c	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? If 'Yes,' complete Schedule L. Part IV	28c		X
29	Did the organization receive more than \$25,000 in non-cash contributions? If 'Yes,' complete Schedule M	29	X	
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If 'Yes,' complete Schedule $M$	30		_X
31	Did the organization liquidate, terminate, or dissolve and cease operations? If 'Yes,' complete Schedule N, Part I	31		_X_
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If 'Yes,' complete Schedule N, Part II	32		Х
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301 7701-2 and 301 7701-3? If 'Yes,' complete Schedule R, Part I	33		Х
34	Was the organization related to any tax-exempt or taxable entity? If 'Yes,' complete Schedule R, Parts II, III, IV, and V, line 1	34		Х
35	Is any related organization a controlled entity within the meaning of section 512(b)(13)?	35		Χ
a	a Did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If 'Yes,' complete Schedule R, Part V, line 2  Yes X No			
36	<b>Section 501(c)(3) organizations.</b> Did the organization make any transfers to an exempt non-charitable related organization? If 'Yes,' complete Schedule R, Part V, line 2	36		Х
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? If 'Yes,' complete Schedule R, Part VI	37		Х
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11 and 19? <b>Note.</b> All Form 990 filers are required to complete Schedule O	38	Х	
BAA	· · · · · · · · · · · · · · · · · · ·	Form	990 (	(2010)

Par	t V Statements Regarding Other IRS Filings and Tax Compliance  Check if Schedule O contains a response to any question in this Part V			
			Yes	No
	Enter the number reported in Box 3 of Form 1096 Enter -0- if not applicable	-l I		
	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable.	4 !		
C	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c		
2 a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return  2a (	)		
Ŀ	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b		
	Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)			
3 a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a		X
t	If 'Yes' has it filed a Form 990-T for this year? If 'No,' provide an explanation in Schedule O	3 b		
	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)?  • If 'Yes,' enter the name of the foreign country   • BERMUDA	4a	X	
	See instructions for filing requirements for Form TD F 90-22 1, Report of Foreign Bank and Financial Accounts	7		
5 a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a	,	X
	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5 b		Х
	: If 'Yes,' to line 5a or 5b, did the organization file Form 8886-T?	5 c		
	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?	6a		Х
ł	o If 'Yes,' did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b		A
7	Organizations that may receive deductible contributions under section 170(c).			
á	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?	7a		Х
ŀ	of the organization notify the donor of the value of the goods or services provided?	7b		
	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file			-
•	Form 8282?	7c		X
(	If 'Yes,' indicate the number of Forms 8282 filed during the year 7d	_		
•	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e		X
ſ	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	<b>7</b> f		X
Ġ	g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g		
ı	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7h		
8	Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?	8	*	
9	Sponsoring organizations maintaining donor advised funds.			_
á	a Did the organization make any taxable distributions under section 4966?	9 a	J	
ı	Did the organization make a distribution to a donor, donor advisor, or related person?	9b		
10	Section 501(c)(7) organizations. Enter	<b>'</b> ,	` %'	
i	a Initiation fees and capital contributions included on Part VIII, line 12			
	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities 10b	7 ,	) ·	
11	Section 501(c)(12) organizations. Enter	]		() B
	a Gross income from members or shareholders			*
ı	Gross income from other sources (Do not net amounts due or paid to other sources	7		
	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?	12 a		
١	o If 'Yes,' enter the amount of tax-exempt interest received or accrued during the year			
13	Section 501(c)(29) qualified nonprofit health insurance issuers.			
	a Is the organization licensed to issue qualified health plans in more than one state?	13a		
	Note. See the instructions for additional information the organization must report on Schedule O			Ľ
ı	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		; ·	10 ×
•	Enter the amount of reserves on hand	. il.		dille
14	a Did the organization receive any payments for indoor tanning services during the tax year?	14a	L	X
- 1	b If 'Yes,' has it filed a Form 720 to report these payments? If 'No,' provide an explanation in Schedule O	14b		

Governance, Management and Disclosure For each 'Yes' response to lines 2 through 7b below, and for a 'No' response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O See instructions X Check if Schedule O contains a response to any question in this Part VI Section A. Governing Body and Management Yes No 1a Enter the number of voting members of the governing body at the end of the tax year 13 1 a 13 b Enter the number of voting members included in line 1a, above, who are independent 1b Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee or key employee? SEE SCHEDULE O officer, director, trustee or key employee? 2 X Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person? 3 Did the organization make any significant changes to its governing documents 4 since the prior Form 990 was filed? Did the organization become aware during the year of a significant diversion of the organization's assets? 5 Х Does the organization have members or stockholders? 6 Х 7a Does the organization have members, stockholders, or other persons who may elect one or more members of the governing body? 7a Х b Are any decisions of the governing body subject to approval by members, stockholders, or other persons? 7 b X Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following Χ a The governing body? 8 a Χ b Each committee with authority to act on behalf of the governing body? 8 b Is there any officer, director or trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If 'Yes,' provide the names and addresses in Schedule O 9 Χ Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code., Yes No 10a Does the organization have local chapters, branches, or affiliates? 10a Χ b If 'Yes,' does the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with those of the organization? 10b 11 a Has the organization provided a copy of this Form 990 to all members of its governing body before filing the form? Х 11 a **b** Describe in Schedule O the process, if any, used by the organization to review this Form 990 X 12a Does the organization have a written conflict of interest policy? If 'No,' go to line 13 12a **b** Are officers, directors or trustees, and key employees required to disclose annually interests that could give rise to conflicts? 12b Х c Does the organization regularly and consistently monitor and enforce compliance with the policy? If 'Yes,' describe in Χ Schedule O how this is done SEE SCHÉDULE O 12c Χ 13 Does the organization have a written whistleblower policy? 13 14 Does the organization have a written document retention and destruction policy? 14 Х Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? a The organization's CEO, Executive Director, or top management official 15 a Х **b** Other officers of key employees of the organization 15<sub>b</sub> If 'Yes' to line 15a or 15b, describe the process in Schedule O (See instructions ) **16 a** Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? 16a b If 'Yes,' has the organization adopted a written policy or procedure requiring the organization to evaluate its إذا participation in joint venture arrangements under applicable federal tax law, and taken steps to safeguard the organization's exempt status with respect to such arrangements? 16b Section C. Disclosure List the states with which a copy of this Form 990 is required to be filed ► NONE Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you make these available. Check all that apply Own website Another's website |X| Upon request Describe in Schedule O whether (and if so, how) the organization makes its governing documents, conflict of interest policy, and financial 19 SEE SCHEDULE O statements available to the public State the name, physical address, and telephone number of the person who possesses the books and records of the organization ► GEOFFREY STACK 18802 BARDEEN AVE IRVINE CA 92612 949 756-5959

Form <b>990</b> (2010)	CYSTINOSIS	RESEARCH	FOUNDATION

32-0067668

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

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

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

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

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

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

(A)	(B)	T TOTAL O	<u>. u - u .</u>		C)	1011 00	рс	(D)	(E)	(F)		
Name and title	Average hours per week (describe hours for related	ndividual trustee or director	nstitutional trustee	Officer	a Key employee	an Highest co	Former	Reportable compensation from the organization (W 2/1099 MISC)	Reportable compensation from related organizations (W 2/1099 MISC)	Estimated amount of other compensation from the organization and related		
•	organiza tions in Schedule O)	trustee	al trustee		yee	Highest compensated employee				organizations		
(1) GEOFFREY STACK TRUSTEE	- 0	Х				İ		0.	0.	0.		
(2) NANCY STACK TRUSTEE	40	Х		-	-			0.	0.	0.		
(3) DONALD L. SOLSBY TREASURER	- 0	X	-					0.	0.	0.		
(4) BRUCE CRAIR DIRECTOR	- 0	X						0.	0.	0.		
(5) RENEE CARTER	- 0	X	-					0.	0.	0.		
DIRECTOR  (6) DAVID CHRISTENSEN								0.				
DIRECTOR  (7) JASON GRIER	- 0	X							0.	0.		
DIRECTOR (8) JOHN S. HAGESTAD	0	X				-		0.	0.	0.		
DIRECTOR (9) LYNETTE HAYDE	0	X	-				-	0.	0.	0.		
DIRECTOR (10) MICHAEL K. HAYDE	0	Х						0.	0.	0.		
DIRECTOR (11) KRIS K. ELFTMANN	0	X				<u>-</u>	-	0.	0.	0.		
DIRECTOR (12) KEVIN PARTINGTON	0	X			-			0.	0.	0.		
DIRECTOR (13) TERESA PARTINGTON	0	X						0.	0.	0.		
DIRECTOR (14) TRICIA STURGIS	0	Х	-				 	0.	0.	0.		
DIRECTOR (15) WHITNEY GLAIZE	0	X	<u> </u>					0.	0.	0.		
DIRECTOR (16)	0	X			_		_	0.	0.	0.		
47	-	ļ <u>-</u>		_	_							
	<u> </u>											

Part VII   Section A. Officers, Directors, Trus	tees, k	(ey	Em	ıplo	ye	es, a	ano	d Highest Con	pensated Em	ployee	<b>s</b> (co	nt)
` (A)	(B)			(0				(D)	(E)		(F)	
Name and title	Average hours per week							Reportable compensation from the organization	Reportable compensation from	om Estimated amount of o compensat		lher
	(describe	dıvıdı	strtuti	Officer	Key employee	ghest	Former	(W-2/1099 MISC)	related organizations (W 2/1099 MISC)	OI	from the ganization	
	organi-	al tru	onal		ploy	ee				la	nd relate janizatio	ed
	per week (describe hours for related organi- zations in Sch O)	ustee	Institutional trustee		ee	Highest compensated						
			й			ated						
(18)	<u> </u>		_			-	_			-		
	<u> </u>											
_(19)												
(20)							_					
(21)						_				-		
(22)						_						
(23)		-	_							-		
			_						·			
_(24)												
(25)												
(26)												
(27)						_						<del></del>
(28)									-	-		
(29)						-				-	·	
1 b Sub-total	_					•	<b>-</b>	0.	0			0.
c Total from continuation sheets to Part VII, Section d Total (add lines 1b and 1c)	Α					·	_	0. 0.	0			0.
Total number of individuals (including but not limite	d to tho	se li	sted	abo	ove)	who	rec				mpens	
from the organization   0	<u>-</u>											
3 Did the organization list any former officer, director	or truct	00	4014	omr	Nove		r hi	about component	ad amplayas	,	Yes	No
on line 1a? If 'Yes,' complete Schedule J for such ii	ndıvıduz	al	чеу	cmp	лоус	.e, oi		gnest compensati	ed employee	3	<u> </u>	X
4 For any individual listed on line 1a, is the sum of re the organization and related organizations greater ti such individual	portable han \$15	cor 60,00	npei 10? /	nsat If 'Y	ion es' d	and o	oth elete	er compensation e Schedule J for	from		_	
5 Did any person listed on line 1a receive or accrue of for services rendered to the organization? If 'Yes,' or accrue to the organization of t	ompens	atio	n fro	om a	any u	unrel	ate	d organization or	ındıvıdual	4		X
Section B. Independent Contractors	Jonpieu	9 30	neut	uie .	<i>J</i> 101	Suci	T P	erson		5		<u> X</u>
Complete this table for your five highest compensation from the organization	ed inde	pend	lent	con	trac	tors	tha	t received more th	nan \$100,000 of			
(A)				•••				(B)			(C)	
Name and business addres	s							Description of	of services	Comp	eńsatio	n ———
							-					
							$\dashv$				<u> </u>	
	<del>_</del>						_					
2 Total number of independent contractors (including	but not	limi	ed t	to th	1056	liste	 d a	hove) who receive	ed more than	<del></del>	*	
\$100,000 in compensation from the organization			(		.000		u d	STO, WIND TECETO	oo more triair			;

Pai	rt VIII   Statement of Revenue				
•		<b>(A)</b> Total revenue	(B) Related or exempt function revenue	<b>(C)</b> Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514
CONTRIBUTIONS, GIFTS, GRANTS AND OTHER SIMILAR AMOUNTS		2,220,084.			
PROGRAM SERVICE REVENUE	Business Code  2 a  b  c  d  e  f All other program service revenue  g Total. Add lines 2a-2f				
	3 Investment income (including dividends, interest and other similar amounts) 4 Income from investment of tax-exempt bond proceeds 5 Royalties  (i) Real (ii) Personal 6a Gross Rents b Less rental expenses c Rental income or (loss)	20,489.	20,489.		
i	d Net rental income or (loss)  7 a Gross amount from sales of assets other than inventory  b Less cost or other basis and sales expenses  c Gain or (loss)  d Net gain or (loss)	18,683.	18,683.		
OTHER REVENUE	8a Gross income from fundraising events (not including \$		4	,	1
	9a Gross income from gaming activities See Part IV, line 19  b Less direct expenses c Net income or (loss) from gaming activities  10a Gross sales of inventory, less returns and allowances a b Less cost of goods sold b		; ; ; 5 v		, , ,
	c Net income or (loss) from sales of inventory  Miscellaneous Revenue  Business Code  11 a  b  c  d All other revenue				
	e Total. Add lines 11a-11d  12 Total revenue. See instructions	2,259,256.	39,172.	0.	0.

# Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns All other organizations must complete column (A) but are not required to complete columns (B), (C), and (D)

	ude amounts reported on lines 9b, and 10b of Part VIII.	(A) Total expenses	<b>(B)</b> Program service expenses	(C) Management and general expenses	( <b>D)</b> Fundraising expenses
1 Grants and or line 21	s and other assistance to governments ganizations in the U.S. See Part IV,	1,478,152.	1,478,152.		
	s and other assistance to individuals in S See Part IV, line 22				
organi	s and other assistance to governments, izations, and individuals outside the See Part IV, lines 15 and 16	1,094,243.	1,094,243.		
5 Comp	Its paid to or for members ensation of current officers, directors, es, and key employees	0.	0.	0.	0.
disqua section	ensation not included above, to alified persons (as defined under n 4958(f)(1)) and persons described tion 4958(c)(3)(B)	0.	0.	0.	0.
7 Other	salaries and wages				
sectio	on plan contributions (include n 401(k) and section 403(b) yer contributions)				
9 Other	employee benefits				
10 Payro	II taxes				
11 Fees f	for services (non-employees)				<del></del>
a Manag	gement				
<b>b</b> Legal					
<b>c</b> Accou	inting.	25,744.		21,417.	4,327.
<b>d</b> Lobby	ıng				
e Profess	ional fundraising services See Part IV, line 17				
<b>f</b> Invest	ment management fees				
<b>g</b> Other					
12 Adver	tising and promotion	1,000.			1,000.
13 Office	expenses				
14 Inform	nation technology				
15 Royali	ties				
<b>16</b> Occup	pancy				-
<b>17</b> Trave	l				
expen	ents of travel or entertainment ises for any federal, state, or local officials				
19 Confe	rences, conventions, and meetings				
20 Intere	st				
,	ents to affiliates				
22 Depre	ciation, depletion, and amortization	9,233.		9,233.	
23 Insura	· L				- · · · · · · · · · · · · · · · · · · ·
covere in line of line	expenses Itemize expenses not ed above (List miscellaneous expenses e 24f If line 24f amount exceeds 10% e 25, column (A) amount, list line 24f isses on Schedule O)			\$	,
a SYMI	POSIUM	88,952.	88,952.		
b PRII	NTING AND PUBLICATIONS	82,802.	19,826.	9,909.	53,067.
c OUT	SIDE SERVICES	71,419.		31,951.	39,468.
d HOTI	EL FEES - FUNDRAISER	68,777.			68,777.
	FESSIONAL SERVICES	39,773.		39,773.	
f All oth	ner expenses.	133,298.	44,335.	17,916.	71,047.
25 Total f	unctional expenses Add lines 1 through 24f	3,093,393.	2,725,508.	130,199.	237,686.
26 Joint SOP 9 only 11 (B) jo	costs. Check here  if following 98-2 (ASC 958-720) Complete this line f the organization reported in column int costs from a combined educational aign and fundraising solicitation				
BAA					Form <b>990</b> (2010)

Part X	Balance Sheet						
			(A) Beginning of year		<b>(B)</b> End of year		
1	Cash — non-interest-bearing			1			
2	Savings and temporary cash investments	2,103,655.	2	2,497,521.			
3	Pledges and grants receivable, net		1,202,423.	3	135,821		
4	Accounts receivable, net			4			
5	Receivables from current and former officers, director and highest compensated employees Complete Part		5				
6	Receivables from other disqualified persons (as defin persons described in section 4958(c)(3)(B), and contisponsoring organizations of section 501(c)(9) volunta organizations (see instructions)		6				
S 7 8 T	Notes and loans receivable, net			7			
S 8	Inventories for sale or use			8			
š   9	Prepaid expenses and deferred charges		29,691.	9	59,541.		
10 a	Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	10a 56,838.			*		
- 1	Less accumulated depreciation.	10b 20,436.	35,985.	10 c	36,402.		
- 1	Investments – publicly traded securities		638,637.	11	740,616.		
12	Investments – other securities See Part IV, line 11	i		12			
13	Investments – program-related See Part IV, line 11			13			
14	Intangible assets	j		14			
15	Other assets See Part IV, line 11			15			
16	Total assets Add lines 1 through 15 (must equal line	34)	4,010,391.	16	3,469,901.		
17	Accounts payable and accrued expenses	15,304.	17	19,294.			
18	Grants payable		2,092,371.	18	2,305,929.		
19	Deferred revenue			19	2,000,323.		
누 20	Tax-exempt bond liabilities.			20			
A 21	Escrow or custodial account liability Complete Part	IV of Schedule D		21			
22	Payables to current and former officers, directors, tru highest compensated employees, and disqualified pe of Schedule L	istees, key employees, rsons Complete Part II		22			
E 23	Secured mortgages and notes payable to unrelated the	hird parties		23			
24		· '	<del></del>	24			
25	Other liabilities Complete Part X of Schedule D	, parties	<del></del>	25			
26	<b>Total liabilities.</b> Add lines 17 through 25		2,107,675.	26	2,325,223.		
	Organizations that follow SFAS 117, check here	X and complete lines			2,020,220.		
P F	27 through 29 and lines 33 and 34.		*				
§ 27	Unrestricted net assets		1,902,716.	27	1,144,678.		
A 27 E 28 S 29	Temporarily restricted net assets		<u> </u>	28			
š   29				29			
Q R	Organizations that do not follow SFAS 117, check he			_			
1	lines 30 through 34.	ere   and complete					
F   30	Capital stock or trust principal, or current funds		^ 1	30			
Į.		d-in or capital surplus, or land, building, or equipment fund tained earnings, endowment, accumulated income, or other funds					
Ā 32							
B 31 32 NC 33 E 34	Total net assets or fund balances						
š 34	Total liabilities and net assets/fund balances		1,902,716. 4,010,391.	33	1,144,678. 3,469,901.		
BAA					Form <b>990</b> (201		

TEEA0111L 12/21/10

Forn	n 990 (2010) CYSTINOSIS RESEARCH FOUNDATION 32-0	067668		Pa	ge <b>12</b>
Pai	t XI Reconciliation of Net Assets				
•	Check if Schedule O contains a response to any question in this Part XI				X
	ı	1			
1	Total revenue (must equal Part VIII, column (A), line 12)	1		<u>59,2</u>	
2	Total expenses (must equal Part IX, column (A), line 25)	2		<u>93,3</u>	
3	Revenue less expenses Subtract line 2 from line 1	3	-8	<u>34,1</u>	<u>37.</u>
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	1,9	02,7	16.
5	Other changes in net assets or fund balances (explain in Schedule O) SEE SCHEDULE O	5		76,0	99.
6	Net assets or fund balances at end of year Combine lines 3, 4, and 5 (must equal Part X, line 33, column (B))	6	1,1	44,6	78.
Pai	rt XII Financial Statements and Reporting				
	Check if Schedule O contains a response to any question in this Part XII				
		1		Yes	No
1	Accounting method used to prepare the Form 990 Cash X Accrual Other				ŧ
	If the organization changed its method of accounting from a prior year or checked 'Other,' explain in Schedule O				
2	a Were the organization's financial statements compiled or reviewed by an independent accountant?		2a		X
l	b Were the organization's financial statements audited by an independent accountant?		2b	Χ	
,	c If 'Yes' to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the review, or compilation of its financial statements and selection of an independent accountant?	ne audit,	2 c	Х	
	If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O				, -uar
(	d If 'Yes' to line 2a or 2b, check a box below to indicate whether the financial statements for the year were issue separate basis, consolidated basis, or both	ed on a			•
	X Separate basis Consolidated basis Both consolidated and separate basis				.'
3	a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the audit Act and OMB Circular A-133?	Single	3a		<u>X</u>
1	<b>b</b> If 'Yes,' did the organization undergo the required audit or audits? If the organization did not undergo the required audits, explain why in Schedule O and describe any steps taken to undergo such audits.	ired audit	3 b		

Form **990** (2010)

BAA

TEEA0112L 12/21/10

# SCHEDULE A (Form 990 or 990-EZ)

**Public Charity Status and Public Support** 

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

OMB No 1545 0047

Open to Public Inspection

Department of the Treasury Internal Revenue Service

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

Marrie C	or the organization							Employer	identificat	tion number			
	TINOSIS RESEARCH	FOUNDATION						32-00	067668	3			
Parl	Part I Reason for Public Charity Status (All organizations must complete this part.) See instructions												
The c	organization is not a priva	ite foundation becaus	se it is (For lines 1 thro	ugh 11,	check o	nly one	box)						
1	A church, convention	of churches or asso	ciation of churches des	cribed ir	section	170(b)	(1)(A)(i)						
2	A school described in	n section 170(b)(1)(A	)(ii). (Attach Schedule I	E)									
3	A hospital or a coope	erative hospital servic	ce organization describe	ed in <b>se</b>	ction 17	0(b)(1)(A	\)(iii).						
4	A medical research of	organization operated	I in conjunction with a h	ospital	describe	d in <b>sec</b>	tion 17	0(b)(1)(A	<b>()(III)</b> Er	nter the hospital's			
	name, city, and state												
5	170(b)(1)(A)(ıv). (Co	mplete Part II)	of a college or university			-	_	nmental	unit de	scribed in <b>section</b>			
6													
7	An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in section 170(b)(1)(A)(vi). (Complete Part II)												
8	A community trust described in section 170(b)(1)(A)(vi). (Complete Part II )												
9	A community trust described in <b>Section 176(b) 1744(v)</b> . (complete Farth)  An organization that normally receives (1) more than 33-1/3% of its support from contributions, membership fees, and gross receipts												
	from activities related to its exempt functions — subject to certain exceptions, and (2) no more than 33-1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975 See section 509(a)(2). (Complete Part III)												
10	An organization orga	inized and operated e	exclusively to test for pu	ublic saf	ety See	section	1 509(a)	(4).					
11	more publicly suppor	ted organizations de	exclusively for the bene scribed in section 509(a	a)(1) or $s$	section 5	509(a)(2	ictions o	of, or car section 5	rry out th 5 <b>09(a)(3)</b>	ne purposes of one or o. Check the box that			
			tion and complete lines		_				. —				
	<b>a</b> ∐Type I	<b>b</b> Type II	c Type II		_	_			q 🖳	Type III - Other			
e	other than foundation section 509(a)(2)	, I certify that the org n managers and othe	panization is not control r than one or more pub	led dired licly sup	ctly or in ported o	directly organiza	by one itions de	or more escribed	disquali in section	ified persons on 509(a)(1) or			
f	If the organization re check this box	ceived a written dete	rmination from the IRS	that is	a Type I	, Type II	l or Typ	e III sup	porting (	organization,			
g	Since August 17, 200	06, has the organizat	ion accepted any gift o	r contrib	oution fro	om any	of the fo	ollowing	persons	37			
								_		Yes No			
	(i) A person who obelow, the gove	directly or indirectly o erning body of the su	ontrols, either alone or pported organization?	togethe	r with pe	ersons d	lescribe	d in (ii) a	and (III)	11 g (ı)			
	(ii) A family memb	er of a person descri	bed in (i) above?							11g (iı)			
	(iii) A 35% controlle	ed entity of a person	described in (i) or (ii) a	bove?						11g (iii)			
h	Provide the following	information about th	ne supported organization	on(s)									
	(i) Name of supported organization	(II) EIN	(III) Type of organization (described on lines 1 9 above or IRC section (see instructions))	column (	ls the zation in i) listed in overning ment?	the organ	rou notify nization in n (i) of upport?	(vi) li organiza colun organiza U S	ation in	(vii) Amount of support			
				Yes	No	Yes	No	Yes	No				
<u>(A)</u>													
(B)													
(C)													
(D)													
(D)							-						
<u>(E)</u>				· · ·									
Total													

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

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III If the organization fails to qualify under the tests listed below, please complete Part III )

Sec	tion A. Public Support											
Caleı begir	ndar year (or fiscal year nning in) ►	(a) 2006	<b>(b)</b> 2007	(c) 2008	(d) 2009	<b>(e)</b> 2010	(f) Total					
1	Gifts, grants, contributions, and membership fees received (Do not include unusual grants ')	1,668,193.	2,562,050.	2,752,925.	3,223,627.	2,220,084.	12,426,879.					
2	Tax revenues levied for the organization's benefit and either paid to it 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	1,668,193.	2,562,050.	2,752,925.	3,223,627.	2,220,084.	12,426,879.					
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)						5,074,017.					
6	Public support. Subtract line 5 from line 4						7,352,862.					
Sec	tion B. Total Support											
	ndar year (or fiscal year nning in) (a) 2006 (b) 2007 (c) 2008 (d) 2009 (e) 2010											
7	Amounts from line 4	1,668,193.	2,562,050.	2,752,925.	3,223,627.	2,220,084.	12,426,879.					
8	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	48,939.	106,545.	48,418.	38,527.	20,489.	262,918.					
9	Net income from unrelated business activities, whether or not the business is regularly carried on						0.					
10	Other income Do not include gain or loss from the sale of capital assets (Explain in Part IV)						0.					
11	Total support. Add lines 7 through 10						12,689,797.					
12	Gross receipts from related activ	vities, etc (see ins	structions)			12	0.					
13	First five years. If the Form 990 organization, check this box and		ation's first, seco	nd, third, fourth, c	or fifth tax year as	a section 501(c)	(3)					
Sec	tion C. Computation of Pu				<u></u>							
14	Public support percentage for 20			ne 11, column (f))	•	14	57.9%					
15	Public support percentage from	2009 Schedule A	, Part II, line 14			15	62.7%					
16 a	a 33-1/3% support test – 2010. If and stop here. The organization				nd the line 14 is 3	3-1/3% or more,	check this box					
t	b 33-1/3% support test — 2009. If the organization did not check a box on line 13 or 16a, and line 15 is 33-1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization   ■											
17 a	17a 10%-facts-and-circumstances test — 2010. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the 'facts-and-circumstances' test, check this box and stop here. Explain in Part IV how the organization meets the 'facts-and-circumstances' test. The organization qualifies as a publicly supported organization.											
	<b>b 10%-facts-and-circumstances test</b> — <b>2009.</b> If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the 'facts-and-circumstances' test, check this box and <b>stop here.</b> Explain in Part IV how the organization meets the 'facts-and-circumstances' test. The organization qualifies as a publicly supported organization.											
18	Private foundation. If the organ	ization did not che	eck a box on line	13, 16a, 16b, 17a	<u> </u>							
BAA					Sc	hedule A (Form	990 or 990-EZ) 2010					

# Part III | Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 9 of Part I or if the organization failed to qualify under Part II If the organization fails to qualify under the tests listed below, please complete Part II)

Sec	tion A. Public Support						
Calen	dar year (or fiscal yr beginning in)►	(a) 2006	<b>(b)</b> 2007	(c) 2008	(d) 2009	<b>(e)</b> 2010	(f) Total
1	Gifts, grants, contributions and membership fees received (Do not include any unusual grants ')						
	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 5	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf The value of services or						
J	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						
t	Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c	: Add lines 7a and 7b						
	<b>Public support</b> (Subtract line 7c from line 6)						
Sec	tion B. Total Support		<del>,</del>	1			
Calen	dar year (or fiscal yr beginning in)►	(a) 2006	<b>(b)</b> 2007	(c) 2008	(d) 2009	<b>(e)</b> 2010	<b>(f)</b> Total
	Amounts from line 6 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from						
t	similar sources.  Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
	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 IV)						
13	Total support. (Add Ins 9, 10c, 11, and 12)						
	First five years. If the Form 990 organization, check this box and	is for the organiz	ation's first, secoi	nd, third, fourth, c	or fifth tax year as	a section 501(c)(3)	)
							<b>P</b>
	tion C. Computation of Pu			10	<del></del>		
15	Public support percentage for 20	• •	• • • • • • • • • • • • • • • • • • • •	ne 13, column (f))	)	15	<u> </u>
16	Public support percentage from					16	%
Sec	tion D. Computation of Inv				<del></del>	<del></del>	<del></del>
17	Investment income percentage f			•	ımn (f))	17	%
18	Investment income percentage f					18	%
	33-1/3% support tests — 2010. If is not more than 33-1/3%, check	this box and <b>sto</b>	<b>p here.</b> The orgar	nization qualifies a	as a publicly supp	orted organization	▶ [_]
t	33-1/3% support tests – 2009. If Ine 18 is not more than 33-1/3%	the organization , check this box	did not check a b and <b>stop here.</b> Th	oox on line 14 or l e organization qu	line 19a, and line ialifies as a public	16 is more than 33- ly supported organi	·1/3%, and zation ►
20	Private foundation. If the organi				· · · · · · · · · · · · · · · · · · ·	· · · · · ·	▶

schedure A	(FORM 990 OF 990-EZ)	2010 CISITNOS	TO KESEAKCH L	OUNDATION	32-006/66	Page 4
Part IV	Supplemental Info Part II, line 17a or (See instructions)	ormation. Completed 17b, and Part III,	te this part to pro line 12 Also co	ovide the explanati implete this part fo	ons required by Part r any additional infor	II, line 10, mation
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# (Form 990)

Department of the Treasury Internal Revenue Service

# Supplemental Financial Statements

► Complete if the organization answered 'Yes,' to Form 990, Part IV, lines 6, 7, 8, 9, 10, 11, or 12.

► Attach to Form 990. ► See separate instructions.

OMB No 1545 0047

Open to Public Inspection

Name of the organization Employer identification number CYSTINOSIS RESEARCH FOUNDATION 32-0067668 Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts. Complete if the organization answered 'Yes' to Form 990, Part IV, line 6 (a) Donor advised funds (b) Funds and other accounts 1 Total number at end of year Aggregate contributions to (during year) Aggregate grants from (during year) Aggregate value at end of year Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? No Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? Nο Part II | Conservation Easements. Complete if the organization answered 'Yes' to Form 990, Part IV, line 7 Purpose(s) of conservation easements held by the organization (check all that apply) Preservation of land for public use (e.g., recreation or education) Preservation of an historically important land area Protection of natural habitat Preservation of a certified historic structure Preservation of open space Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year Held at the End of the Tax Year 2a a Total number of conservation easements b Total acreage restricted by conservation easements 2b 2 c c Number of conservation easements on a certified historic structure included in (a) d Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register 2dNumber of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year ► Number of states where property subject to conservation easement is located > Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? Staff and volunteer hours devoted to monitoring, inspecting, and enforcing conservation easements during the year 6 7 Amount of expenses incurred in monitoring, inspecting, and enforcing conservation easements during the year ▶\$ Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section  $170(h)(4)(B)(ii)^{2}$ In Part XIV, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Complete if the organization answered 'Yes' to Form 990, Part IV, line 8 1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIV, the text of the footnote to its financial statements that describes these items b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items (i) Revenues included in Form 990, Part VIII, line 1 ▶\$ (ii) Assets included in Form 990, Part X ▶\$ If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items a Revenues included in Form 990, Part VIII, line 1 ▶\$

b Assets included in Form 990, Part X

▶\$

Schedule <b>D</b> (Form 990) 2010 CYSTI	MOSTS RES	SFARCH FOUNDAT	TON	32-006	57668 Page <b>2</b>
Part III Organizations Maintain					
3 Using the organization's acquisition items (check all that apply)					
a Public exhibition		<b>d</b> Loan	or exchange programs		
<b>b</b> Scholarly research		e Other			
c Preservation for future genera	ations				
4 Provide a description of the organ Part XIV	nization's colle	ections and explain ho	w they further the organ	nization's exempt purpo	se in
5 During the year, did the organizat assets to be sold to raise funds ra	ather than to b	oe maintained as part	of the organization's co	llection?	Yes No
Part IV Escrow and Custodial 9, or reported an amou	Arrangement on Form	ents. Complete if 990, Part X, line	organization answe 21	ered 'Yes' to Form S	990, Part IV, line
1a Is the organization an agent, trust included on Form 990, Part X?	tee, custodian	, or other intermedially	for contributions or oth	ner assets not	Yes No
<b>b</b> If 'Yes,' explain the arrangement	ın Part XIV ar	nd complete the follow	ıng table		
					Amount
c Beginning balance				1c	
<b>d</b> Additions during the year				1 d	
e Distributions during the year				1 e	
f Ending balance				1f	
2a Did the organization include an ar	mount on Forr	n 990, Part X, line 21	?		Yes No
<b>b</b> If 'Yes,' explain the arrangement					
Part V   Endowment Funds. Co	mplete if th	e organization an	swered 'Yes' to For	m 990, Part IV, Im	e 10
	(a) Current y	ear (b) Prior yea	r (c) Two years bac	k (d) Three years back	(e) Four years back
1 a Beginning of year balance					
<b>b</b> Contributions					
c Net investment earnings, gains, and losses					
<b>d</b> Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					*
<b>g</b> End of year balance					
2 Provide the estimated percentage	of the year e	nd balance held as			
a Board designated or quasi-endow	ment ►	%			
<b>b</b> Permanent endowment	%	<del>.</del>			
c Term endowment ►	ું જ				
3a Are there endowment funds not in organization by	n the possess	ion of the organization	that are held and adm	inistered for the	Yes No
(i) unrelated organizations					3a(ı)
(II) related organizations					3a(ii)
<b>b</b> If 'Yes' to 3a(II), are the related o	rganizations li	isted as required on S	chedule R?		3b
4 Describe in Part XIV the intended	uses of the c	organization's endowm	ent funds		
Part VI Land, Buildings, and E	quipment.	See Form 990, P.	art X, line 10		
Description of investment		(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
<b>1 a</b> Land					
<b>b</b> Buildings					

c Leasehold improvements 56,838. 20,436 36,402. **d** Equipment e Other Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c)) 36,402.

BAA

Schedule **D** (Form 990) 2010

	D (Form 990) 2010 CYSTINOSIS RESEARC			32-0067668 Page 3
	Investments-Other Securities. See F			
•	(a) Description of security or category (including name of security)	(b) Book value	(c) N Cost or e	Method of valuation and-of-year market value
(1) Financ	cial derivatives			
(2) Closel	ly-held equity interests			
(3) Other				
	. <b></b>			
<u>(B)</u>	<b></b>			
<u>(C)</u>	. <b></b>			
<u>(D)</u>	. <b></b>			
<u>(E)</u>				
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_(l)				
	umn (b) must equal Form 990 Part X, column (B) line 12)			
Part VII	I Investments-Program Related. (See			
	(a) Description of investment type	(b) Book value	(c) N	Method of valuation and-of-year market value
(1)			Cost of e	nu-or-year market value
(2)				
(3)				
(4)				
(5)				
(6)				
(7)			1	
(8)			<u> </u>	
(9)				
(10)				
<del></del>	umn (b) must equal Form 990, Part X, column (B) line 13)			
Part IX		line 15) N/A	A	
	<b>(a)</b> De	scription		(b) Book value
(1)				
(2)				
(3)				
(4)			····	
(5)			· · · · · · · · · · · · · · · · · · ·	
(6)		·		
(7)				
(8)				
(9)				
(10)				
	Column (b) must equal Form 990 Part X, column(E			<u> </u>
Part X	Other Liabilities. (See Form 990, Part	<del></del>		
	(a) Description of liability	(b) Amount		\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \
	leral income taxes			
(2)				
(3)				
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(5)				
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(10)				
(11)	uma (h) must sound Force 000 Part V salvers (D) line 25	<b>•</b>		
rotal (Colt	umn (b) must equal Form 990, Part X, column (B) line 25)		I	

2. FIN 48 (ASC 740) Footnote In Part XIV, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740)

Schedule D (Form 990) 2010 CISTINOSIS RESEARCH FOUNDATION	<del> </del>	-0067	668 Page <b>4</b>
Part XI   Reconciliation of Change in Net Assets from Form 990 to Audited Fin	nancial Statements		
1 Total revenue (Form 990, Part VIII, column (A), line 12)		L	2,259,256.
2 Total expenses (Form 990, Part IX, column (A), line 25)			3,093,393.
3 Excess or (deficit) for the year Subtract line 2 from line 1		L	-834,137.
4 Net unrealized gains (losses) on investments			76,099.
5 Donated services and use of facilities		L	
6 Investment expenses			
7 Prior period adjustments		L	
8 Other (Describe in Part XIV)			
9 Total adjustments (net) Add lines 4 through 8			76,099.
10 Excess or (deficit) for the year per audited financial statements. Combine lin	nes 3 and 9		-758,038.
Part XII Reconciliation of Revenue per Audited Financial Statem	nents With Revenue per Re	turn	
1 Total revenue, gains, and other support per audited financial statements		1	2,335,355.
2 Amounts included on line 1 but not on Form 990, Part VIII, line 12			
a Net unrealized gains on investments	2a 76,099.		
<b>b</b> Donated services and use of facilities	2b		
c Recoveries of prior year grants	2c		
d Other (Describe in Part XIV)	2 d		
e Add lines 2a through 2d		2 e	76,099.
3 Subtract line 2e from line 1		3	2,259,256.
4 Amounts included on Form 990, Part VIII, line 12, but not on line 1			, ,
a Investments expenses not included on Form 990, Part VIII, line 7b	4a		
<b>b</b> Other (Describe in Part XIV.)	4b		
c Add lines <b>4a</b> and <b>4b</b>		4c	
5 Total revenue Add lines 3 and 4c. (This must equal Form 990, Part I, line 1	12)	5	2,259,256.
Part XIII Reconciliation of Expenses per Audited Financial State			
Total expenses and losses per audited financial statements		1	3,093,393.
2 Amounts included on line 1 but not on Form 990, Part IX, line 25			
a Donated services and use of facilities	2a		
<b>b</b> Prior year adjustments	2 b		
c Other losses	2c		
d Other (Describe in Part XIV.)	2d		
e Add lines 2a through 2d		2 e	
3 Subtract line 2e from line 1		3	3,093,393.
4 Amounts included on Form 990, Part IX, line 25, but not on line 1:	] ]		3,033,333.
a Investments expenses not included on Form 990, Part VIII, line 7b	4 a		
<b>b</b> Other (Describe in Part XIV )	4b		
c Add lines 4a and 4b		4c	
5 Total expenses Add lines 3 and 4c. (This must equal Form 990, Part I, line	18)	5	3,093,393.
Part XIV   Supplemental Information			
Complete this part to provide the descriptions required for Part II, lines 3, 5, and 9 Part V, line 4, Part X, line 2, Part XI, line 8, Part XII, lines 2d and 4b, and Part XI any additional information	9, Part III, lines 1a and 4, Part IV, III, lines 2d and 4b Also complete	lines 1t this pa	o and 2b, rt to provide
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TEEA3304L 02/11/11

Schedule **D** (Form 990) 2010

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Schedule <b>D</b>	(Form 990) 2010	CYSTINOSIS RESEARCH Information (continued)	FOUNDATION	32-0067668	Page <b>5</b>
Part XIV	Supplemental	Information (continued)			
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## Schedule F (Form 990)

# Statement of Activities Outside the United States

OMB No 1545 0047

Department of the Treasury Internal Revenue Service

► Complete if the organization answered 'Yes' to Form 990, Part IV, line 14b, 15, or 16. ► Attach to Form 990. ► See separate instructions.

Open to Public Inspection

Name of the organization

Employer identification number

Part I General Information on Activities Outside the United States. Complete if the organization answered 'Yes' to Form 990, Part IV, line 14b

1 For grantmakers. Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? X Yes No

2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of grant funds outside the United States

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

(a) Region (b) Number of offices in the offices in the offices in the offices, in the offices, in the offices, in the offices in the offi

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in region	(d) Activities conducted in region (by type) (e.g., fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for and investments in region
(1)					
(2)		_			·
(3)					
(4)					
(5)					
(6)					
(7)					<u>.</u>
(8)					
(9)	<u> </u>				
(10)					·
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)		-			
<b>3a</b> Sub-total <b>b</b> Total from continuation				λ*	
sheets to Part I c Totals (add lines 3a and 3b)	0	0		200	0.

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

Schedule **F** (Form 990) 2010

32-0067668

Page 2

Schedule F (Form 990) 2010 CYSTINOSIS RESEARCH FOUNDATION

Part II Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 15, for any recipient who received more than \$5,000 Check this box if no one recipient received more than \$5,000 Part II can be duplicated if additional space is needed.

(i) Method of valuation (book, FMV, appraisal, other)																
(h) Description of non-cash assistance																
(g) Amount of non-cash assistance																
(f) Manner of cash disbursement	СНЕСК	CHECK	CHECK	CHECK	CHECK											
(e) Amount of cash grant	233, 999.	236,000.	169,384.	146,258.	308,602.											
(d) Purpose of grant	RESEARCH	RESEARCH	RESEARCH	RESEARCH	RESEARCH											
(c) Region	BELGIUM	BELGIUM	FRANCE	IRELAND	ITALY											
(b) IRS code section and EIN (if applicable)																
(a) Name of organization																
-	€	8	ම	4	(9)	9	6	<b>⊚</b>	. 9	<u></u>	E	(12)	(£13)	(4.P)	; *** ( <b>5</b> 1)* ;	(16)

the grantee or counsel has provided a section 501(c)(3) equivalency letter

3 Enter total number of other organizations or entities

BAA

Schedule F (Form 990) 2010

Page 3

Schedule F (Form 990) 2010 CYSTINOSIS RESEARCH FOUNDATION

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

(f) Amount of non-cash assistance non-cash assistance non-cash assistance (book, FMV, appraisal, other)																	
(e) Manner of cash disbursement																	
(c) Number of recipients cash grant																	
(b) Region																	
(a) Type of grant or assistance	(3)	(2)	(3)	(4)	(5)	(9)	ω	(8)	(6)	(10)	(11)	(12)	(13)	(14)	(15)	(16)	(17)

Sche	dule F (Form 990) 2010 CYSTINOSIS RESEARCH FOUNDATION 32	:-006/668	Page 4
Par	t IV Foreign Forms		
i	Was the organization a U.S. transferor of property to a foreign corporation during the tax year? If 'Yes,' the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see instructions for Form 926)	Yes	X No
2	Did the organization have an interest in a foreign trust during the tax year? If 'Yes,' the organization may be required to file Form 3520, Annual Return To Report Transactions with Foreign Trusts and Receipt of Certa 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)		X No
3	Did the organization have an ownership interest in a foreign corporation during the tax year? If 'Yes,' the organization may be required to file Form 5471, Information Return of U.S. Persons with respect to Certain Foreign Corporations (see instructions for Form 5471)	Yes	X No
4	Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualifier electing fund during the tax year? If 'Yes,' the organization may be required to file Form 8621, Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see instructions for Form 8621)	d Yes	X No
5	Did the organization have an ownership interest in a foreign partnership during the tax year? If 'Yes,' the organization may be required to file Form 8865 Return of U.S. Persons with respect to Certain Foreign Partnerships (see instructions for Form 8865)	Yes	X No
6	Did the organization have any operations in or related to any boycotting countries during the tax year? If 'Yes,' the organization may be required to file Form 5713, International Boycott Report (see instructions for Form 5713)	Yes	X No
BAA	TEEA3505L 10/27/10	Schedule <b>F</b> (F	orm 990) 2010

Schedule	<b>F</b> (Form 990) 2010	CYSTINOSIS RESEAR	RCH FOUNDATION		32-0067668	Page <b>5</b>
Part V ·	Supplemental Complete this 3, column (f) ( Part III, colum any additional	Information part to provide the information accounting method), P n (c) (estimated number information (see instru	ormation required lart II, line 1 (accorder of recipients), a actions).	by Part I, line 2 (monit unting method), Part II s applicable Also com	oring of funds), Pa I (accounting meth iplete t his part to	art I, line nod); and provide
ADD	DITIONAL SUPP	LEMENTAL INFORMA	IION	· <del></del>	<del></del>	<b></b>
SUM	MARY_OF_GRAN	TEES:			<b></b>	
1)	ACS_DU_CNRS,	16 RUE PIERRE ET	MARIE_CURIE, E	ARIS, FRANCE		
2) _	<u>BAMBINO_GESU</u>	_CHILDRENS_HOSP&	RESEARCH, PIA	ZZA_SONOFRIO,_R	OME, ITALY	
3) _	UNIVERSITY H	OSPITAL LEUVEN HEF	ESM, 49 3000 I	EUVEN, LEUVEN, BEL	<u>.GIUM</u>	
4) _	UNIVERSITY C	OLLEGE CORK, WESTE	RN_ROAD,_CORK,	_IRELAND		
5_) _	<u>DE DUVE INST</u>	ITUTE, AVENUE HIPF	OCRATE 75, 120	0 BRUSSELS, BELGI	<u>.UM</u>	
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# SCHEDULE I

Department of the Treasury Internal Revenue Service

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

Complete if the organization answered 'Yes,' to Form 990, Part IV, lines 21 or 22. ► Attatch to Form 990.

OMB No 1545 0047

Open to Public Inspection

ž (h) Purpose of grant or assistance **A** RESEARCH RESEARCH RESEARCH RESEARCH MEDICAL MEDICAL MEDICAL MEDICAL Employer identification number Form 990, Part IV, line 21 for any recipient that received more than \$5,000. Check this box if no one recipient received more than \$5,000. XYes Part II Grants and Other Assistance to Governments and Organizations in the United States. Complete if the organization answered 'Yes' to 32-0067668 (g) Description of non cash assistance 1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? (f) Method of valuation (book, FMV appraisal other) 0 0 0 0 (e) Amount of non cash assistance Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States (d) Amount of cash grant 301,825 942,703 129,557 104,067 (c) IRC section if applicable Part II can be duplicated if additional space is needed Enter total number of section 501(c)(3) and government organizations Part I General Information on Grants and Assistance 04-1564655 14-1368361 95-6006144 33-0435954 (b) EIN CYSTINOSIS RESEARCH FOUNDATION Enter total number of other organizations (1) MASSACHUSETTS GENERAL H THE SCRIPPS RESEARCH IN 10550 N. TORREY PINES R LA JOLLA, CA 92037 - 9500 GILMAN DRIVE, DEPT LA JOLLA, CA 92093 (4) UNIVERSITY OF CALIFORNI (3) UNIVERSITY OF BUFFALO. 1 (a) Name and address of organization or government NY 14260 BOSTON, MA 02199 402 CROFTS HALL Name of the organization BUFFALO, 1 1 1 <u>(2)</u> 3 9 6 8

Schedule I (Form 990) 2010

TEEA3901L 10/29/10

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

Page 2 Schedule I (Form 990) 2010 Grants and Other Assistance to Individuals in the United States. Complete if the organization answered 'Yes' to Form 990, Part IV, line 22. Part III can be duplicated if additional space is needed (f) Description of non-cash assistance Part IV | Supplemental Information. Complete this part to provide the information required in Part I, line 2, and any other additional information. (e) Method of valuation (book FMV appraisal other) (d) Amount of non cash assistance (c) Amount of cash grant CYSTINOSIS RESEARCH FOUNDATION (b) Number of recipients (a) Type of grant or assistance Schedule 1 (Form 990) 2010 Part III BAA က വ 9 8 4

# SCHEDULE L (Form 990 or 990-EZ)

**Transactions With Interested Persons** 

► Complete If the organization answered
'Yes' on Form 990, Part IV, line 25a, 25b, 26, 27, 28a, 28b, or 28c,
or Form 990-EZ, Part V, line 38a or 40b.
► Attach to Form 990 or Form 990-EZ. ► See separate instructions.

OMB No 1545-0047

2010

Open to Public Inspection

Department of the Treasury Internal Revenue Service

Name of the organization Employer identification number CYSTINOSIS RESEARCH FOUNDATION 32-0067668 Excess Benefit Transactions (section 501(c)(3) and section 501(c)(4) organizations only). Complete if the organization answered 'Yes' on Form 990, Part IV, line 25a or 25b, or Form 990-EZ, Part V, line 40b. Part I (c) Corrected? 1 (a) Name of disqualified person (b) Description of transaction (1) (2) (3) (4) (5) (6) Enter the amount of tax imposed on the organization managers or disqualified persons during the year under **►**\$ ▶\$ 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 9	90, Part IV, line 26 or	Form 990-EZ, Part V,	line 38a	•				
(a) Name of interested person and purpose	e (b) Loan the orga	to or from anization?	(c) Original principal amount	(d) Balance due	(e) In default?		(f) Approved by board or committee?		(g) Written agreement?	
	То	From			Yes	No	Yes	No	Yes	No
(1)					_					
(2)										
(3)										
(4)			i							
(5)								L		
(6)										
(7)										
(8)										
(9)										
(10)										
Total			▶\$							

Part III Grants or Assistance Benefitting Interested Persons.

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

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount and type 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) 2010

(a) Name of interested person	(b) Relationship between interested person and the	(c) Amount of transaction	(d) Description of transaction	(e) Sharin organizati revenue
	organization			Yes
(1) KRIS K. ELFTMANN	DIRECTOR		SEE NOTE (1)	les i
(2) DONALD L. SOLSBY	DIRECTOR		SEE NOTE (2)	
(3)				
(4)				
(5)				
(6)				
(7)			<del></del>	
(8)				
(9) (10)				
Part V Supplemental Information				
Complete this part to provide ad-		es to questions on Sch	nedule L (see instructions)	
Complete this part to provide ad-	altional information for response	es to questions on oci	icadic E (see instructions)	
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# **SCHEDULE M** (Form 990)

**Noncash Contributions** 

► Complete if the organizations answered 'Yes' on Form 990, Part IV, lines 29 or 30. ► Attach to Form 990.

OMB No 1545-0047

2010

Open To Public Inspection

Department of the Treasury Internal Revenue Service

Name of the organization CYSTINOSIS RESEARCH FOUNDATION Employer identification number

	YSTINOSIS RESEARCH FOUNDATION 32-0067668								
Par	t I Types of Property								
		(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	Metho noncash	od of c contrib	letermin	iing mounts	
1	Art-Works of art								
2	Art—Historical treasures								
3	Art-Fractional interests								
4	Books and publications								
5	Clothing and household goods								
6	Cars and other vehicles								
7	Boats and planes								
8	Intellectual property								
9	Securities—Publicly traded								
10	Securities-Closely held stock								
11	Securities-Partnership, LLC, or trust interests								
12	Securities-Miscellaneous					•			
13	Qualified conservation contribution— Historic structures						·		
14	Qualified conservation contribution—Other								
15	Real estate—Residential								
16	Real estate-Commercial								
17	Real estate-Other								
18	Collectibles								
19	Food inventory		•						
20	Drugs and medical supplies								
21	Taxidermy								
22	Historical artifacts								
23	Scientific specimens								
24	Archeological artifacts								
25	Other ► ()								
26	Other ► ()						-		
27	Other ► (								
28	Other ► (								
29	Number of Forms 8283 received by the organization completed Form 8283, Part IV, Done	ion during the ee Acknowled	e tax year for contribut Igement	tions for which the	29				
							Yes	No	
30	a During the year, did the organization receive by chold for at least three years from the date of the purposes for the entire holding period?	contribution ai initial contrib	ny property reported in ution, and which is no	n Part I, lines 1-28 that t required to be used fo		30 a	** * \**	X	
ı	o If 'Yes,' describe the arrangement in Part II								
	Does the organization have a gift acceptance poli	icy that requi	res the review of any r	non-standard contribution	ons?	31		Χ.	
32	a Does the organization hire or use third parties or noncash contributions?	related organ	nizations to solicit, pro	cess, or sell		32 a		X	
1	f 'Yes,' describe in Part II							1	
33	If the organization did not report an amount in co- describe in Part II	olumn (c) for	a type of property for v	which column (a) is che	ecked,			rå.	
	uescribe III Fait II					l		<b>₩</b>	

Schedule	M (Form	990) 2010	CYSTINOS	IS RE	SEARCH	FOUNDATION		32-0067	668	Page 2
Part II	Supple	mental l	nformation.	Compl	ete this	part to provide	the information requi ition	red by Part I,	lines 30b,	32b,
•	and 33	Also co	mplete this p	part for	r any ad	ditional informa	tion			
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# SCHEDULE O (Form 990 or 990-EZ)

# Supplemental Information to Form 990 or 990-EZ

OMB No 1545 0047

2010

Open to Public Inspection

Employer identification number

Department of the Treasury Internal Revenue Service Name of the organization

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.

CYS	TINOSIS RESEARCH FOUNDATION 32-0067668
	FORM 990, PART III, LINE 1 - ORGANIZATION MISSION
	THE CYSTINOSIS RESEARCH FOUNDATION'S MISSION IS TO SUPPORT CLINICAL RESEARCH INTO
	BETTER TREATMENT AND ULTIMATELY TO FIND A CURE FOR CYSTINOSIS. CRF HAS BEEN
	INSTRUMENTAL IN ESTABLISHING A WORLD-WIDE PATIENT REGISTRY TO BRING TOGETHER ALL
	THOSE WHO SUFFER FROM THIS DISEASE.
	FORM 990, PART III, LINE 4B - PROGRAM SERVICE ACCOMPLISHMENTS
	CRF ANNOUNCES TWO GLOBAL CALLS FOR RESEARCH PROPOSALS EACH YEAR. AFTER EVALUATION BY
	OUR SCIENTIFIC REVIEW BOARD, RESEARCH GRANTS ARE ISSUED. THE SCIENTIFIC REVIEW BOARD
	IS COMPOSED OF LEADING CYSTINOSIS SCIENTISTS, RESEARCHERS AND DOCTORS FROM AROUND
	THE WORLD. THE MEMBERS ARE ACTIVELY INVOLVED IN THE GRANT REVIEW PROCESS AND ADVISE
	THE CYSTINOSIS RESEARCH FOUNDATION ON THE MERIT OF EACH PROPOSAL, SUBMIT FUNDING
	RECOMMENDATIONS AND OFFER GENERAL RESEARCH GUIDELINES. IN 2006, THE FOUNDATION
	ESTABLISHED THE FIRST CYSTINOSIS RESEARCH FELLOWSHIP PROGRAM DESIGNED TO SUPPORT
	SCIENTISTS AND NEW RESEARCHERS WHO HAVE AN INTEREST IN CYSTINOSIS.
	TO DATE, THE CRF HAS FUNDED AND COMMITTED OVER \$11.8 MILLION FOR CYSTINOSIS RESEARCH
	AND HAS FUNDED MORE THAN 78 RESEARCH STUDIES AND FELLOWSHIPS IN EIGHT COUNTRIES.
	TODAY, WITH THE SUPPORT OF OUR NETWORK OF FAMILIES AND FRIENDS WE HAVE MADE A
	SIGNIFICANT AND DRAMATIC DIFFERENCE IN THE COURSE OF CYSTINOSIS RESEARCH.
	THE CYSTINOSIS RESEARCH FOUNDATION'S PRIMARY FOCUS IS TO FIND A CURE FOR CYSTINOSIS.
	A GROUP OF LEADING RESEARCHERS IN STEM CELL AND GENE THERAPIES, MOLECULAR BIOLOGY
	AND CLINICAL PATHOPHYSIOLOGY HAVE FORMED THE CYSTINOSIS RESEARCH FOUNDATION (CRF)
	GENE THERAPY CONSORTIUM, WITH THE GOAL TO ADVANCE PROGRESS ON THE MOST PROMISING
	CURRENT FINDINGS, INCLUDING MOVING NOVEL THERAPEUTIC MODALITIES INTO HUMAN PATIENTS
	AS QUICKLY AS POSSIBLE. THE CRF GENE THERAPY CONSORTIUM HOLDS THE FIRST REAL PROMISE

BAA

DIRECTORS, MICHAEL AND LYNETTE HAYDE, ARE HUSBAND AND WIFE.

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

Schedule <b>0</b> (Form 990 or 990-EZ) 2010	Page <b>2</b>
Name of the organization  CYSTINOSIS RESEARCH FOUNDATION	Employer identification number 32-0067668
FORM 990, PART VI, LINE 11B - FORM 990 REVIEW PROCESS	
FORM 990 IS REVIEWED BY BOARD OF DIRECTORS PRIOR TO FILING. AUD	TORS FOR THE
FOUNDATION HAVE REVIEWED THE RETURN AND PROVIDED COMMENTS TO TH	E TAX PREPARER.
FORM 990, PART VI, LINE 12C - EXPLANATION OF MONITORING AND ENFORCEME	ENT OF CONFLICTS
BOARD REVIEWS POSSIBLE CONFLICTS ON A REGULAR BASIS AND DISCLOS	SES REVIEW AT BOARD
MEETINGS	
FORM 990, PART VI, LINE 19 - OTHER ORGANIZATION DOCUMENTS PUBLICLY AV	'AILABLE
CRF MAINTAINS THE GOVERNING DOCUMENTS, POLICIES AND PROCEDURES	AND FINANCIAL
STATEMENTS AT ITS OFFICES IN IRVINE, CALIFORNIA. COPIES OF TH	IESE DOCUMENTS ARE
AVAILABLE TO THE PUBLIC UPON REQUEST. OUR FORM 990 IS POSTED C	N GUIDESTAR ON THE
INTERNET.	·
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2010

# **SCHEDULE O - SUPPLEMENTAL INFORMATION**

PAGE 2

CYSTINOSIS RESEARCH FOUNDATION

32-0067668

FORM 990, PART XI, LINE 5 OTHER CHANGES IN NET ASSETS OR FUND BALANCES

NET UNREALIZED GAINS OR LOSSES ON INVESTMENTS

TOTAL \$ 76,099.

2010

• 1 ·

# FEDERAL SUPPLEMENTAL INFORMATION

PAGE 1

### CYSTINOSIS RESEARCH FOUNDATION

32-0067668

SCHEDULE L - PART IV

NOTE (1)

DIRECTOR KRIS ELFTMANN IS THE OWNER OF NOELLE MARKETING GROUP WHICH PROVIDES MARKETING SERVICES FOR THE FOUNDATION. TOTAL FEES PAID TO NOELLE MARKETING GROUP IN 2010 WERE \$78,388.

NOTE (2)

DIRECTOR DONALD SOLSBY'S WIFE, ZOE SOLSBY, IS A CONSULTANT TO THE FOUNDATION. MRS. SOLSBY RECEIVED COMPENSATION OF \$35,000 IN 2010.

SCHEDULE B - PART I, ITEM 2 AND PART II, ITEM 1 - NON-CASH GIFTS

NOTE (3)

THE BALANCE CONSISTS OF APPROXIMATELY 50 NON-CASH GIFTS NONE OF WHICH EXCEEDED 2% OF FORM 990, PART VIII, LINE 1(H)

SCHEDULE G - PART II

NOTE (4) - FUNDRAISERS

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.

# (Rev January 2011)

Department of the Treasury

# Application for Extension of Time To File an Exempt Organization Return

► File a senarate application for each return.

OMB No 1545 1709

Inte	rnal Revenue Service	The a Separate application for each return.	<u> </u>
•	If you are filing for an	Automatic 3-Month Extension, complete only Part I and check this box	
•	If you are filing for an	Additional (Not Automatic) 3-Month Extension, complete only Part II (on page 2 of this fo	rm)

Do not complete Part II unless you have already been granted an automatic 3-month extension on a previously filed Form 8868

corporation request an Associated	filing (e-file). You can electronically file Form 8860 required to file Form 990-T), or an additional (no extension of time to file any of the forms listed in With Certain Personal Benefit Contracts, which milling of this form, visit www.irs.gov/efile and click	t automatic) Part I or P nust be sent	) 3-month extension of time. You can el art II with the exception of Form 8870, I : to the IRS in paper format (see instruc	ectronically file Form nformation Return fo	n 8868 to or Transfers
Part I	Automatic 3-Month Extension of Time. (	Only subn	nit original (no copies needed).		
A corporati	on required to file Form 990-T and requesting an	automatic 6	-month extension - check this box and	complete Part I only	, ▶ 📗
All other co	orporations (including 1120-C filers), partnerships, returns	REMICS, a	and trusts must use Form 7004 to reque	st an extension of tin	ne to file
	Name of exempt organization			Employer identification	number
Type or print					
•	CYSTINOSIS RESEARCH FOUNDATIO			32-0067668	
File by the due date for	Number street and room or suite number. If a P O box see i	nstructions			
filing your return See	18802 BARDEEN AVE.				
instructions	City town or post office, state, and ZIP code. For a foreign add	dress, see instru	ictions		
	IRVINE, CA 92612				
	Return code for the return that this application is fo	· · · · ·	· · · · · · · · · · · · · · · · · · ·		01
Application Is For	1	Return Code	Application Is For		Return Code
Form 990		01	Form 990-T (corporation)		07
Form 990-E	3L	02	Form 1041-A		08
Form 990-E	Ζ	03	Form 4720		09
Form 990-F	PF	04	Form 5227		10
Form 990-	「 (section 401(a) or 408(a) trust)	05	Form 6069		11
Form 990-	「(trust other than above)	06	Form 8870	12	
Telepho If the o If this i check t	ension is for	r digit Group ck this box	De United States, check this box  DEXEMPTION Number (GEN)  and attach a list with the names	and EINs of all mem	
until The e	Lest an automatic 3-month (6 months for a corpor $8/15$ , 20 $11$ , to file the exempt or extension is for the organization's return for $\overline{X}$ calendar year 20 $\underline{10}$ or tax year beginning, 20 tax year entered in line 1 is for less than 12 months than 30 months accounting period	ganization r	eturn for the organization named above		
nonre	s application is for Form 990-BL, 990-PF, 990-T, 4 efundable credits. See instructions s application is for Form 990-PF, 990-T, 4720, or 6			3a\$	0.
paym	nents made Include any prior year overpayment a	llowed as a	credit	х 3ь\$	0.
EFTF	nce due. Subtract line 3b from line 3a Include you S (Electronic Federal Tax Payment System) See	instruction	S	3c \$	0.
Caution. If payment in	you are going to make an electronic fund withdranstructions	wal with thi	s Form 8868, see Form 8453-EO and Fo	orm 8879-EO for	