

Form

990

Department of the Treasury
Internal Revenue Service

Return of Organization Exempt From Income Tax

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

Do not enter social security numbers on this form as it may be made public.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2024

Open to Public Inspection

A For the 2024 calendar year, or tax year beginning , and ending

B Check if applicable:
☐ Address change
☐ Name change
☐ Initial return
☐ Final return/terminated
☐ Amended return
☐ Application pending

C Name of organization
Cystinosis Research Network, Inc
Doing business as
Number and street (or P.O. box if mail is not delivered to street address) Room/suite
P.O. Box 702
City or town, state or province, and ZIP or foreign postal code
Lake Forest IL 60045

D Employer identification number
04-3323789

E Telephone number
847-735-0471

G Gross receipts\$ **646,021**

F Name and address of principal officer:
Clair Johnstone
PO Box 702
Lake Forest IL 60045

H(a) Is this a group return for subordinates? ☐ Yes ☒ No
H(b) Are all subordinates included? ☐ Yes ☐ No
If "No," attach a list. See instructions

I Tax-exempt status: ☒ 501(c)(3) ☐ 501(c) () (insert no.) ☐ 4947(a)(1) or ☐ 527

J Website: **www.cystinosis.org**

H(c) Group exemption number

K Form of organization: ☒ Corporation ☐ Trust ☐ Association ☐ Other

L Year of formation: **1996**

M State of legal domicile: **MA**

Part I Summary

Activities & Governance

1 Briefly describe the organization's mission or most significant activities:
See Schedule O

2 Check this box ☐ if the organization discontinued its operations or disposed of more than 25% of its net assets.

3 Number of voting members of the governing body (Part VI, line 1a) **3 13**

4 Number of independent voting members of the governing body (Part VI, line 1b) **4 13**

5 Total number of individuals employed in calendar year 2024 (Part V, line 2a) **5 0**

6 Total number of volunteers (estimate if necessary) **6 20**

7a Total unrelated business revenue from Part VIII, column (C), line 12 **7a 0**

7b Net unrelated business taxable income from Form 990-T, Part I, line 11 **7b 0**

Revenue

8 Contributions and grants (Part VIII, line 1h) **508,084**

9 Program service revenue (Part VIII, line 2g) **0**

10 Investment income (Part VIII, column (A), lines 3, 4, and 7d) **2,967**

11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) **0**

12 Total revenue – add lines 8 through 11 (must equal Part VIII, column (A), line 12) **511,051**

13 Grants and similar amounts paid (Part IX, column (A), lines 1–3) **127,547**

14 Benefits paid to or for members (Part IX, column (A), line 4) **0**

15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10) **0**

16a Professional fundraising fees (Part IX, column (A), line 11e) **0**

16b Total fundraising expenses (Part IX, column (D), line 25) **16,350**

17 Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e) **562,990**

18 Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25) **690,537**

19 Revenue less expenses. Subtract line 18 from line 12 **-179,486**

Net Assets or Fund Balances

20 Total assets (Part X, line 16) **298,290**

21 Total liabilities (Part X, line 26) **26,085**

22 Net assets or fund balances. Subtract line 21 from line 20 **272,205**

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

Sign Here

Signature of officer
Clair Johnstone
Type or print name and title
Executive Director

Date

Paid Preparer Use Only

Preparer's name
John Coombs, CPA

Preparer's signature

Date
08/26/25

Check ☐ if self-employed ☐ PTIN
P00144604

Firm's name
Mattina, Kent & Gibbons, P.C.

Firm's EIN
38-2808585

Firm's address
**1214 N Main St
Rochester, MI 48307**

Phone no.
248-601-9500

May the IRS discuss this return with the preparer shown above? See instructions ☐ Yes ☐ No

For Paperwork Reduction Act Notice, see the separate instructions. Form 990 (2024)

DAA

Part III

Statement of Program Service Accomplishments

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

X

- 1 Briefly describe the organization's mission:
See Schedule O
- 2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?
If "Yes," describe these new services on Schedule O. ☐ Yes ☒ No
- 3 Did the organization cease conducting, or make significant changes in how it conducts, any program services?
If "Yes," describe these changes on Schedule O. ☐ Yes ☒ No
- 4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code:) (Expenses \$ 55,791 including grants of \$ 55,791) (Revenue \$)

The organization establishes and funds fellowships and research grants focusing on clinical and research training in cystinosis.

4b (Code:) (Expenses \$ 187,667 including grants of \$ 5,000) (Revenue \$)

The organization raises awareness and reinforces strong relationships through representation at national medical conferences, affiliation with other organizations, publication of periodic newsletters and awards or educational scholarships to individuals with Cystinosis and their siblings.

4c (Code:) (Expenses \$ 23,839 including grants of \$ 4,197) (Revenue \$)

The organization provides information and opportunities to network for individuals with Cystinosis and their families through participation in a biennial conference on Cystinosis. It also supports newly diagnosed and existing families by providing access to world experts via advisory boards, moderation of an email support group and information packets.

4d Other program services (Describe on Schedule O.)
(Expenses \$ including grants of \$) (Revenue \$)

4e Total program service expenses 267,297

Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A	X	
2 Is the organization required to complete Schedule B, Schedule of Contributors? See instructions		X
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I		X
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II		X
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Rev. Proc. 98-19? If "Yes," complete Schedule C, Part III		X
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I		X
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III		X
9 Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? If "Yes," complete Schedule D, Part IV		X
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		X
11 If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X, as applicable.		
a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI	X	
b Did the organization report an amount for investments—other securities in Part X, line 12, that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII		X
c Did the organization report an amount for investments—program related in Part X, line 13, that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII		X
d Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part IX		X
e Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X		X
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X		X
12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII	X	
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		X
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E		X
14a Did the organization maintain an office, employees, or agents outside of the United States?		X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? If "Yes," complete Schedule F, Parts I and IV	X	
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? If "Yes," complete Schedule F, Parts II and IV	X	
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV		X
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I. See instructions		X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II		X
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		X
20a Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H		X
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II	X	

Part IV Checklist of Required Schedules (continued)

	Yes	No
22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22 X	
23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	23	X
24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>	24a	X
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	
25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a	X
b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>	25b	X
26 Did the organization report any amount on Part X, line 5 or 22, for receivables from or 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? <i>If "Yes," complete Schedule L, Part II</i>	26	X
27 Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>	27	X
28 Was the organization a party to a business transaction with one of the following parties? (See the Schedule L, Part IV, instructions for applicable filing thresholds, conditions, and exceptions).		
a A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i>	28a	X
b A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i>	28b	X
c A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i>	28c	X
29 Did the organization receive more than \$25,000 in noncash contributions? <i>If "Yes," complete Schedule M</i>	29	X
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>	30	X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31	X
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>	32	X
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>	33	X
34 Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>	34	X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a	X
b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35b	
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	36	X
37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>	37	X
38 Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19? Note: All Form 990 filers are required to complete Schedule O.	38 X	

Part V Statements Regarding Other IRS Filings and Tax ComplianceCheck if Schedule O contains a response or note to any line in this Part V ☐

	Yes	No
1a Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable	1a 6	
b Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable	1b 0	
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	X

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 0		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b		
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a		X
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O	3b		
4a	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		X
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).			
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b		X
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c		
6a	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?	6a		X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b		
7	Organizations that may receive deductible contributions under section 170(c).			
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?	7a		
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b		
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c		
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?	7e		
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f		
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g		
h	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. 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?	9a		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9b		
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	10b		
11	Section 501(c)(12) organizations. Enter:			
a	Gross income from members or shareholders	11a		
b	Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.)	11b		
12a	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.			
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	13c		
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a		X
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O	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? If "Yes," see instructions and file Form 4720, Schedule N.	15		X
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
17	Section 501(c)(21) organizations. Did the trust, any disqualified or other person, engage in any activities that would result in the imposition of an excise tax under section 4951, 4952, or 4953? If "Yes," complete Form 6069.	17		

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
1a Enter the number of voting members of the governing body at the end of the tax year	1a	13		
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.				
b Enter the number of voting members included on line 1a, above, who are independent	1b	13		
2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?		2	X	
3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person?		3		X
4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		4		X
5 Did the organization become aware during the year of a significant diversion of the organization's assets?		5		X
6 Did the organization have members or stockholders?		6		X
7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?		7a		X
b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?		7b		X
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:				
a The governing body?		8a	X	
b Each committee with authority to act on behalf of the governing body?		8b	X	
9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses on Schedule O		9		X

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

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

Section C. Disclosure

17 List the states with which a copy of this Form 990 is required to be filed **IL, MA**

18 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
☒ Own website ☐ Another's website ☒ Upon request ☐ Other (explain on Schedule O)

19 Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.

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

Allison Goldberg
Lake Forest

PO Box 702

IL 60045

857-650-0835

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent ContractorsCheck 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****1a** 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, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) 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 the instructions for the order in which to list the persons above.

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/ 1099-MISC/ 1099-NEC)	(E) Reportable compensation from related organizations (W-2/ 1099-MISC/ 1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) Johnathan Dicks										
President, VP Dev.	16.00 0.00	X		X				0	0	0
(2) Karen Gledhill										
Secretary	2.00 0.00	X		X				0	0	0
(3) Carol Hughes										
Director	7.00 0.00	X						0	0	0
(4) Clair Johnstone										
Executive Director	4.00 0.00	X		X				0	0	0
(5) Marybeth Krummenacker										
VP Education	4.00 0.00	X		X				0	0	0
(6) Chelsea Meschke										
VP Family Support	2.00 0.00	X		X				0	0	0
(7) Megan Morrill										
Director	3.00 0.00	X						0	0	0
(8) Gail Potts										
Director	2.00 0.00	X						0	0	0
(9) Heather Fields Rothrock										
Director	1.00 0.00	X						0	0	0
(10) Terri Schleuder										
Director	1.00 0.00	X						0	0	0
(11) Kristina Sevel										
VP Research	2.00 0.00	X		X				0	0	0

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/ 1099-MISC/ 1099-NEC)	(E) Reportable compensation from related organizations (W-2/ 1099-MISC/ 1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(12) Herberth Sigler										
(12) Director	1.00 0.00	X						0	0	0
(13) Jen Wyman										
(13) Director	2.00 0.00	X						0	0	0
(14) Tim Wyman										
(14) Treasurer	1.00 0.00	X		X				0	0	0
(15)										
(16)										
(17)										
(18)										
(19)										
1b Subtotal										
c Total from continuation sheets to Part VII, Section A										
d Total (add lines 1b and 1c)										
2	Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization 0									

	Yes	No
3 Did the organization list any former officer, director, trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		X
4 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? <i>If "Yes," complete Schedule J for such individual</i>		X
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		X

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

(A) Name and business address	(B) Description of services	(C) Compensation
2	Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization 0	

Part VIII Statement of RevenueCheck if Schedule O contains a response or note to any line in this Part VIII ☐

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514	
Contributions, Gifts, Grants, and Other Similar Amounts	1a Federated campaigns	1a						
	b Membership dues	1b						
	c Fundraising events	1c						
	d Related organizations	1d						
	e Government grants (contributions)	1e						
	f All other contributions, gifts, grants, and similar amounts not included above	1f	632,738					
	g Noncash contributions included in lines 1a-1f	1g	\$					
	h Total. Add lines 1a-1f			632,738				
Program Service Revenue			Business Code					
	2a							
	b							
	c							
	d							
	e							
	f All other program service revenue							
g Total. Add lines 2a-2f								
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)			13,283			13,283	
	4 Income from investment of tax-exempt bond proceeds							
	5 Royalties							
	6a Gross rents	6a	(i) Real	(ii) Personal				
	b Less: rental expenses	6b						
	c Rental inc. or (loss)	6c						
	d Net rental income or (loss)							
	7a Gross amount from sales of assets other than inventory	7a	(i) Securities	(ii) Other				
	b Less: cost or other basis and sales exps.	7b						
	c Gain or (loss)	7c						
	d Net gain or (loss)							
	8a Gross income from fundraising events (not including \$ of contributions reported on line 1c). See Part IV, line 18	8a						
b Less: direct expenses	8b							
c Net income or (loss) from fundraising events								
9a Gross income from gaming activities. See Part IV, line 19	9a							
b Less: direct expenses	9b							
c Net income or (loss) from gaming activities								
10a Gross sales of inventory, less returns and allowances	10a							
b Less: cost of goods sold	10b							
c Net income or (loss) from sales of inventory								
Miscellaneous Revenue			Business Code					
	11a							
	b							
	c							
	d All other revenue							
e Total. Add lines 11a-11d								
12 Total revenue. See instructions			646,021	0	0	13,283		

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

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

☒**Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.**

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	36,666	36,666		
2 Grants and other assistance to domestic individuals. See Part IV, line 22	9,197	9,197		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	19,125	19,125		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees				
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7 Other salaries and wages				
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits				
10 Payroll taxes				
11 Fees for services (nonemployees):				
a Management				
b Legal				
c Accounting	15,015		15,015	
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees				
g Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Schedule O.)	85,679	27,500	53,221	4,958
12 Advertising and promotion	4,121	4,068		53
13 Office expenses				
14 Information technology				
15 Royalties				
16 Occupancy				
17 Travel				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	115,166	107,104		8,062
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization				
23 Insurance	794		794	
24 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.)				
a Supplies	58,937	51,637	4,023	3,277
b Scholarships and Sponsors	12,000	12,000		
c				
d				
e All other expenses				
25 Total functional expenses. Add lines 1 through 24e	356,700	267,297	73,053	16,350
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ☐ if following SOP 98-2 (ASC 958-720)				

Part X Balance SheetCheck if Schedule O contains a response or note to any line in this Part X ☐

		(A) Beginning of year		(B) End of year
Assets	1 Cash—non-interest-bearing	58,290	1	131,422
	2 Savings and temporary cash investments	240,000	2	473,564
	3 Pledges and grants receivable, net		3	
	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 section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges		9	
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 28,600		
	b Less: accumulated depreciation	10b 28,600	10c	
	11 Investments—publicly traded securities		11	
	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)	298,290	16	604,986	
Liabilities	17 Accounts payable and accrued expenses	14,395	17	30,992
	18 Grants payable		18	
	19 Deferred revenue	11,690	19	12,468
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22 Loans and other payables to 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	26,085	26	43,460
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here ☒ and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	206,837	27	514,557
	28 Net assets with donor restrictions	65,368	28	46,969
	Organizations that do not follow FASB ASC 958, check here ☐ and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		29	
	30 Paid-in or capital surplus, or land, building, or equipment fund		30	
	31 Retained earnings, endowment, accumulated income, or other funds		31	
	32 Total net assets or fund balances	272,205	32	561,526
33 Total liabilities and net assets/fund balances	298,290	33	604,986	

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	646,021
2	Total expenses (must equal Part IX, column (A), line 25)	2	356,700
3	Revenue less expenses. Subtract line 2 from line 1	3	289,321
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	272,205
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	561,526

Part XII Financial Statements and Reporting

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

		Yes	No
1	Accounting method used to prepare the Form 990: ☐ Cash ☒ Accrual ☐ Other If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.		
2a	Were the organization's financial statements compiled or reviewed by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both. ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis		X
b	Were the organization's financial statements audited by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both. ☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis	X	
c	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.	X	
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Uniform Guidance, 2 C.F.R. Part 200, Subpart F?		X
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits		

SCHEDULE A
(Form 990)Department of the Treasury
Internal Revenue Service**Public Charity Status and Public Support**

OMB No. 1545-0047

2024**Open to Public
Inspection**

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

Attach to Form 990 or Form 990-EZ.

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

Name of the organization

Cystinosis Research Network, Inc

Employer identification number

04-3323789**Part I Reason for Public Charity Status.** (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

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

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

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

Cat. No. 11285F

Schedule A (Form 990) 2024

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

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	526,401	542,497	345,873	508,084	632,738	2,555,593
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	526,401	542,497	345,873	508,084	632,738	2,555,593
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)						1,402,732
6 Public support. Subtract line 5 from line 4						1,152,861

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
7 Amounts from line 4	526,401	542,497	345,873	508,084	632,738	2,555,593
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	1,096	713	394	2,967	13,283	18,453
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
11 Total support. Add lines 7 through 10						2,574,046

12 Gross receipts from related activities, etc. (see instructions)	12	
13 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here		☐

Section C. Computation of Public Support Percentage

14 Public support percentage for 2024 (line 6, column (f), divided by line 11, column (f))	14	44.79 %
15 Public support percentage from 2023 Schedule A, Part II, line 14	15	39.40 %
16a 33 1/3% support test — 2024. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here . The organization qualifies as a publicly supported organization		☒
b 33 1/3% support test — 2023. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here . The organization qualifies as a publicly supported organization		☐
17a 10%-facts-and-circumstances test — 2024. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here . Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization		☐
b 10%-facts-and-circumstances test — 2023. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here . Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization		☐
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions		☐

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

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II.
If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						
14 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here						☐

Section C. Computation of Public Support Percentage

15 Public support percentage for 2024 (line 8, column (f), divided by line 13, column (f))	15	%
16 Public support percentage from 2023 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2024 (line 10c, column (f), divided by line 13, column (f))	17	%
18 Investment income percentage from 2023 Schedule A, Part III, line 17	18	%
19a 33 1/3% support tests — 2024. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here . The organization qualifies as a publicly supported organization		☐
b 33 1/3% support tests — 2023. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and stop here . The organization qualifies as a publicly supported organization		☐
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions		☐

Part IV Supporting Organizations

(Complete only if you checked a box on 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 and D, and complete Part V.)

Section A. All Supporting Organizations

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

Part IV Supporting Organizations (continued)

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

Section B. Type I Supporting Organizations

	Yes	No
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.		
1		
2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.		
2		

Section C. Type II Supporting Organizations

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

Section D. All Type III Supporting Organizations

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

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 each of its supported organizations, and how the organization determined that these activities constituted substantially all of its activities.			
2a			
b Did the activities described on 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.			
2b			
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 .			
3a			
b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.			
3b			

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

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

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

Section B – Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):		
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	Total (add lines 1a, 1b, and 1c)	1d	
e	Discount claimed for blockage or other factors (<i>explain in detail in Part VI</i>):		
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	

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

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

Section D – Distributions		Current Year
1	Amounts paid to supported organizations to accomplish exempt purposes	1
2	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2
3	Administrative expenses paid to accomplish exempt purposes of supported organizations	3
4	Amounts paid to acquire exempt-use assets	4
5	Qualified set-aside amounts (prior IRS approval required—provide details in Part VI)	5
6	Other distributions (describe in Part VI). See instructions.	6
7	Total annual distributions. Add lines 1 through 6.	7
8	Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions.	8
9	Distributable amount for 2024 from Section C, line 6	9
10	Line 8 amount divided by line 9 amount	10

Section E – Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2024	(iii) Distributable Amount for 2024
1 Distributable amount for 2024 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2024 (reasonable cause required—explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2024			
a From 2019			
b From 2020			
c From 2021			
d From 2022			
e From 2023			
f Total of lines 3a through 3e			
g Applied to underdistributions of prior years			
h Applied to 2024 distributable amount			
i Carryover from 2019 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2024 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2024 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2024, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI . See instructions.			
6 Remaining underdistributions for 2024. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI . See instructions.			
7 Excess distributions carryover to 2025. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2020			
b Excess from 2021			
c Excess from 2022			
d Excess from 2023			
e Excess from 2024			

Part VI

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

SCHEDULE D
(Form 990)
(Rev. December 2024)
Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements
Complete if the organization answered "Yes" on Form 990,
Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.
Attach to Form 990.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public
Inspection

Name of the organization	Employer identification number
Cystinosis Research Network, Inc	04-3323789

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts
Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year)		
4 Aggregate value at end of year		
5 Did the organization inform all donors and 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?		☐ Yes ☐ No
6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit?		☐ Yes ☐ No

Part II Conservation Easements
Complete if the organization answered "Yes" on Form 990, Part IV, line 7.

1 Purpose(s) of conservation easements held by the organization (check all that apply).	
☐ Preservation of land for public use (for example, recreation or education)	☐ Preservation of a historically important land area
☐ Protection of natural habitat	☐ Preservation of a certified historic structure
☐ Preservation of open space	
2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.	
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included on line 2a	2c
d Number of conservation easements included on line 2c acquired after July 25, 2006, and not on a historic structure listed in the National Register	2d
3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year	
4 Number of states where property subject to conservation easement is located	
5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?	☐ Yes ☐ No
6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conversation easements during the year	
7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year	\$
8 Does each conservation easement reported on line 2d above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)?	☐ Yes ☐ No
9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.	

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets
Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

1a If the organization elected, as permitted under FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide in Part XIII the text of the footnote to its financial statements that describes these items.	
b If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items.	
(i) Revenue included on Form 990, Part VIII, line 1	\$
(ii) Assets included in Form 990, Part X	\$
2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items.	
a Revenue included on Form 990, Part VIII, line 1	\$
b Assets included in Form 990, Part X	\$

Part III

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

- 3
- Using the organization's acquisition, accession, and other records, check any of the following that make significant use of its collection items (check all that apply).
- a

☐

Public exhibition

b

☐

Scholarly research

c

☐

Preservation for future generations

d

☐

Loan or exchange program

e

☐

Other
- 4
- Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5
- During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?
- ☐

Yes

☐

No

Part IV

Escrow and Custodial Arrangements

Complete if the organization answered "Yes" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

- 1a
- Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?
- ☐

Yes

☐

No
- b
- If "Yes," explain the arrangement in Part XIII and complete the following table.
- | | |
|----|--------|
| | Amount |
| 1c | |
| 1d | |
| 1e | |
| 1f | |
- 2a
- Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability?
- ☐

Yes

☐

No
- b
- If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII
- ☐

Part V

Endowment Funds

Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

- | | | | | | |
|----|--|----------------|--------------------|----------------------|---------------------|
| | (a) Current year | (b) Prior year | (c) Two years back | (d) Three years back | (e) Four years back |
| 1a | Beginning of year balance | | | | |
| b | Contributions | | | | |
| c | Net investment earnings, gains, and losses | | | | |
| d | Grants or scholarships | | | | |
| e | Other expenditures for facilities and programs | | | | |
| f | Administrative expenses | | | | |
| g | End of year balance | | | | |
- 2
- Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a

Board designated or quasi-endowment

%

b

Permanent endowment

%

c

Term endowment

%
- The percentages on lines 2a, 2b, and 2c should equal 100%.
- 3a
- Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- (i)

Unrelated organizations?

(ii)

Related organizations?
- 3a(i)

☐

Yes

☐

No

3a(ii)

☐

Yes

☐

No

3b

☐

Yes

☐

No
- b
- If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R?
- ☐
- 4
- Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI

Land, Buildings, and Equipment

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment				
e Other		28,600	28,600	
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, line 10c, column (B))				

Part VII Investments – Other Securities

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

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

Part VIII Investments – Program Related

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

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

Part IX Other Assets

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

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

Part X Other Liabilities

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

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

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 ☐

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	646,021
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	2b		
c Recoveries of prior year grants	2c		
d Other (Describe in Part XIII.)	2d		
e Add lines 2a through 2d		2e	
3 Subtract line 2e from line 1		3	646,021
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.)	4b		
c Add lines 4a and 4b		4c	
5 Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)		5	646,021

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

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

1 Total expenses and losses per audited financial statements		1	356,700
2 Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a Donated services and use of facilities	2a		
b Prior year adjustments	2b		
c Other losses	2c		
d Other (Describe in Part XIII.)	2d		
e Add lines 2a through 2d		2e	
3 Subtract line 2e from line 1		3	356,700
4 Amounts included on Form 990, Part IX, line 25, but not on line 1:			
a Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b Other (Describe in Part XIII.)	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	356,700

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.

Part XIII Supplemental Information (continued)

DAA

SCHEDULE F
(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

Name of the organization

Statement of Activities Outside the United States

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

Attach to Form 990.

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

OMB No. 1545-0047

Open to Public
Inspection

Cystinosis Research Network, Inc

Employer identification number

04-3323789

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

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

☒ Yes ☐ No
- 2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.
- 3 Activities per Region. (The following Part I, line 3 table can be duplicated if additional space is needed.)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
Europe - Albania, Andorra, Austria, Belg			Grantmaking		
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
3a Subtotal					
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b)					

Part II

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

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
(1)			Europe	Research	19,125	wire transfer			
(2)									
(3)									
(4)									
(5)									
(6)									
(7)									
(8)									
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as a tax exempt 501(c)(3) organization by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter

3 Enter total number of other organizations or entities

Part III

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

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

Part IV Foreign Forms

- 1

Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see the Instructions for Form 926)*

☐ Yes

☒ No
- 2

Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see the Instructions for Forms 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 the Instructions for Form 5471)*

☐ Yes

☒ No
- 4

Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see the Instructions for Form 8621)*

☐ Yes

☒ No
- 5

Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see the Instructions for Form 8865)*

☐ Yes

☒ No
- 6

Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see the Instructions for Form 5713; don't file with Form 990)*

☐ Yes

☒ No

Part V

Supplemental Information

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.

Part I, Line 2 - Procedures for Monitoring the Use of Grant Funds

All grants are reviewed by a scientific review board of physicians familiar with cystinosis. Per grant agreement, researchers are to provide periodic progress reports showing research progress and expenses incurred thus far.

Part I, Line 3 - Activities per Region		
Region	Expenditures	Investments
Europe - Albania, Andorra, Austria, Belg	\$ 0	\$ 0

SCHEDULE I
(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

Grants and Other Assistance to Organizations,
Governments, and Individuals in the United States
Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.
Attach to Form 990.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public
Inspection

Name of the organization	Cystinosis Research Network, Inc	Employer identification number	04-3323789
--------------------------	----------------------------------	--------------------------------	------------

Part I General Information on Grants and Assistance

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

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

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

1	(a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1)	The Regents of the University of California PO Box 748872 Los Angeles CA 90074	94-3067788	501c3	36,666				Research Grant
(2)								
(3)								
(4)								
(5)								
(6)								
(7)								
(8)								
(9)								

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

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

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 Scholarships	3	5,000			
2 Awards	5	4,197			
3					
4					
5					
6					
7					

Part IV

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

Part I, Line 2 - Procedures for Monitoring the Use of Grant Funds

All grants are reviewed by a scientific review board of physicians familiar with cystinosis. Per grant agreement, researchers are to provide periodic progress reports showing research progress and expenses incurred thus far.

SCHEDULE O
(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

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 Form 990-EZ.

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

OMB No. 1545-0047

Open to Public
Inspection

Name of the organization

Cystinosis Research Network, Inc

Employer identification number

04-3323789

Form 990 - Organization's Mission

The Cystinosis Research Network is an all volunteer, non-profit organization dedicated to supporting and advocating research, providing family assistance and educating the public and medical communities about Cystinosis.

Form 990, Part VI, Line 2 - Related Party Information Among Officers

Tim Wyman

Jen Wyman

Family Relationship

Form 990, Part VI, Line 11b - Organization's Process to Review Form 990

The draft copy of form 990 is reviewed by the treasurer and requests to review will be made to the executive committee prior to signature by the treasurer or executive director. A copy of the final form 990 is provided to all board members prior to filing.

Form 990, Part VI, Line 12c - Enforcement of Conflicts Policy

On an annual basis, the organization discusses the existing policy with the board members and asks that all members disclose any relationships or situations that may go against this policy.

Form 990, Part VI, Line 19 - Governing Documents Disclosure Explanation

All available upon request of executive director.

Form 990, Part IX, Line 11g - Other Fees for Services

Description

Tot/Prog Service	Mgt & General	Fundraising
Operations:Independent Contra		
\$ 27,500	\$ 53,221	\$ 4,958

Asset	Description	Date In Service	Cost	Bus %	Sec 179	Bonus	Basis for Depr	PerConv Meth	Prior	Current
Prior MACRS:										
1	Website	1/01/20	28,600			X	0	5 HY 200DB	28,600	0
			28,600				0		28,600	0
Grand Totals			28,600				0		28,600	0
Less: Dispositions and Transfers			0				0		0	0
Less: Start-up/Org Expense			0				0		0	0
Net Grand Totals			28,600				0		28,600	0

Form 990	Two Year Comparison Report		2023 & 2024
Name		Taxpayer Identification Number	
Cystinosis Research Network, Inc		04-3323789	

		2023	2024	Differences
Revenue	1. Contributions, gifts, grants	1. 508,084	632,738	124,654
	2. Membership dues and assessments	2.		
	3. Government contributions and grants	3.		
	4. Program service revenue	4.		
	5. Investment income	5. 2,967	13,283	10,316
	6. Proceeds from tax exempt bonds	6.		
	7. Net gain or (loss) from sale of assets other than inventory	7.		
	8. Net income or (loss) from fundraising events	8.		
	9. Net income or (loss) from gaming	9.		
	10. Net gain or (loss) on sales of inventory	10.		
	11. Other revenue	11.		
	12. Total revenue. Add lines 1 through 11	12. 511,051	646,021	134,970
Expenses	13. Grants and similar amounts paid	13. 127,547	64,988	-62,559
	14. Benefits paid to or for members	14.		
	15. Compensation of officers, directors, trustees, etc.	15.		
	16. Salaries, other compensation, and employee benefits	16.		
	17. Professional fundraising fees	17.		
	18. Other professional fees	18. 76,962	100,694	23,732
	19. Occupancy, rent, utilities, and maintenance	19.		
	20. Depreciation and Depletion	20.		
	21. Other expenses	21. 486,028	191,018	-295,010
	22. Total expenses. Add lines 13 through 21	22. 690,537	356,700	-333,837
	23. Excess or (Deficit). Subtract line 22 from line 12	23. -179,486	289,321	468,807
Other Information	24. Total exempt revenue	24. 511,051	646,021	134,970
	25. Total unrelated revenue	25.		
	26. Total excludable revenue	26. 2,967	13,283	10,316
	27. Total assets	27. 298,290	604,986	306,696
	28. Total liabilities	28. 26,085	43,460	17,375
	29. Retained earnings	29. 272,205	561,526	289,321
	30. Number of voting members of governing body	30. 12	13	
31. Number of independent voting members of governing body	31. 12	13		
32. Number of employees	32. 0	0		
33. Number of volunteers	33. 20	20		

Form 990	Tax Return History	2024
-----------------	---------------------------	-------------

Name Cystinosis Research Network, Inc	Employer Identification Number 04-3323789
---	---

	2020	2021	2022	2023	2024	2025
Contributions, gifts, grants			345,873	508,084	632,738	
Membership dues						
Program service revenue						
Capital gain or loss						
Investment income			394	2,967	13,283	
Fundraising revenue (income/loss) ..						
Gaming revenue (income/loss)						
Other revenue						
Total revenue			346,267	511,051	646,021	
Grants and similar amounts paid			333,727	127,547	64,988	
Benefits paid to or for members						
Compensation of officers, etc.						
Other compensation						
Professional fees			73,117	76,962	100,694	
Occupancy costs						
Depreciation and depletion			1,550			
Other expenses			129,042	486,028	191,018	
Total expenses			537,436	690,537	356,700	
Excess or (Deficit)			-191,169	-179,486	289,321	
Total exempt revenue			346,267	511,051	646,021	
Total unrelated revenue						
Total excludable revenue			394	2,967	13,283	
Total Assets			505,368	298,290	604,986	
Total Liabilities			53,677	26,085	43,460	
Net Fund Balances			451,691	272,205	561,526	

Illinois Diagnostics

Critical Messages

None

Informational Messages

☐ Illinois Department of Revenue does not support electronic filing

Missing Data

Prior Year Data

Illinois General Information	
☒ Late report filing fee	X

11/17/25

Filing Instructions

Cystinosis Research Network, Inc

Form AG990-IL - Charitable Organization Annual Report

Taxable Year Ended December 31, 2024

Date Due: June 30, 2025

Remittance: The filing fee for the tax year ended 12/31/24 is \$15. Include a check payable to the Illinois Charity Bureau Fund and write "E.I.N. 04-3323789, for the year ended 12/31/24" on the check.

Mail To: Office of the Illinois Attorney General
Charitable Trust Bureau
115 S. LaSalle St
Chicago, IL 60603

Signature: Form AG990-IL must be signed and dated by two authorized officers of the organization.

ILLINOIS CHARITABLE ORGANIZATION ANNUAL REPORT

Form AG990-IL

Revised 10/24

For Office Use Only

PMT #	
AMT	
INIT	

Illinois Attorney General Kwame Raoul
Charitable Trust Bureau, 115 S. LaSalle St
Chicago, IL 60603

CO # **01-050724**

Report for the Fiscal Period:

Beginning **01/01/2024**

& Ending **12/31/2024**

MO DAY YR

Check all items attached:

- ☒ Copy of IRS Return
- ☒ Audited Financial Statements
- ☐ Reviewed Financial Statements
- ☐ Copy of Form IFC
- ☒ \$15 Annual Report Filing Fee
- ☐ \$100 Late Report Filing Fee

Make Checks
Payable to
Illinois Charity
Bureau Fund

Federal ID # **04-3323789**

Are contributions to the organization tax deductible? Yes ☒ No ☐

Date organization was created: **08/06/1996**
MO DAY YR

Legal Name: Cystinosis Research Network, Inc	YEAR-END AMOUNTS	
Mail Address: P.O. Box 702	A) ASSETS	A) \$ 604,986
City, State: Lake Forest IL	B) LIABILITIES	B) \$ 43,460
Zip Code: 60045	C) NET ASSETS	C) \$ 561,526
Email Address: cjohnstone@cystinosis.org		
I. SUMMARY OF ALL REVENUE ITEMS DURING THE YEAR:	PERCENTAGE	AMOUNT
D) PUBLIC SUPPORT, CONTRIBUTIONS AND PROGRAM SERVICE REV.(GROSS AMTS.)	98 %	D) \$ 632,738
E) GOVERNMENT GRANTS AND MEMBERSHIP DUES	0 %	E) \$ 0
F) OTHER REVENUES	2 %	F) \$ 13,283
G) TOTAL REVENUES, INCOME AND CONTRIBUTIONS RECEIVED (ADD D, E & F)	100%	G) \$ 646,021
II. SUMMARY OF ALL EXPENDITURES DURING THE YEAR		
H) OPERATING CHARITABLE PROGRAM EXPENSE	57 %	H) \$ 202,309
I) EDUCATION PROGRAM SERVICE EXPENSE	%	I) \$
J) TOTAL CHARITABLE PROGRAM SERVICE EXPENSE (ADD H & I)	57 %	J) \$ 202,309
J1) JOINT COSTS ALLOCATED TO PROGRAM SERVICES (INCLUDED IN J)		
K) GRANTS TO OTHER CHARITABLE ORGANIZATIONS	18 %	K) \$ 64,988
L) TOTAL CHARITABLE PROGRAM SERVICE EXPENDITURE (ADD J & K)	75 %	L) \$ 267,297
M) MANAGEMENT AND GENERAL EXPENSE	20 %	M) \$ 73,053
N) FUNDRAISING EXPENSE	5 %	N) \$ 16,350
O) TOTAL EXPENDITURES THIS PERIOD (ADD L, M & N)	100%	O) \$ 356,700
III. SUMMARY OF ALL PAID FUNDRAISER & CONSULTANT ACTIVITIES		
(Attach Attorney General Report of Individual Fundraising Campaign (Form IFC). One for each PFR.)		
PROFESSIONAL FUNDRAISERS:		
P) TOTAL AMOUNT RAISED BY PAID PROFESSIONAL FUNDRAISERS	100%	P) \$
Q) TOTAL FUNDRAISERS FEES AND EXPENSES	%	Q) \$
R) NET RECEIVED BY THE CHARITY (P MINUS Q = R)	%	R) \$
PROFESSIONAL FUNDRAISING CONSULTANTS:		
S) TOTAL AMOUNT PAID TO PROFESSIONAL FUNDRAISING CONSULTANTS		S) \$
IV. COMPENSATION TO THE (3) HIGHEST PAID PERSONS DURING THE YEAR:		
T) NAME, TITLE: No compensation was paid during theyear		T) \$
U) NAME, TITLE:		U) \$
V) NAME, TITLE:		V) \$
V. CHARITABLE PROGRAM DESCRIPTION: CHARITABLE PROGRAM (3 HIGHEST BY \$ EXPENDED) CODE CATEGORIES	List on back side of Instructions CODE	
W) DESCRIPTION: Other medical and disease research	W) #	053
X) DESCRIPTION: Seminars and conferences	X) #	011
Y) DESCRIPTION: family and individual services	Y) #	111

Cystinosis Research Network, Inc 04-3323789

THE QUESTIONS BELOW ARE APPLICABLE TO THE CURRENT REPORTING PERIOD. IF THE ANSWER TO ANY OF THE FOLLOWING QUESTIONS IS YES, ATTACH A DETAILED EXPLANATION:

	YES	NO
1. WAS THE ORGANIZATION THE SUBJECT OF ANY COURT ACTION, FINE, PENALTY OR JUDGEMENT?		X
2. DID THE ORGANIZATION MAKE A GRANT AWARD OR CONTRIBUTION TO ANY ORGANIZATION IN WHICH ANY OF ITS OFFICERS, DIRECTORS OR TRUSTEES OWNS AN INTEREST; OR WAS IT A PART TO ANY TRANSACTION IN WHICH ANY OF ITS OFFICERS, DIRECTORS OR TRUSTEES HAS A MATERIAL FINANCIAL INTEREST; OR DID ANY OFFICER, DIRECTOR OR TRUSTEE RECEIVE ANYTHING OF VALUE NOT REPORTED AS COMPENSATION?		X
3. HAS THE ORGANIZATION INVESTED IN ANY CORPORATE STOCK IN WHICH ANY OFFICER, DIRECTOR OR TRUSTEE OWNS MORE THAN 10% OF THE OUTSTANDING SHARES?		X
4. IS ANY PROPERTY OF THE ORGANIZATION HELD IN THE NAME OF OR COMMINGLED WITH THE PROPERTY OF ANY OTHER PERSON OR ORGANIZATION?		X
5. DID THE ORGANIZATION USE THE SERVICES OF A PROFESSIONAL FUNDRAISER? (ATTACH FORM IFC.)		X
6a. DID THE ORGANIZATION ALLOCATE THE COST OF ANY SOLICITATION, MAILING, ADVERTISEMENT OR LITERATURE COSTS BETWEEN PROGRAM SERVICE AND FUNDRAISING EXPENSES?		X
6b. IF "YES", ENTER		
(I) THE AGGREGATE AMOUNT OF THESE JOINT COSTS \$ _____ ;		
(II) THE AMOUNT ALLOCATED TO PROGRAM SERVICES \$ _____ ;		
(III) THE AMOUNT ALLOCATED TO MANAGEMENT AND GENERAL \$ _____ ; AND		
(IV) THE AMOUNT ALLOCATED TO FUNDRAISING \$ _____ .		
7. DID THE ORGANIZATION EXPEND ITS RESTRICTED FUNDS FOR PURPOSES OTHER THAN RESTRICTED PURPOSES?		X
8. HAS THE ORGANIZATION EVER BEEN REFUSED REGISTRATION OR HAD ITS REGISTRATION OR TAX EXEMPTION SUSPENDED OR REVOKED BY ANY GOVERNMENTAL AGENCY?		X
9. DID THE ORGANIZATION LEARN OR BECOME AWARE OF ANY KICKBACK, BRIBE OR ANY THEFT, DEFALCATION, MISAPPROPRIATION, COMMINGLING OR MISUSE OF ORGANIZATIONAL FUNDS IN THE CURRENT OR PREVIOUS FISCAL YEARS?		X
10. LIST THE NAME AND ADDRESS OF THE FINANCIAL INSTITUTIONS WHERE THE ORGANIZATION MAINTAINS ITS THREE LARGEST ACCOUNTS: Raymond James & Associates - 24800 Denso Dr Ste 300 Southfield, MI 48033		
11. NAME AND TELEPHONE NUMBER OF CONTACT PERSON Allison Goldberg - 857-650-0835		

• ALL ATTACHMENTS MUST ACCOMPANY THIS REPORT – SEE INSTRUCTIONS •

UNDER PENALTY OF PERJURY, I (WE) THE UNDERSIGNED DECLARE AND CERTIFY THAT I (WE) HAVE EXAMINED THIS ANNUAL REPORT AND THE ATTACHED DOCUMENTS, INCLUDING ALL THE SCHEDULES AND STATEMENTS, AND THE FACTS THEREIN STATED ARE TRUE AND COMPLETE AND FILED WITH THE ILLINOIS ATTORNEY GENERAL FOR THE PURPOSE OF HAVING THE PEOPLE OF THE STATE OF ILLINOIS RELY THEREUPON. I HEREBY FURTHER AUTHORIZE AND AGREE TO SUBMIT MYSELF AND THE REGISTRANT HEREBY TO THE JURISDICTION OF THE STATE OF ILLINOIS.

BE SURE TO INCLUDE ALL FEES DUE:

- 1.) REPORTS ARE DUE WITHIN SIX MONTHS OF YOUR FISCAL YEAR END.
2.) FOR FEES DUE, SEE INSTRUCTIONS.
3.) REPORTS THAT ARE LATE OR INCOMPLETE ARE SUBJECT TO A \$100.00 PENALTY.

PRESIDENT OR OTHER AUTHORIZED
OFFICE OR TRUSTEE (PRINT NAME)

SIGNATURE

DATE

CHIEF FISCAL OFFICER OR TRUSTEE (PRINT NAME)

SIGNATURE

DATE

John Coombs, CPA

PREPARER (PRINT NAME)

SIGNATURE

DATE

Form

990

Department of the Treasury
Internal Revenue Service

Return of Organization Exempt From Income Tax

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

Do not enter social security numbers on this form as it may be made public.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2024

Open to Public Inspection

A For the 2024 calendar year, or tax year beginning , and ending

B Check if applicable:
☐ Address change
☐ Name change
☐ Initial return
☐ Final return/terminated
☐ Amended return
☐ Application pending

C Name of organization
Cystinosis Research Network, Inc
Doing business as
Number and street (or P.O. box if mail is not delivered to street address) Room/suite
P.O. Box 702
City or town, state or province, and ZIP or foreign postal code
Lake Forest IL 60045

D Employer identification number
04-3323789

E Telephone number
847-735-0471

G Gross receipts\$ **646,021**

F Name and address of principal officer:
Clair Johnstone
PO Box 702
Lake Forest IL 60045

H(a) Is this a group return for subordinates? ☐ Yes ☒ No
H(b) Are all subordinates included? ☐ Yes ☐ No
If "No," attach a list. See instructions

I Tax-exempt status: ☒ 501(c)(3) ☐ 501(c) () (insert no.) ☐ 4947(a)(1) or ☐ 527

J Website: **www.cystinosis.org**

H(c) Group exemption number

K Form of organization: ☒ Corporation ☐ Trust ☐ Association ☐ Other

L Year of formation: **1996**

M State of legal domicile: **MA**

Part I Summary

Activities & Governance

1 Briefly describe the organization's mission or most significant activities:
See Schedule O

2 Check this box ☐ if the organization discontinued its operations or disposed of more than 25% of its net assets.

3 Number of voting members of the governing body (Part VI, line 1a) **3 13**

4 Number of independent voting members of the governing body (Part VI, line 1b) **4 13**

5 Total number of individuals employed in calendar year 2024 (Part V, line 2a) **5 0**

6 Total number of volunteers (estimate if necessary) **6 20**

7a Total unrelated business revenue from Part VIII, column (C), line 12 **7a 0**

7b Net unrelated business taxable income from Form 990-T, Part I, line 11 **7b 0**

Revenue

8 Contributions and grants (Part VIII, line 1h) **508,084**

9 Program service revenue (Part VIII, line 2g) **0**

10 Investment income (Part VIII, column (A), lines 3, 4, and 7d) **2,967**

11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) **0**

12 Total revenue – add lines 8 through 11 (must equal Part VIII, column (A), line 12) **511,051**

13 Grants and similar amounts paid (Part IX, column (A), lines 1–3) **127,547**

14 Benefits paid to or for members (Part IX, column (A), line 4) **0**

15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10) **0**

16a Professional fundraising fees (Part IX, column (A), line 11e) **0**

16b Total fundraising expenses (Part IX, column (D), line 25) **16,350**

17 Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e) **562,990**

18 Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25) **690,537**

19 Revenue less expenses. Subtract line 18 from line 12 **-179,486**

Net Assets or Fund Balances

20 Total assets (Part X, line 16) **298,290**

21 Total liabilities (Part X, line 26) **26,085**

22 Net assets or fund balances. Subtract line 21 from line 20 **272,205**

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

Sign Here

Signature of officer
Clair Johnstone
Type or print name and title
Executive Director

Date

Paid Preparer Use Only

Preparer's name
John Coombs, CPA

Preparer's signature

Date
08/26/25

Check ☐ if self-employed ☐ PTIN
P00144604

Firm's name
Mattina, Kent & Gibbons, P.C.

Firm's EIN
38-2808585

Firm's address
**1214 N Main St
Rochester, MI 48307**

Phone no.
248-601-9500

May the IRS discuss this return with the preparer shown above? See instructions ☐ Yes ☐ No

For Paperwork Reduction Act Notice, see the separate instructions. Form 990 (2024)

DAA

Part III

Statement of Program Service Accomplishments

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

X

- 1 Briefly describe the organization's mission:
See Schedule O
- 2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?
If "Yes," describe these new services on Schedule O. ☐ Yes ☒ No
- 3 Did the organization cease conducting, or make significant changes in how it conducts, any program services?
If "Yes," describe these changes on Schedule O. ☐ Yes ☒ No
- 4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code:) (Expenses \$ 55,791 including grants of \$ 55,791) (Revenue \$)

The organization establishes and funds fellowships and research grants focusing on clinical and research training in cystinosis.

4b (Code:) (Expenses \$ 187,667 including grants of \$ 5,000) (Revenue \$)

The organization raises awareness and reinforces strong relationships through representation at national medical conferences, affiliation with other organizations, publication of periodic newsletters and awards or educational scholarships to individuals with Cystinosis and their siblings.

4c (Code:) (Expenses \$ 23,839 including grants of \$ 4,197) (Revenue \$)

The organization provides information and opportunities to network for individuals with Cystinosis and their families through participation in a biennial conference on Cystinosis. It also supports newly diagnosed and existing families by providing access to world experts via advisory boards, moderation of an email support group and information packets.

4d Other program services (Describe on Schedule O.)
(Expenses \$ including grants of \$) (Revenue \$)

4e Total program service expenses 267,297

Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A	X	
2 Is the organization required to complete Schedule B, Schedule of Contributors? See instructions		X
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I		X
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II		X
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Rev. Proc. 98-19? If "Yes," complete Schedule C, Part III		X
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I		X
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III		X
9 Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? If "Yes," complete Schedule D, Part IV		X
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		X
11 If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X, as applicable.		
a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI	X	
b Did the organization report an amount for investments—other securities in Part X, line 12, that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII		X
c Did the organization report an amount for investments—program related in Part X, line 13, that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII		X
d Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part IX		X
e Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X		X
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X		X
12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII	X	
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		X
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E		X
14a Did the organization maintain an office, employees, or agents outside of the United States?		X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? If "Yes," complete Schedule F, Parts I and IV	X	
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? If "Yes," complete Schedule F, Parts II and IV	X	
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV		X
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I. See instructions		X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II		X
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		X
20a Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H		X
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II	X	

Part IV Checklist of Required Schedules (continued)

	Yes	No
22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22 X	
23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	23	X
24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>	24a	X
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	
25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a	X
b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>	25b	X
26 Did the organization report any amount on Part X, line 5 or 22, for receivables from or 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? <i>If "Yes," complete Schedule L, Part II</i>	26	X
27 Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>	27	X
28 Was the organization a party to a business transaction with one of the following parties? (See the Schedule L, Part IV, instructions for applicable filing thresholds, conditions, and exceptions).		
a A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i>	28a	X
b A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i>	28b	X
c A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i>	28c	X
29 Did the organization receive more than \$25,000 in noncash contributions? <i>If "Yes," complete Schedule M</i>	29	X
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>	30	X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31	X
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>	32	X
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>	33	X
34 Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>	34	X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a	X
b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35b	
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	36	X
37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>	37	X
38 Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19? Note: All Form 990 filers are required to complete Schedule O.	38 X	

Part V Statements Regarding Other IRS Filings and Tax ComplianceCheck if Schedule O contains a response or note to any line in this Part V ☐

	Yes	No
1a Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable	1a 6	
b Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable	1b 0	
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	X

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 0		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b		
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a		X
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O	3b		
4a	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		X
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).			
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b		X
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c		
6a	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?	6a		X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b		
7	Organizations that may receive deductible contributions under section 170(c).			
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?	7a		
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b		
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c		
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?	7e		
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f		
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g		
h	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. 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?	9a		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9b		
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	10b		
11	Section 501(c)(12) organizations. Enter:			
a	Gross income from members or shareholders	11a		
b	Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.)	11b		
12a	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.			
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	13c		
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a		X
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O	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? If "Yes," see instructions and file Form 4720, Schedule N.	15		X
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
17	Section 501(c)(21) organizations. Did the trust, any disqualified or other person, engage in any activities that would result in the imposition of an excise tax under section 4951, 4952, or 4953? If "Yes," complete Form 6069.	17		

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
1a Enter the number of voting members of the governing body at the end of the tax year	1a	13		
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.				
b Enter the number of voting members included on line 1a, above, who are independent	1b	13		
2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?		2	X	
3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person?		3		X
4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		4		X
5 Did the organization become aware during the year of a significant diversion of the organization's assets?		5		X
6 Did the organization have members or stockholders?		6		X
7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?		7a		X
b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?		7b		X
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:				
a The governing body?		8a	X	
b Each committee with authority to act on behalf of the governing body?		8b	X	
9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses on Schedule O		9		X

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

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

Section C. Disclosure

17 List the states with which a copy of this Form 990 is required to be filed **IL, MA**

18 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
☒ Own website ☐ Another's website ☒ Upon request ☐ Other (explain on Schedule O)

19 Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.

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

Allison Goldberg
Lake Forest

PO Box 702

IL 60045

857-650-0835

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent ContractorsCheck 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****1a** 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, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) 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 the instructions for the order in which to list the persons above.

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/ 1099-MISC/ 1099-NEC)	(E) Reportable compensation from related organizations (W-2/ 1099-MISC/ 1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) Johnathan Dicks										
President, VP Dev.	16.00 0.00	X		X				0	0	0
(2) Karen Gledhill										
Secretary	2.00 0.00	X		X				0	0	0
(3) Carol Hughes										
Director	7.00 0.00	X						0	0	0
(4) Clair Johnstone										
Executive Director	4.00 0.00	X		X				0	0	0
(5) Marybeth Krummenacker										
VP Education	4.00 0.00	X		X				0	0	0
(6) Chelsea Meschke										
VP Family Support	2.00 0.00	X		X				0	0	0
(7) Megan Morrill										
Director	3.00 0.00	X						0	0	0
(8) Gail Potts										
Director	2.00 0.00	X						0	0	0
(9) Heather Fields Rothrock										
Director	1.00 0.00	X						0	0	0
(10) Terri Schleuder										
Director	1.00 0.00	X						0	0	0
(11) Kristina Sevel										
VP Research	2.00 0.00	X		X				0	0	0

Part VII

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/ 1099-MISC/ 1099-NEC)	(E) Reportable compensation from related organizations (W-2/ 1099-MISC/ 1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(12) Herberth Sigler										
(12) Director	1.00 0.00	X						0	0	0
(13) Jen Wyman										
(13) Director	2.00 0.00	X						0	0	0
(14) Tim Wyman										
(14) Treasurer	1.00 0.00	X		X				0	0	0
(15)										
(16)										
(17)										
(18)										
(19)										
1b Subtotal										
c Total from continuation sheets to Part VII, Section A										
d Total (add lines 1b and 1c)										
2	Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization 0									

		Yes	No
3	Did the organization list any former officer, director, trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		X
4	For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? <i>If "Yes," complete Schedule J for such individual</i>		X
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		X

Section B. Independent Contractors

1	Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.									
	(A) Name and business address	(B) Description of services						(C) Compensation		
2	Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization 0									

Part VIII Statement of RevenueCheck if Schedule O contains a response or note to any line in this Part VIII ☐

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514
Contributions, Gifts, Grants, and Other Similar Amounts	1a Federated campaigns	1a					
	b Membership dues	1b					
	c Fundraising events	1c					
	d Related organizations	1d					
	e Government grants (contributions)	1e					
	f All other contributions, gifts, grants, and similar amounts not included above	1f	632,738				
	g Noncash contributions included in lines 1a-1f	1g	\$				
	h Total. Add lines 1a-1f						
Program Service Revenue				Business Code			
	2a						
	b						
	c						
	d						
	e						
	f All other program service revenue						
g Total. Add lines 2a-2f							
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)			13,283			13,283
	4 Income from investment of tax-exempt bond proceeds						
	5 Royalties						
	6a Gross rents	6a	(i) Real	(ii) Personal			
	b Less: rental expenses	6b					
	c Rental inc. or (loss)	6c					
	d Net rental income or (loss)						
	7a Gross amount from sales of assets other than inventory	7a	(i) Securities	(ii) Other			
	b Less: cost or other basis and sales exps.	7b					
	c Gain or (loss)	7c					
	d Net gain or (loss)						
	8a Gross income from fundraising events (not including \$ of contributions reported on line 1c). See Part IV, line 18	8a					
b Less: direct expenses	8b						
c Net income or (loss) from fundraising events							
9a Gross income from gaming activities. See Part IV, line 19	9a						
b Less: direct expenses	9b						
c Net income or (loss) from gaming activities							
10a Gross sales of inventory, less returns and allowances	10a						
b Less: cost of goods sold	10b						
c Net income or (loss) from sales of inventory							
Miscellaneous Revenue				Business Code			
	11a						
	b						
	c						
	d All other revenue						
e Total. Add lines 11a-11d							
12 Total revenue. See instructions				646,021	0	0	13,283

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

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

☒**Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.**

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	36,666	36,666		
2 Grants and other assistance to domestic individuals. See Part IV, line 22	9,197	9,197		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	19,125	19,125		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees				
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7 Other salaries and wages				
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits				
10 Payroll taxes				
11 Fees for services (nonemployees):				
a Management				
b Legal				
c Accounting	15,015		15,015	
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees				
g Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Schedule O.)	85,679	27,500	53,221	4,958
12 Advertising and promotion	4,121	4,068		53
13 Office expenses				
14 Information technology				
15 Royalties				
16 Occupancy				
17 Travel				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	115,166	107,104		8,062
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization				
23 Insurance	794		794	
24 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.)				
a Supplies	58,937	51,637	4,023	3,277
b Scholarships and Sponsors	12,000	12,000		
c				
d				
e All other expenses				
25 Total functional expenses. Add lines 1 through 24e	356,700	267,297	73,053	16,350
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ☐ if following SOP 98-2 (ASC 958-720)				

Part X Balance SheetCheck if Schedule O contains a response or note to any line in this Part X ☐

		(A) Beginning of year		(B) End of year
Assets	1 Cash—non-interest-bearing	58,290	1	131,422
	2 Savings and temporary cash investments	240,000	2	473,564
	3 Pledges and grants receivable, net		3	
	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 section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges		9	
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 28,600		
	b Less: accumulated depreciation	10b 28,600	10c	
	11 Investments—publicly traded securities		11	
	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)	298,290	16	604,986	
Liabilities	17 Accounts payable and accrued expenses	14,395	17	30,992
	18 Grants payable		18	
	19 Deferred revenue	11,690	19	12,468
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22 Loans and other payables to 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	26,085	26	43,460
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here ☒ and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	206,837	27	514,557
	28 Net assets with donor restrictions	65,368	28	46,969
	Organizations that do not follow FASB ASC 958, check here ☐ and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		29	
	30 Paid-in or capital surplus, or land, building, or equipment fund		30	
	31 Retained earnings, endowment, accumulated income, or other funds		31	
	32 Total net assets or fund balances	272,205	32	561,526
33 Total liabilities and net assets/fund balances	298,290	33	604,986	

Part XI **Reconciliation of Net Assets**

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	646,021
2	Total expenses (must equal Part IX, column (A), line 25)	2	356,700
3	Revenue less expenses. Subtract line 2 from line 1	3	289,321
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	272,205
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	561,526

Part XII **Financial Statements and Reporting**

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

		Yes	No
1	Accounting method used to prepare the Form 990: ☐ Cash ☒ Accrual ☐ Other If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.		
2a	Were the organization's financial statements compiled or reviewed by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both. ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis		X
b	Were the organization's financial statements audited by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both. ☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis	X	
c	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.	X	
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Uniform Guidance, 2 C.F.R. Part 200, Subpart F?		X
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits		

SCHEDULE A
(Form 990)Department of the Treasury
Internal Revenue Service**Public Charity Status and Public Support**

OMB No. 1545-0047

2024**Open to Public
Inspection**

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

Attach to Form 990 or Form 990-EZ.

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

Name of the organization

Cystinosis Research Network, Inc

Employer identification number

04-3323789**Part I Reason for Public Charity Status.** (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

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

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

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

Cat. No. 11285F

Schedule A (Form 990) 2024

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

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	526,401	542,497	345,873	508,084	632,738	2,555,593
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	526,401	542,497	345,873	508,084	632,738	2,555,593
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)						1,402,732
6 Public support. Subtract line 5 from line 4						1,152,861

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
7 Amounts from line 4	526,401	542,497	345,873	508,084	632,738	2,555,593
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	1,096	713	394	2,967	13,283	18,453
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
11 Total support. Add lines 7 through 10						2,574,046

12 Gross receipts from related activities, etc. (see instructions)	12	
13 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here		☐

Section C. Computation of Public Support Percentage

14 Public support percentage for 2024 (line 6, column (f), divided by line 11, column (f))	14	44.79 %
15 Public support percentage from 2023 Schedule A, Part II, line 14	15	39.40 %
16a 33 1/3% support test — 2024. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization		☒
b 33 1/3% support test — 2023. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization		☐
17a 10%-facts-and-circumstances test — 2024. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization		☐
b 10%-facts-and-circumstances test — 2023. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization		☐
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions		☐

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

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II.
If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						
14 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here						☐

Section C. Computation of Public Support Percentage

15 Public support percentage for 2024 (line 8, column (f), divided by line 13, column (f))	15	%
16 Public support percentage from 2023 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2024 (line 10c, column (f), divided by line 13, column (f))	17	%
18 Investment income percentage from 2023 Schedule A, Part III, line 17	18	%
19a 33 1/3% support tests — 2024. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here . The organization qualifies as a publicly supported organization		☐
b 33 1/3% support tests — 2023. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and stop here . The organization qualifies as a publicly supported organization		☐
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions		☐

Part IV Supporting Organizations

(Complete only if you checked a box on 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 and D, and complete Part V.)

Section A. All Supporting Organizations

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

Part IV Supporting Organizations (continued)

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

Section B. Type I Supporting Organizations

	Yes	No
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.		
1		
2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.		
2		

Section C. Type II Supporting Organizations

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

Section D. All Type III Supporting Organizations

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

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 each of its supported organizations, and how the organization determined that these activities constituted substantially all of its activities.			
2a			
b Did the activities described on 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.			
2b			
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 .			
3a			
b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.			
3b			

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

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

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

Section B – Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):		
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	Total (add lines 1a, 1b, and 1c)	1d	
e	Discount claimed for blockage or other factors (<i>explain in detail in Part VI</i>):		
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	

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

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

Section D – Distributions		Current Year
1	Amounts paid to supported organizations to accomplish exempt purposes	1
2	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2
3	Administrative expenses paid to accomplish exempt purposes of supported organizations	3
4	Amounts paid to acquire exempt-use assets	4
5	Qualified set-aside amounts (prior IRS approval required—provide details in Part VI)	5
6	Other distributions (describe in Part VI). See instructions.	6
7	Total annual distributions. Add lines 1 through 6.	7
8	Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions.	8
9	Distributable amount for 2024 from Section C, line 6	9
10	Line 8 amount divided by line 9 amount	10

Section E – Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2024	(iii) Distributable Amount for 2024
1 Distributable amount for 2024 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2024 (reasonable cause required—explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2024			
a From 2019			
b From 2020			
c From 2021			
d From 2022			
e From 2023			
f Total of lines 3a through 3e			
g Applied to underdistributions of prior years			
h Applied to 2024 distributable amount			
i Carryover from 2019 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2024 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2024 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2024, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI . See instructions.			
6 Remaining underdistributions for 2024. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI . See instructions.			
7 Excess distributions carryover to 2025. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2020			
b Excess from 2021			
c Excess from 2022			
d Excess from 2023			
e Excess from 2024			

Part VI

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

SCHEDULE D
(Form 990)
(Rev. December 2024)
Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements
Complete if the organization answered "Yes" on Form 990,
Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.
Attach to Form 990.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047
Open to Public Inspection

Name of the organization	Employer identification number
Cystinosis Research Network, Inc	04-3323789

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts
Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year)		
4 Aggregate value at end of year		
5 Did the organization inform all donors and 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?		☐ Yes ☐ No
6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit?		☐ Yes ☐ No

Part II Conservation Easements
Complete if the organization answered "Yes" on Form 990, Part IV, line 7.

1 Purpose(s) of conservation easements held by the organization (check all that apply).	
☐ Preservation of land for public use (for example, recreation or education)	☐ Preservation of a historically important land area
☐ Protection of natural habitat	☐ Preservation of a certified historic structure
☐ Preservation of open space	
2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.	
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included on line 2a	2c
d Number of conservation easements included on line 2c acquired after July 25, 2006, and not on a historic structure listed in the National Register	2d
3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year	
4 Number of states where property subject to conservation easement is located	
5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?	☐ Yes ☐ No
6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conversation easements during the year	
7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year	\$
8 Does each conservation easement reported on line 2d above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)?	☐ Yes ☐ No
9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.	

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets
Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

1a If the organization elected, as permitted under FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide in Part XIII the text of the footnote to its financial statements that describes these items.	
b If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items.	
(i) Revenue included on Form 990, Part VIII, line 1	\$
(ii) Assets included in Form 990, Part X	\$
2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items.	
a Revenue included on Form 990, Part VIII, line 1	\$
b Assets included in Form 990, Part X	\$

Part III

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

- 3
- Using the organization's acquisition, accession, and other records, check any of the following that make significant use of its collection items (check all that apply).
- a

☐

Public exhibition

b

☐

Scholarly research

c

☐

Preservation for future generations

d

☐

Loan or exchange program

e

☐

Other
- 4
- Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5
- During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?
- ☐

Yes

☐

No

Part IV

Escrow and Custodial Arrangements

Complete if the organization answered "Yes" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

- 1a
- Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?
- ☐

Yes

☐

No
- b
- If "Yes," explain the arrangement in Part XIII and complete the following table.
- | | |
|----|--------|
| | Amount |
| 1c | |
| 1d | |
| 1e | |
| 1f | |
- 2a
- Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability?
- ☐

Yes

☐

No
- b
- If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII
- ☐

Part V

Endowment Funds

Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

- | | | | | | |
|----|--|----------------|--------------------|----------------------|---------------------|
| | (a) Current year | (b) Prior year | (c) Two years back | (d) Three years back | (e) Four years back |
| 1a | Beginning of year balance | | | | |
| b | Contributions | | | | |
| c | Net investment earnings, gains, and losses | | | | |
| d | Grants or scholarships | | | | |
| e | Other expenditures for facilities and programs | | | | |
| f | Administrative expenses | | | | |
| g | End of year balance | | | | |
- 2
- Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a

Board designated or quasi-endowment

%

b

Permanent endowment

%

c

Term endowment

%
- The percentages on lines 2a, 2b, and 2c should equal 100%.
- 3a
- Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- (i)

Unrelated organizations?

(ii)

Related organizations?
- 3a(i)

☐

Yes

☐

No

3a(ii)

☐

Yes

☐

No

3b

☐

Yes

☐

No
- b
- If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R?
- ☐
- 4
- Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI

Land, Buildings, and Equipment

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment				
e Other		28,600	28,600	
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, line 10c, column (B))				

Part VII Investments – Other Securities

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

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

Part VIII Investments – Program Related

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

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

Part IX Other Assets

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

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

Part X Other Liabilities

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

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

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 ☐

Part XIII Supplemental Information (continued)

DAA

SCHEDULE F
(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

Name of the organization

Statement of Activities Outside the United States

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

Attach to Form 990.

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

OMB No. 1545-0047

Open to Public
Inspection

Cystinosis Research Network, Inc

Employer identification number

04-3323789

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

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

2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

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

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
Europe - Albania, Andorra, Austria, Belg			Grantmaking		
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
3a Subtotal					
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b)					

Part II

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

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
(1)			Europe	Research	19,125	wire transfer			
(2)									
(3)									
(4)									
(5)									
(6)									
(7)									
(8)									
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									

2

Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as a tax exempt 501(c)(3) organization by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter

3

Enter total number of other organizations or entities

Part III

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

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

Part IV Foreign Forms

- 1

Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see the Instructions for Form 926)*

☐ Yes

☒ No
- 2

Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see the Instructions for Forms 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 the Instructions for Form 5471)*

☐ Yes

☒ No
- 4

Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see the Instructions for Form 8621)*

☐ Yes

☒ No
- 5

Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see the Instructions for Form 8865)*

☐ Yes

☒ No
- 6

Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see the Instructions for Form 5713; don't file with Form 990)*

☐ Yes

☒ No

Part V

Supplemental Information

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.

Part I, Line 2 - Procedures for Monitoring the Use of Grant Funds

All grants are reviewed by a scientific review board of physicians familiar with cystinosis. Per grant agreement, researchers are to provide periodic progress reports showing research progress and expenses incurred thus far.

Part I, Line 3 - Activities per Region		
Region	Expenditures	Investments
Europe - Albania, Andorra, Austria, Belg	\$ 0	\$ 0

SCHEDULE I
(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

Grants and Other Assistance to Organizations,
Governments, and Individuals in the United States
Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.
Attach to Form 990.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public
Inspection

Name of the organization	Cystinosis Research Network, Inc	Employer identification number	04-3323789
--------------------------	----------------------------------	--------------------------------	------------

Part I General Information on Grants and Assistance

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

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

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

1	(a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1)	The Regents of the University of California PO Box 748872 Los Angeles CA 90074	94-3067788	501c3	36,666				Research Grant
(2)								
(3)								
(4)								
(5)								
(6)								
(7)								
(8)								
(9)								

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

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

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 Scholarships	3	5,000			
2 Awards	5	4,197			
3					
4					
5					
6					
7					

Part IV

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

Part I, Line 2 - Procedures for Monitoring the Use of Grant Funds

All grants are reviewed by a scientific review board of physicians familiar with cystinosis. Per grant agreement, researchers are to provide periodic progress reports showing research progress and expenses incurred thus far.

SCHEDULE O
(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

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 Form 990-EZ.

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

OMB No. 1545-0047

Open to Public
Inspection

Name of the organization

Cystinosis Research Network, Inc

Employer identification number

04-3323789

Form 990 - Organization's Mission

The Cystinosis Research Network is an all volunteer, non-profit organization dedicated to supporting and advocating research, providing family assistance and educating the public and medical communities about Cystinosis.

Form 990, Part VI, Line 2 - Related Party Information Among Officers

Tim Wyman

Jen Wyman

Family Relationship

Form 990, Part VI, Line 11b - Organization's Process to Review Form 990

The draft copy of form 990 is reviewed by the treasurer and requests to review will be made to the executive committee prior to signature by the treasurer or executive director. A copy of the final form 990 is provided to all board members prior to filing.

Form 990, Part VI, Line 12c - Enforcement of Conflicts Policy

On an annual basis, the organization discusses the existing policy with the board members and asks that all members disclose any relationships or situations that may go against this policy.

Form 990, Part VI, Line 19 - Governing Documents Disclosure Explanation

All available upon request of executive director.

Form 990, Part IX, Line 11g - Other Fees for Services

Description

Tot/Prog Service	Mgt & General	Fundraising
Operations:Independent Contra		
\$ 27,500	\$ 53,221	\$ 4,958

Massachusetts Diagnostics

Critical Messages

None

Informational Messages

☐ Massachusetts Department of Revenue does not support third party electronic filing

Form M-990T Return Summary

For calendar year 2024, or taxable period beginning , and ending

04-3323789

Cystinosis Research Network, Inc

Income

Total unrelated business taxable income
Taxable income

Tax Computation

Excise tax before credits
Total credits
Voluntary contribution - endangered wildlife
Total excise tax

Payments / Refundable Credits / Penalties

Payments / refundable credits
M-2220 penalty
Late filing interest
Failure to file penalty
Failure to pay penalty
Total payments / penalties

Overpayment credited to next year's estimated tax

Refund

Tax due

Next Year's Estimates

1st quarter
2nd quarter
3rd quarter
4th quarter
Total

Miscellaneous Information

Amended return
Return / extended due date 03/17/25

Form PC / Short Form PC - Annual Report

Filing fee 250
Amended return
Return / extended due date 08/15/25

Filing Instructions

Cystinosis Research Network, Inc

Form PC - Massachusetts Annual Report

Taxable Year Ended December 31, 2024

Date Due: AS SOON AS POSSIBLE

Remittance: The filing fee for the tax year ended 12/31/24 is \$250. Form PC should be filed online for the Commonwealth of Massachusetts at the charity filing portal.

WORKSHEET ONLY - DO NOT FILE**THE COMMONWEALTH OF MASSACHUSETTS
OFFICE OF THE ATTORNEY GENERAL****NON-PROFIT ORGANIZATIONS/PUBLIC CHARITIES DIVISION**MAURA HEALEY
ATTORNEY GENERALONE ASHBURTON PLACE
BOSTON, MASSACHUSETTS 02108(617) 727-2200, ext. 2101
www.mass.gov/ago/charities**Worksheet PC**Report for the Fiscal Period: 01/01/2024 to 12/31/2024AG Account #: 036476 Federal ID #: 04-3323789Electronic Payment Confirmation #: _____
Attach printout of electronic payment confirmation.

Electronic Payment Date: _____

When did the organization first engage in
charitable work in Massachusetts? 08/06/1996Has the organization applied for or been
granted IRS tax exempt status?☒ Yes ☐ NoIf yes, date of application **OR** date of determination letter: 11/30/1996IRS Exemption under 501(c): 3If exempt under 501(c), are contributions to the organization
tax deductible as charitable contributions?☒ Yes ☐ No**Check all items attached
(if applicable)**☒ Filing Fee or Printout of
Electronic Payment
Confirmation☒ Copy of IRS Return☒ Audited Financial
Statements/Review☐ Amended Articles/
By-Laws☐ Schedule A-1☐ Schedule A-2☐ Schedule RO☐ Schedule VCO☐ Probate Account**Organization Data**Name: Cystinosis Research Network, IncMailing Address: P.O. Box 702City: Lake ForestState: ILZip: 60045Phone Number: 847-735-0471

Fax Number: _____

Email: cjohnstone@cystinosis.orgWebsite: www.cystinosis.org

In the table below, please enter the appropriate codes from the corresponding tables found in the instructions.

Enter **up to 2** codes from Table 3 for your organization's main purpose(s)

Category	Code	Category	Code
County (Table 1)	<u>15</u>	Organization Purpose Code 1	<u>21</u>
Type of Organization (Table 2)	<u>8</u>	Organization Purpose Code 2	

Please check box if final return prior to dissolution: ☐

WORKSHEET ONLY - DO NOT FILE

All questions must be completed in their entirety whether or not similar questions are answered in an attached federal form.
See instructions and definition section for guidance.

1. On what date was the organization created? 08/06/1996

2. Where was the organization created? Massachusetts

3. What is the form of organization? (check one)

Corporation



Testamentary Trust



Unincorporated Association



Inter Vivos Trust



Other (please describe): _____

4. Was your organization related to any other organization(s) during the reporting year (see definition "Related Organization")? If yes, please complete the Schedule RO on pages 13 and 14. ☐ Yes ☒ No

5. Enter your summary of financial data:

	Financial Data	Amounts
A.	Contributions, gifts, grants, and similar amounts received	632,738
B.	Gross support and revenue	646,021
C.	Program services and similar amounts paid out	267,297
D.	Fundraising expenses	16,350
E.	Management and general expenses	73,053
F.	Payments to affiliates	
G.	Total expenses	356,700
H.	Net assets or fund balances at the end of the year	561,526

6. List the total compensation you provided to your five highest paid employees:

	Name/Title	Hrs/ Week	Salary and Other Income	Benefit Plans	Other Compensation
1.					
2.					
3.					
4.					
5.					

7. Was any compensation provided to any of the individuals listed in question 6 above which was not quantified in your response to 6? If yes, please provide explanation (attach separate sheet). ☐ Yes ☐ No

WORKSHEET ONLY - DO NOT FILE

8. List the name, amount of compensation paid, and the nature of services rendered by each of the organization's five highest paid consultants providing professional services (e.g. attorneys, architects, accountants, management companies, investment advisors, professional solicitors, professional fundraising counsel).

	Name/Title	Amount of Compensation	Type(s) of Service
1.			
2.			
3.			
4.			
5.			

9. Bank(s) in which the organization's funds are deposited (include bank addresses and phone number):

Bank	Address	Phone Number
Old Second National Bank	37 S River St Aurora IL 60506	

10. What is the organization's accounting method? ☐ Cash ☒ Accrual

☐ Other (specify): _____

11. If organization's mailing address is a P.O. Box, list the organization's full street address:

Address: 1250 Hazel Avenue

City: Deerfield State: IL Zip Code: 60015

12. Contact Person Name: Clair Johnstone

Street Address: PO Box 702

City: Lake Forest State: IL Zip Code: 60045

Phone Number: 609-234-2461

WORKSHEET ONLY - DO NOT FILE

13. During the fiscal year reported here, did your organization solicit contributions or have funds solicited on its behalf? ☐ Yes ☒ No

14. At any time during the fiscal year following the year reported here, will your organization, or others acting on its behalf, solicit contributions? ☐ Yes ☒ No

If you answered yes to Question 13 or 14, you must complete Schedule A-1 and/or Schedule A-2 unless you are exempt from the solicitation certificate requirement.

15. If you are claiming an exemption from the solicitation certificate requirement, please indicate by checking the box to the right to identify which exemption applies to your organization.

a religious organization	☐
an organization which: (a) does not raise more than \$5,000 during a calendar year OR does not receive contributions from more than ten persons during a calendar year; AND (b) carries out all of its activities, including fundraising, through unpaid volunteers. [The conditions at both (a) and (b) must be met for your organization to qualify for this exemption.]	☐

16. Attach a list of names, addresses (street and/or mailing), and telephone numbers of other offices/chapters/branches/affiliates. **None**

17. Attach a list of names, titles, and addresses (street and/or mailing) of officers, directors, trustees, and the principal salaried executives of organization. **See Statement 1**

18. Attach a list of name, titles, and addresses (street and/or mailing) of any individual(s) authorized to sign checks, and any individual(s) responsible for: custody of funds; distribution of funds; fundraising; and custody of financial records. **See Statement 2**

19. Has this organization or any of its officers, directors, employees or fundraisers solicited funds in any other state? ☒ Yes ☐ No

See Statement 3
If you attach list of states where solicitation was conducted, including registered agency, dates of registration, registration numbers, any other names under which the organization was/is registered, and the dates and type (mail, telephone, door to door, special events, etc.) of the solicitation conducted.

WORKSHEET ONLY - DO NOT FILE

1022

20. Has this organization or any of its officers, directors, or employees:

If yes, please attach an explanation.

(a) Been enjoined or otherwise prohibited by a government agency/court from operating or soliciting contributions?

☐ Yes ☒ No

(b) Ever been refused registration or had its registration or tax exemption denied, suspended, modified or revoked by a governmental agency?

☐ Yes ☒ No

(c) Been the subject of a proceeding regarding any solicitation or registration?

☐ Yes ☒ No

(d) Entered into a voluntary agreement of compliance or consent judgment with, any government agency or in a case before a court or administrative agency?

☐ Yes ☒ No

21. Have any restrictions been removed during the year from donor-restricted funds?

If yes, please attach an explanation.

☐ Yes ☒ No

22. Have donor-restricted funds been loaned to unrestricted funds?

If yes, please attach an explanation.

☐ Yes ☒ No

23. This question involves "Termination of Employment or Changes of Control Compensatory Arrangements" with certain "Related Parties" (*see instructions and definition sections*). Report only if payments made or promised to any individual are in excess of four months salary or \$100,000, whichever dollar amount is less.

(a) Did you make actual payments or otherwise transfer value under such an arrangement to any individual described in Related Party definition, sections (a) or (b), which payments are not reported in Question 6 or 7 above?

☐ Yes ☒ No

(b) Do you have an agreement with any individual described in Related Party definition, sections (a) or (b), containing such an agreement?

☐ Yes ☒ No

*If you answered **yes** for Question 23(a) or 23(b) above, please attach an explanation identifying the individual(s) involved, stating the amount of any payments made or value transferred, and describing the terms of each agreement.*

WORKSHEET ONLY - DO NOT FILE

24. This question applies to related party transactions, which include transactions with officers, directors, trustees, certain employees, relative, and organizations they own or control. Please consult the instructions and definition sections for the definition of a "Related Party" and "Indebtedness" before answering. Note that transactions involving related parties must be reported even when there is no accounting recognition (e.g. in-kind gifts, waiver or interest not otherwise reported).

*If the answer to any part of Question 24 is **yes**, attach a schedule stating the name and address of the related party, the nature of the transaction, the value or the amounts involved in the transaction, and the procedure followed in authorizing the transaction.*

During the year:		
A.	Has your organization sold or transferred assets to or purchased assets from or exchanged assets with a related party?	☐ Yes ☒ No
B.	Has your organization leased assets to or leased assets from a related party?	☐ Yes ☒ No
C.	Has your organization been indebted to a related party?	☐ Yes ☒ No
D.	Has your organization allowed a related party to be indebted to it?	☐ Yes ☒ No
E.	Has your organization made or held an investment in a related party?	☐ Yes ☒ No
F.	Has your organization furnished goods, services, or facilities to a related party?	☐ Yes ☒ No
G.	Has your organization acquired goods, services, or facilities from a related party who received compensation or other value in return?	☐ Yes ☒ No
H.	Has your organization paid or became obligated to pay wages, salary, or other compensation to a related party?	☐ Yes ☒ No
I.	Has your organization transferred income or assets to or for use by a related party?	☐ Yes ☒ No
J.	Was your organization a party to any transaction in which any of its officers, directors, or trustees has a material financial interest, or did any officer, director or trustee receive anything of value not reported as compensation?	☐ Yes ☒ No
K.	Has your organization invested in any corporate stock of a company in which any officer, director, or trustee owns more than 10% of the outstanding shares?	☐ Yes ☒ No
L.	Is any property of the organization held in the name of or commingled with the property of any other person or organization?	☐ Yes ☒ No
M.	Did your organization make a grant award or contribution to any other organization in which any of this organization's officers, directors or trustees has a relationship?	☐ Yes ☒ No

WORKSHEET ONLY - DO NOT FILE

Signature Required

Under penalty of perjury, I declare that the information furnished in this report, including all attachments, is true and correct to the best of my knowledge.

Signature: _____ Date: _____

Printed Name: Clair Johnstone

Title: Executive Director

Name of Preparer: Mattina, Kent & Gibbons, P.C.

Address 1214 N Main St
Rochester, MI 48307

City _____ State _____ Zip Code _____

Phone Number 248-601-9500

Massachusetts Statements

Statement 1 - Form PC, Page 4, Line 17 - Officers, Directors, Trustees, and Principal Salaried Executives

Name	Title	Address	City	State	Zip Code
Johnathan Dicks	President, V	PO Box 702	Lake Forest	IL	60045
Kristina Sevel	VP Research	PO Box 702	Lake Forest	IL	60045
Marybeth Krummenacker	VP Education	PO Box 702	Lake Forest	IL	60045
Tim Wyman	Treasurer	PO Box 702	Lake Forest	IL	60045
Karen Gledhill	Secretary	PO Box 702	Lake Forest	IL	60045
Megan Morrill	Director	PO Box 702	Lake Forest	IL	60045
Chelsea Meschke	VP Family Su	PO Box 702	Lake Forest	IL	60045
Jen Wyman	Director	PO Box 702	Lake Forest	IL	60045
Herberth Sigler	Director	PO Box 702	Lake Forest	IL	60045
Terri Schleuder	Director	PO Box 702	Lake Forest	IL	60045
Heather Fields Rothrock	Director	PO Box 702	Lake Forest	IL	60045
Gail Potts	Director	PO Box 702	Lake Forest	IL	60045
Carol Hughes	Director	PO Box 702	Lake Forest	IL	60045
Clair Johnstone	Executive Di	PO Box 702	Lake Forest	IL	60045

Massachusetts Statements

Statement 2 - Form PC, Page 4, Line 18 - Individuals Authorized to Sign Checks or Responsible for Funds

Name	Title	Address	City	State	Zip
See statement 1					

Statement 3 - Form PC, Page 4, Line 19 - States Where Solicitation Conducted

Description
Illinois AG Charitable Trust Bureau Date of Reg 4/2/07 Reg number 01050724 Solicit date 4/2/07 Type other

Form

990

Department of the Treasury
Internal Revenue Service

Return of Organization Exempt From Income Tax

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

Do not enter social security numbers on this form as it may be made public.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2024

Open to Public Inspection

A For the 2024 calendar year, or tax year beginning , and ending

B Check if applicable:
☐ Address change
☐ Name change
☐ Initial return
☐ Final return/terminated
☐ Amended return
☐ Application pending

C Name of organization
Cystinosis Research Network, Inc
Doing business as
Number and street (or P.O. box if mail is not delivered to street address) Room/suite
P.O. Box 702
City or town, state or province, and ZIP or foreign postal code
Lake Forest IL 60045

D Employer identification number
04-3323789
E Telephone number
847-735-0471
G Gross receipts\$ **646,021**

F Name and address of principal officer:
Clair Johnstone
PO Box 702
Lake Forest IL 60045

H(a) Is this a group return for subordinates? ☐ Yes ☒ No
H(b) Are all subordinates included? ☐ Yes ☐ No
If "No," attach a list. See instructions
H(c) Group exemption number

I Tax-exempt status: ☒ 501(c)(3) ☐ 501(c) () (insert no.) ☐ 4947(a)(1) or ☐ 527

J Website: **www.cystinosis.org**

K Form of organization: ☒ Corporation ☐ Trust ☐ Association ☐ Other

L Year of formation: **1996**

M State of legal domicile: **MA**

Part I Summary

Activities & Governance

1 Briefly describe the organization's mission or most significant activities:
See Schedule O

2 Check this box ☐ if the organization discontinued its operations or disposed of more than 25% of its net assets.

3 Number of voting members of the governing body (Part VI, line 1a) **3 13**

4 Number of independent voting members of the governing body (Part VI, line 1b) **4 13**

5 Total number of individuals employed in calendar year 2024 (Part V, line 2a) **5 0**

6 Total number of volunteers (estimate if necessary) **6 20**

7a Total unrelated business revenue from Part VIII, column (C), line 12 **7a 0**

7b Net unrelated business taxable income from Form 990-T, Part I, line 11 **7b 0**

Revenue

8 Contributions and grants (Part VIII, line 1h) **508,084**

9 Program service revenue (Part VIII, line 2g) **0**

10 Investment income (Part VIII, column (A), lines 3, 4, and 7d) **2,967**

11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) **0**

12 Total revenue – add lines 8 through 11 (must equal Part VIII, column (A), line 12) **511,051**

13 Grants and similar amounts paid (Part IX, column (A), lines 1–3) **127,547**

14 Benefits paid to or for members (Part IX, column (A), line 4) **0**

15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10) **0**

16a Professional fundraising fees (Part IX, column (A), line 11e) **0**

16b Total fundraising expenses (Part IX, column (D), line 25) **16,350**

17 Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e) **562,990**

18 Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25) **690,537**

19 Revenue less expenses. Subtract line 18 from line 12 **-179,486**

Net Assets or Fund Balances

20 Total assets (Part X, line 16) **298,290**

21 Total liabilities (Part X, line 26) **26,085**

22 Net assets or fund balances. Subtract line 21 from line 20 **272,205**

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

Sign Here

Signature of officer
Clair Johnstone
Type or print name and title
Executive Director

Date

Paid Preparer Use Only

Preparer's name
John Coombs, CPA

Preparer's signature

Date
08/26/25

Check ☐ if self-employed ☐ PTIN
P00144604

Firm's name
Mattina, Kent & Gibbons, P.C.

Firm's EIN
38-2808585

Firm's address
**1214 N Main St
Rochester, MI 48307**

Phone no.
248-601-9500

May the IRS discuss this return with the preparer shown above? See instructions ☐ Yes ☐ No

For Paperwork Reduction Act Notice, see the separate instructions. Form 990 (2024)

DAA

Part III

Statement of Program Service Accomplishments

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

X

- 1 Briefly describe the organization's mission:
See Schedule O
- 2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ?
If "Yes," describe these new services on Schedule O. ☐ Yes ☒ No
- 3 Did the organization cease conducting, or make significant changes in how it conducts, any program services?
If "Yes," describe these changes on Schedule O. ☐ Yes ☒ No
- 4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code:) (Expenses \$ 55,791 including grants of \$ 55,791) (Revenue \$)

The organization establishes and funds fellowships and research grants focusing on clinical and research training in cystinosis.

4b (Code:) (Expenses \$ 187,667 including grants of \$ 5,000) (Revenue \$)

The organization raises awareness and reinforces strong relationships through representation at national medical conferences, affiliation with other organizations, publication of periodic newsletters and awards or educational scholarships to individuals with Cystinosis and their siblings.

4c (Code:) (Expenses \$ 23,839 including grants of \$ 4,197) (Revenue \$)

The organization provides information and opportunities to network for individuals with Cystinosis and their families through participation in a biennial conference on Cystinosis. It also supports newly diagnosed and existing families by providing access to world experts via advisory boards, moderation of an email support group and information packets.

4d Other program services (Describe on Schedule O.)
(Expenses \$ including grants of \$) (Revenue \$)

4e Total program service expenses 267,297

Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A</i>	X	
2 Is the organization required to complete Schedule B, Schedule of Contributors? See instructions		X
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i>		X
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II</i>		X
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Rev. Proc. 98-19? <i>If "Yes," complete Schedule C, Part III</i>		X
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I</i>		X
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i>		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i>		X
9 Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV</i>		X
10 Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i>		X
11 If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X, as applicable.		
a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI</i>	X	
b Did the organization report an amount for investments—other securities in Part X, line 12, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII</i>		X
c Did the organization report an amount for investments—program related in Part X, line 13, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII</i>		X
d Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX</i>		X
e Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i>		X
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i>		X
12a Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i>	X	
b Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i>		X
13 Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>		X
14a Did the organization maintain an office, employees, or agents outside of the United States?		X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV</i>	X	
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV</i>	X	
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV</i>		X
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I. See instructions</i>		X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II</i>		X
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i>		X
20a Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>		X
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	X	

Part IV Checklist of Required Schedules (continued)

	Yes	No
22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22 X	
23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	23	X
24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>	24a	X
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	
25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a	X
b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>	25b	X
26 Did the organization report any amount on Part X, line 5 or 22, for receivables from or 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? <i>If "Yes," complete Schedule L, Part II</i>	26	X
27 Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>	27	X
28 Was the organization a party to a business transaction with one of the following parties? (See the Schedule L, Part IV, instructions for applicable filing thresholds, conditions, and exceptions).		
a A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i>	28a	X
b A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i>	28b	X
c A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i>	28c	X
29 Did the organization receive more than \$25,000 in noncash contributions? <i>If "Yes," complete Schedule M</i>	29	X
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>	30	X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31	X
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>	32	X
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>	33	X
34 Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>	34	X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a	X
b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35b	
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	36	X
37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>	37	X
38 Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19? Note: All Form 990 filers are required to complete Schedule O.	38 X	

Part V Statements Regarding Other IRS Filings and Tax ComplianceCheck if Schedule O contains a response or note to any line in this Part V ☐

	Yes	No
1a Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable	1a 6	
b Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable	1b 0	
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	X

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 0		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b		
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a		X
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O	3b		
4a	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		X
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).			
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b		X
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c		
6a	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?	6a		X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b		
7	Organizations that may receive deductible contributions under section 170(c).			
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?	7a		
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b		
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c		
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?	7e		
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f		
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g		
h	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. 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?	9a		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9b		
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	10b		
11	Section 501(c)(12) organizations. Enter:			
a	Gross income from members or shareholders	11a		
b	Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.)	11b		
12a	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.			
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	13c		
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a		X
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O	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? If "Yes," see instructions and file Form 4720, Schedule N.	15		X
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
17	Section 501(c)(21) organizations. Did the trust, any disqualified or other person, engage in any activities that would result in the imposition of an excise tax under section 4951, 4952, or 4953? If "Yes," complete Form 6069.	17		

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
1a Enter the number of voting members of the governing body at the end of the tax year	1a	13		
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.				
b Enter the number of voting members included on line 1a, above, who are independent	1b	13		
2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?		2	X	
3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person?		3		X
4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		4		X
5 Did the organization become aware during the year of a significant diversion of the organization's assets?		5		X
6 Did the organization have members or stockholders?		6		X
7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?		7a		X
b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?		7b		X
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:				
a The governing body?		8a	X	
b Each committee with authority to act on behalf of the governing body?		8b	X	
9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses on Schedule O		9		X

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

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

Section C. Disclosure

17 List the states with which a copy of this Form 990 is required to be filed **IL, MA**

18 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
☒ Own website ☐ Another's website ☒ Upon request ☐ Other (explain on Schedule O)

19 Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.

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

Allison Goldberg
Lake Forest

PO Box 702

IL 60045

857-650-0835

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent ContractorsCheck 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****1a** 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, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) 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 the instructions for the order in which to list the persons above.

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/ 1099-MISC/ 1099-NEC)	(E) Reportable compensation from related organizations (W-2/ 1099-MISC/ 1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) Johnathan Dicks										
President, VP Dev.	16.00 0.00	X		X				0	0	0
(2) Karen Gledhill										
Secretary	2.00 0.00	X		X				0	0	0
(3) Carol Hughes										
Director	7.00 0.00	X						0	0	0
(4) Clair Johnstone										
Executive Director	4.00 0.00	X		X				0	0	0
(5) Marybeth Krummenacker										
VP Education	4.00 0.00	X		X				0	0	0
(6) Chelsea Meschke										
VP Family Support	2.00 0.00	X		X				0	0	0
(7) Megan Morrill										
Director	3.00 0.00	X						0	0	0
(8) Gail Potts										
Director	2.00 0.00	X						0	0	0
(9) Heather Fields Rothrock										
Director	1.00 0.00	X						0	0	0
(10) Terri Schleuder										
Director	1.00 0.00	X						0	0	0
(11) Kristina Sevel										
VP Research	2.00 0.00	X		X				0	0	0

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/ 1099-MISC/ 1099-NEC)	(E) Reportable compensation from related organizations (W-2/ 1099-MISC/ 1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(12) Herberth Sigler										
(12) Director	1.00 0.00	X						0	0	0
(13) Jen Wyman										
(13) Director	2.00 0.00	X						0	0	0
(14) Tim Wyman										
(14) Treasurer	1.00 0.00	X		X				0	0	0
(15)										
(16)										
(17)										
(18)										
(19)										
1b Subtotal										
c Total from continuation sheets to Part VII, Section A										
d Total (add lines 1b and 1c)										
2	Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization 0									

	Yes	No
3 Did the organization list any former officer, director, trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		X
4 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? <i>If "Yes," complete Schedule J for such individual</i>		X
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		X

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

(A) Name and business address	(B) Description of services	(C) Compensation
2	Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization 0	

Part VIII Statement of RevenueCheck if Schedule O contains a response or note to any line in this Part VIII ☐

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514	
Contributions, Gifts, Grants, and Other Similar Amounts	1a Federated campaigns	1a						
	b Membership dues	1b						
	c Fundraising events	1c						
	d Related organizations	1d						
	e Government grants (contributions)	1e						
	f All other contributions, gifts, grants, and similar amounts not included above	1f	632,738					
	g Noncash contributions included in lines 1a-1f	1g	\$					
	h Total. Add lines 1a-1f			632,738				
Program Service Revenue			Business Code					
	2a							
	b							
	c							
	d							
	e							
	f All other program service revenue							
g Total. Add lines 2a-2f								
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)			13,283			13,283	
	4 Income from investment of tax-exempt bond proceeds							
	5 Royalties							
	6a Gross rents	6a	(i) Real	(ii) Personal				
	b Less: rental expenses	6b						
	c Rental inc. or (loss)	6c						
	d Net rental income or (loss)							
	7a Gross amount from sales of assets other than inventory	7a	(i) Securities	(ii) Other				
	b Less: cost or other basis and sales exps.	7b						
	c Gain or (loss)	7c						
	d Net gain or (loss)							
	8a Gross income from fundraising events (not including \$ of contributions reported on line 1c). See Part IV, line 18	8a						
b Less: direct expenses	8b							
c Net income or (loss) from fundraising events								
9a Gross income from gaming activities. See Part IV, line 19	9a							
b Less: direct expenses	9b							
c Net income or (loss) from gaming activities								
10a Gross sales of inventory, less returns and allowances	10a							
b Less: cost of goods sold	10b							
c Net income or (loss) from sales of inventory								
Miscellaneous Revenue			Business Code					
	11a							
	b							
	c							
	d All other revenue							
e Total. Add lines 11a-11d								
12 Total revenue. See instructions			646,021	0	0	13,283		

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

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

☒**Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.**

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	36,666	36,666		
2 Grants and other assistance to domestic individuals. See Part IV, line 22	9,197	9,197		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	19,125	19,125		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees				
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7 Other salaries and wages				
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits				
10 Payroll taxes				
11 Fees for services (nonemployees):				
a Management				
b Legal				
c Accounting	15,015		15,015	
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees				
g Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Schedule O.)	85,679	27,500	53,221	4,958
12 Advertising and promotion	4,121	4,068		53
13 Office expenses				
14 Information technology				
15 Royalties				
16 Occupancy				
17 Travel				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	115,166	107,104		8,062
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization				
23 Insurance	794		794	
24 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.)				
a Supplies	58,937	51,637	4,023	3,277
b Scholarships and Sponsors	12,000	12,000		
c				
d				
e All other expenses				
25 Total functional expenses. Add lines 1 through 24e	356,700	267,297	73,053	16,350
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ☐ if following SOP 98-2 (ASC 958-720)				

Part X Balance SheetCheck if Schedule O contains a response or note to any line in this Part X ☐

		(A) Beginning of year		(B) End of year
Assets	1 Cash—non-interest-bearing	58,290	1	131,422
	2 Savings and temporary cash investments	240,000	2	473,564
	3 Pledges and grants receivable, net		3	
	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 section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges		9	
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 28,600		
	b Less: accumulated depreciation	10b 28,600	10c	
	11 Investments—publicly traded securities		11	
	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)	298,290	16	604,986	
Liabilities	17 Accounts payable and accrued expenses	14,395	17	30,992
	18 Grants payable		18	
	19 Deferred revenue	11,690	19	12,468
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22 Loans and other payables to 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	26,085	26	43,460
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here ☒ and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	206,837	27	514,557
	28 Net assets with donor restrictions	65,368	28	46,969
	Organizations that do not follow FASB ASC 958, check here ☐ and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		29	
	30 Paid-in or capital surplus, or land, building, or equipment fund		30	
	31 Retained earnings, endowment, accumulated income, or other funds		31	
	32 Total net assets or fund balances	272,205	32	561,526
33 Total liabilities and net assets/fund balances	298,290	33	604,986	

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	646,021
2	Total expenses (must equal Part IX, column (A), line 25)	2	356,700
3	Revenue less expenses. Subtract line 2 from line 1	3	289,321
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	272,205
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	561,526

Part XII Financial Statements and Reporting

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

		Yes	No
1	Accounting method used to prepare the Form 990: ☐ Cash ☒ Accrual ☐ Other If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.		
2a	Were the organization's financial statements compiled or reviewed by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both. ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis		X
b	Were the organization's financial statements audited by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both. ☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis	X	
c	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.	X	
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Uniform Guidance, 2 C.F.R. Part 200, Subpart F?		X
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits		

SCHEDULE A
(Form 990)Department of the Treasury
Internal Revenue Service**Public Charity Status and Public Support**

OMB No. 1545-0047

2024**Open to Public
Inspection**

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

Attach to Form 990 or Form 990-EZ.

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

Name of the organization

Cystinosis Research Network, Inc

Employer identification number

04-3323789**Part I Reason for Public Charity Status.** (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

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

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

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

Cat. No. 11285F

Schedule A (Form 990) 2024

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

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	526,401	542,497	345,873	508,084	632,738	2,555,593
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	526,401	542,497	345,873	508,084	632,738	2,555,593
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)						1,402,732
6 Public support. Subtract line 5 from line 4						1,152,861

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
7 Amounts from line 4	526,401	542,497	345,873	508,084	632,738	2,555,593
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	1,096	713	394	2,967	13,283	18,453
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
11 Total support. Add lines 7 through 10						2,574,046
12 Gross receipts from related activities, etc. (see instructions)					12	

13 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here** ☐

Section C. Computation of Public Support Percentage

14 Public support percentage for 2024 (line 6, column (f), divided by line 11, column (f))	14	44.79 %
15 Public support percentage from 2023 Schedule A, Part II, line 14	15	39.40 %
16a 33 1/3% support test — 2024. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ☒		
b 33 1/3% support test — 2023. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ☐		
17a 10%-facts-and-circumstances test — 2024. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization ☐		
b 10%-facts-and-circumstances test — 2023. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization ☐		
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions ☐		

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

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II.
If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						
14 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here						☐

Section C. Computation of Public Support Percentage

15 Public support percentage for 2024 (line 8, column (f), divided by line 13, column (f))	15	%
16 Public support percentage from 2023 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2024 (line 10c, column (f), divided by line 13, column (f))	17	%
18 Investment income percentage from 2023 Schedule A, Part III, line 17	18	%
19a 33 1/3% support tests — 2024. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here . The organization qualifies as a publicly supported organization		☐
b 33 1/3% support tests — 2023. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and stop here . The organization qualifies as a publicly supported organization		☐
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions		☐

Part IV Supporting Organizations

(Complete only if you checked a box on 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 and D, and complete Part V.)

Section A. All Supporting Organizations

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

Part IV Supporting Organizations (continued)

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

Section B. Type I Supporting Organizations

	Yes	No
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.		
1		
2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.		
2		

Section C. Type II Supporting Organizations

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

Section D. All Type III Supporting Organizations

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

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 each of its supported organizations, and how the organization determined that these activities constituted substantially all of its activities.			
2a			
b Did the activities described on 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.			
2b			
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 .			
3a			
b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.			
3b			

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

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

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

Section B – Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):		
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	Total (add lines 1a, 1b, and 1c)	1d	
e	Discount claimed for blockage or other factors (<i>explain in detail in Part VI</i>):		
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	

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

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

Section D – Distributions		Current Year
1	Amounts paid to supported organizations to accomplish exempt purposes	1
2	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2
3	Administrative expenses paid to accomplish exempt purposes of supported organizations	3
4	Amounts paid to acquire exempt-use assets	4
5	Qualified set-aside amounts (prior IRS approval required—provide details in Part VI)	5
6	Other distributions (describe in Part VI). See instructions.	6
7	Total annual distributions. Add lines 1 through 6.	7
8	Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions.	8
9	Distributable amount for 2024 from Section C, line 6	9
10	Line 8 amount divided by line 9 amount	10

Section E – Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2024	(iii) Distributable Amount for 2024
1 Distributable amount for 2024 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2024 (reasonable cause required—explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2024			
a From 2019			
b From 2020			
c From 2021			
d From 2022			
e From 2023			
f Total of lines 3a through 3e			
g Applied to underdistributions of prior years			
h Applied to 2024 distributable amount			
i Carryover from 2019 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2024 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2024 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2024, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI . See instructions.			
6 Remaining underdistributions for 2024. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI . See instructions.			
7 Excess distributions carryover to 2025. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2020			
b Excess from 2021			
c Excess from 2022			
d Excess from 2023			
e Excess from 2024			

Part VI

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

SCHEDULE D
(Form 990)
(Rev. December 2024)
Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements
Complete if the organization answered "Yes" on Form 990,
Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.
Attach to Form 990.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public
Inspection

Name of the organization

Employer identification number

Cystinosis Research Network, Inc

04-3323789

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts

Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year)		
4 Aggregate value at end of year		
5 Did the organization inform all donors and 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?		☐ Yes ☐ No
6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit?		☐ Yes ☐ No

Part II Conservation Easements

Complete if the organization answered "Yes" on Form 990, Part IV, line 7.

1 Purpose(s) of conservation easements held by the organization (check all that apply).	
☐ Preservation of land for public use (for example, recreation or education)	☐ Preservation of a historically important land area
☐ Protection of natural habitat	☐ Preservation of a certified historic structure
☐ Preservation of open space	
2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.	
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included on line 2a	2c
d Number of conservation easements included on line 2c acquired after July 25, 2006, and not on a historic structure listed in the National Register	2d
3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year	
4 Number of states where property subject to conservation easement is located	
5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?	☐ Yes ☐ No
6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conversation easements during the year	
7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year	\$
8 Does each conservation easement reported on line 2d above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)?	☐ Yes ☐ No
9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.	

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

Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

1a If the organization elected, as permitted under FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide in Part XIII the text of the footnote to its financial statements that describes these items.	
b If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items.	
(i) Revenue included on Form 990, Part VIII, line 1	\$
(ii) Assets included in Form 990, Part X	\$
2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items.	
a Revenue included on Form 990, Part VIII, line 1	\$
b Assets included in Form 990, Part X	\$

Part III

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

- 3
- Using the organization's acquisition, accession, and other records, check any of the following that make significant use of its collection items (check all that apply).
- a☐ Public exhibition

b☐ Scholarly research

c☐ Preservation for future generations

d☐ Loan or exchange program

e☐ Other
- 4
- Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5
- During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?
- ☐ Yes

☐ No

Part IV

Escrow and Custodial Arrangements

Complete if the organization answered "Yes" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

- 1a
- Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?
- ☐ Yes

☐ No
- b
- If "Yes," explain the arrangement in Part XIII and complete the following table.
- | | |
|----|--------|
| | Amount |
| 1c | |
| 1d | |
| 1e | |
| 1f | |
- 2a
- Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability?
- ☐ Yes

☐ No
- b
- If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII
- ☐

Part V

Endowment Funds

Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

- | | | | | | |
|----|--|----------------|--------------------|----------------------|---------------------|
| | (a) Current year | (b) Prior year | (c) Two years back | (d) Three years back | (e) Four years back |
| 1a | Beginning of year balance | | | | |
| b | Contributions | | | | |
| c | Net investment earnings, gains, and losses | | | | |
| d | Grants or scholarships | | | | |
| e | Other expenditures for facilities and programs | | | | |
| f | Administrative expenses | | | | |
| g | End of year balance | | | | |
- 2
- Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a

Board designated or quasi-endowment

%

b

Permanent endowment

%

c

Term endowment

%
- The percentages on lines 2a, 2b, and 2c should equal 100%.
- 3a
- Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- (i)

Unrelated organizations?

(ii)

Related organizations?
- Yes

No

3a(i)

3a(ii)

3b
- b
- If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R?
- ☐
- 4
- Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI

Land, Buildings, and Equipment

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment				
e Other		28,600	28,600	
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, line 10c, column (B))				

Part VII Investments – Other Securities

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

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

Part VIII Investments – Program Related

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

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

Part IX Other Assets

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

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

Part X Other Liabilities

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

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

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 ☐

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

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

1	Total revenue, gains, and other support per audited financial statements	1	646,021
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	2b	
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII.)	2d	
e	Add lines 2a through 2d	2e	
3	Subtract line 2e from line 1	3	646,021
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.)	4b	
c	Add lines 4a and 4b	4c	
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	5	646,021

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

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

1	Total expenses and losses per audited financial statements	1	356,700
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:		
a	Donated services and use of facilities	2a	
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIII.)	2d	
e	Add lines 2a through 2d	2e	
3	Subtract line 2e from line 1	3	356,700
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII.)	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	356,700

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.

Part XIII Supplemental Information (continued)

Schedule D (Form 990) (Rev. 12-2024)

SCHEDULE F
(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

Name of the organization

Statement of Activities Outside the United States

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

Attach to Form 990.

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

OMB No. 1545-0047

Open to Public
Inspection

Cystinosis Research Network, Inc

Employer identification number

04-3323789

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

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

2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

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

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
Europe - Albania, Andorra, Austria, Belg			Grantmaking		
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
3a Subtotal					
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b)					

Part II

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

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
(1)			Europe	Research	19,125	wire transfer			
(2)									
(3)									
(4)									
(5)									
(6)									
(7)									
(8)									
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									

2

Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as a tax exempt 501(c)(3) organization by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter

3

Enter total number of other organizations or entities

Part III

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

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

Part IV Foreign Forms

- 1

Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see the Instructions for Form 926)*

☐ Yes

☒ No
- 2

Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see the Instructions for Forms 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 the Instructions for Form 5471)*

☐ Yes

☒ No
- 4

Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see the Instructions for Form 8621)*

☐ Yes

☒ No
- 5

Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see the Instructions for Form 8865)*

☐ Yes

☒ No
- 6

Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see the Instructions for Form 5713; don't file with Form 990)*

☐ Yes

☒ No

Part V

Supplemental Information

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.

Part I, Line 2 - Procedures for Monitoring the Use of Grant Funds

All grants are reviewed by a scientific review board of physicians familiar with cystinosis. Per grant agreement, researchers are to provide periodic progress reports showing research progress and expenses incurred thus far.

Part I, Line 3 - Activities per Region		
Region	Expenditures	Investments
Europe - Albania, Andorra, Austria, Belg	\$ 0	\$ 0

SCHEDULE I
(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

Grants and Other Assistance to Organizations,
Governments, and Individuals in the United States
Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.
Attach to Form 990.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public
Inspection

Name of the organization

Cystinosis Research Network, Inc

Employer identification number
04-3323789

Part I General Information on Grants and Assistance

- 1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? ☐ Yes ☒ No
- 2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

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

1	(a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1)	The Regents of the University of California PO Box 748872 Los Angeles CA 90074	94-3067788	501c3	36,666				Research Grant
(2)								
(3)								
(4)								
(5)								
(6)								
(7)								
(8)								
(9)								

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

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 Scholarships	3	5,000			
2 Awards	5	4,197			
3					
4					
5					
6					
7					

Part IV

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

Part I, Line 2 - Procedures for Monitoring the Use of Grant Funds

All grants are reviewed by a scientific review board of physicians familiar with cystinosis. Per grant agreement, researchers are to provide periodic progress reports showing research progress and expenses incurred thus far.

