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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
▶ Information about Form 990 and its instructions is at *www IRS gov/form990*

OMB No 1545-0047

2017

Open to Public Inspection

A For the 2017 calendar year, or tax year beginning 01-01-2017 , and ending 12-31-2017

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

C Name of organization
PACHYONYCHIA CONGENITA FUND

Doing business as
PC PROJECT

Number and street (or P O box if mail is not delivered to street address)
PO BOX 17850

Room/suite

City or town, state or province, country, and ZIP or foreign postal code
HOLLADAY, UT 84117

D Employer identification number
68-0567493

E Telephone number
(801) 987-8758

G Gross receipts $ 471,143

F Name and address of principal officer
JANICE N SCHWARTZ
PO BOX 17850
HOLLADAY, UT 84117

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 PACHYONYCHIA ORG

K Form of organization ☑ Corporation ☐ Trust ☐ Association ☐ Other ▶

L Year of formation 2003

M State of legal domicile UT

Part I Summary

1 Briefly describe the organization's mission or most significant activities
THE ORGANIZATION'S MISSION IS TO FIGHT FOR A CURE FOR THE PACHYONYCHIA CONGENITA DISEASE, CONNECT AND HELP PATIENTS, AND EMPOWER RESEARCH

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**	5
4	Number of independent voting members of the governing body (Part VI, line 1b)	**4**	5
5	Total number of individuals employed in calendar year 2017 (Part V, line 2a)	**5**	1
6	Total number of volunteers (estimate if necessary)	**6**	20
7a	Total unrelated business revenue from Part VIII, column (C), line 12	**7a**	0
b	Net unrelated business taxable income from Form 990-T, line 34	**7b**	

		Prior Year	Current Year
8	Contributions and grants (Part VIII, line 1h)	719,507	199,950
9	Program service revenue (Part VIII, line 2g)	7,281	4,058
10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	14,769	54,284
11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	2,302	0
12	Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	743,859	258,292
13	Grants and similar amounts paid (Part IX, column (A), lines 1–3)	66,200	61,936
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)	108,899	54,091
16a	Professional fundraising fees (Part IX, column (A), line 11e)		0
b	Total fundraising expenses (Part IX, column (D), line 25) ▶12,808		
17	Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)	267,676	206,376
18	Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25)	442,775	322,403
19	Revenue less expenses Subtract line 18 from line 12	301,084	-64,111

		Beginning of Current Year	End of Year
20	Total assets (Part X, line 16)	1,420,135	1,423,709
21	Total liabilities (Part X, line 26)	8,731	653
22	Net assets or fund balances Subtract line 21 from line 20	1,411,404	1,423,056

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, inclu
knowledge and belief, it is true, correct, and complete Declaration of prepa
any knowledge

Sign Here

******
Signature of officer

JASON HUNTER CPA TREASURER
Type or print name and title

Paid Preparer Use Only

Print/Type preparer's name
SHALAUN T HOWELL CPA

Preparer's signature
SHALAUN T HOWELL C

Firm's name ▶ SHAW & CO PC

Firm's address ▶ 1564 SOUTH 500 WEST SUITE 201
BOUNTIFUL, UT 840107400

May the IRS discuss this return with the preparer shown above? (see instru

For Paperwork Reduction Act Notice, see the separate instructions.

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission

THE ORGANIZATION'S MISSION IS TO FIGHT FOR A CURE FOR THE PACHYONYCHIA CONGENITA DISEASE, CONNECT AND HELP PATIENTS, AND EMPOWER RESEARCH

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? . . . . . ☐ Yes ☑ No

If "Yes," describe these new services on Schedule O

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? . . . . . ☐ Yes ☑ No

If "Yes," describe these changes on Schedule O

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 $ 68,616 including grants of $) (Revenue $ 4,058)
See Additional Data

4b (Code) (Expenses $ 155,065 including grants of $ 61,936) (Revenue $)
See Additional Data

4c (Code) (Expenses $ 50,164 including grants of $) (Revenue $)
See Additional Data

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

4e **Total program service expenses** ▶ 273,845

Part IV Checklist of Required Schedules

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

Part IV **Checklist of Required Schedules** *(continued)*

			Yes	No
20a	Did the organization operate one or more hospital facilities? *If "Yes," complete Schedule H*	**20a**		No
b	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	**20b**		
21	Did the organization report more than $5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? *If "Yes," complete Schedule I, Parts I and II*	**21**		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? *If "Yes," complete Schedule I, Parts I and III*	**22**		No
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? *If "Yes," complete Schedule J*	**23**		No
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? *If "Yes," answer lines 24b through 24d and complete Schedule K If "No," go to line 25a*	**24a**		No
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? *If "Yes," complete Schedule L, Part I*	**25a**		No
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? *If "Yes," complete Schedule L, Part I*	**25b**		No
26	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? *If "Yes," complete Schedule L, Part II*	**26**		No
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? *If "Yes," complete Schedule L, Part III*	**27**		No
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)			
a	A current or former officer, director, trustee, or key employee? *If "Yes," complete Schedule L, Part IV*	**28a**		No
b	A family member of a current or former officer, director, trustee, or key employee? *If "Yes," complete Schedule L, Part IV*	**28b**		No
c	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? *If "Yes," complete Schedule L, Part IV*	**28c**	Yes	
29	Did the organization receive more than $25,000 in non-cash contributions? *If "Yes," complete Schedule M*	**29**		No
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? *If "Yes," complete Schedule M*	**30**		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? *If "Yes," complete Schedule N, Part I*	**31**		No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? *If "Yes," complete Schedule N, Part II*	**32**		No
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301 7701-2 and 301 7701-3? *If "Yes," complete Schedule R, Part I*	**33**		No
34	Was the organization related to any tax-exempt or taxable entity? *If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1*	**34**		No
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	**35a**		No
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)? *If "Yes," complete Schedule R, Part V, line 2*	**35b**		
36	**Section 501(c)(3) organizations.** Did the organization make any transfers to an exempt non-charitable related organization? *If "Yes," complete Schedule R, Part V, line 2*	**36**		No
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? *If "Yes," complete Schedule R, Part VI*	**37**		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? **Note.** All Form 990 filers are required to complete Schedule O	**38**	Yes	

Part V **Statements Regarding Other IRS Filings and Tax Compliance**

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

				Yes	No
1a	Enter the number reported in Box 3 of Form 1096 Enter -0- if not applicable . .	**1a**	2		
b	Enter the number of Forms W-2G included in 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**		
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**	1		
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? **Note.** If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)		**2b**		No
3a	Did the organization have unrelated business gross income of $1,000 or more during the year? . . .		**3a**		No
b	If "Yes," has it filed a Form 990-T for this year? *If "No" to line 3b, provide an explanation in 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**		No
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**		No
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		**5b**		No
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**		No
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**		No
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**		No
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**		No
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? . .		**7f**		No
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**		
9a	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**		No
b	If "Yes," has it filed a Form 720 to report these payments? *If "No," provide an explanation in Schedule O* . .		**14b**		

Part VI **Governance, Management, and Disclosure** *For each "Yes" response to lines 2 through 7b below, and for a "No" response to lines 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O See instructions*

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

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** 5			
	If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O			
b	Enter the number of voting members included in line 1a, above, who are independent **1b** 5			
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**	Yes	
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person? .	**3**		No
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	**4**		No
5	Did the organization become aware during the year of a significant diversion of the organization's assets? .	**5**		No
6	Did the organization have members or stockholders?	**6**		No
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**		No
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**		No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following			
a	The governing body?	**8a**	Yes	
b	Each committee with authority to act on behalf of the governing body?	**8b**	Yes	
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 in Schedule O*	**9**		No

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**		No
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**	Yes	
b	Describe in 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**	Yes	
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	**12b**	Yes	
c	Did the organization regularly and consistently monitor and enforce compliance with the policy? *If "Yes," describe in Schedule O how this was done*	**12c**	Yes	
13	Did the organization have a written whistleblower policy?	**13**	Yes	
14	Did the organization have a written document retention and destruction policy?	**14**	Yes	
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**		No
b	Other officers or key employees of the organization	**15b**		No
	If "Yes" to line 15a or 15b, describe the process in 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**		No
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▶ AR , CA , CO , CT , DC , FL , GA , IL , KS , LA , MD , MA , MI , MN , MO , NJ , NM , NY , NC , OH , OR , PA , RI , SC , TN , UT , VA , WA , WV , WI

18 Section 6104 requires an organization to make its Form 1023 (or 1024 if applicable), 990, and 990-T (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 in Schedule O)

19 Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements 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 ▶JOANNE UDY 2180 E 4500 S STE 166 HOLLADAY, UT 84117 (801) 987-8758

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

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

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

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 and/or Box 7 of Form 1099-MISC) of more than $100,000 from the organization and any related organizations
- List all of the organization's **former** officers, key employees, or highest compensated employees who received more than $100,000 of reportable compensation from the organization and any related organizations
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than $10,000 of reportable compensation from the organization and any related organizations

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

☑ 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)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(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) BARBARA FEINSTEIN SECRETARY	1 00	X		X				0	0	0
(2) C DAVID HANSEN MD BOARD MEMBER	6 00	X						0	0	0
(3) JASON HUNTER CPA TREASURER	2 00	X		X				0	0	0
(4) JACK PADOVANO BOARD MEMBER	4 00	X						0	0	0
(5) JANICE N SCHWARTZ BOARD CHAIR	20 00	X		X				0	0	0
(6) PRESTON COCHRANE BOARD CHAIR	2 00	X		X				0	0	0
(7) CINDY ATHA EXECUTIVE DI	40 00			X				0	0	0
(8) IRWIN MCLEAN CEO AND CSO	20 00			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)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(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			

1b Sub-Total ▶			
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 ▶

			Yes	No
3	Did the organization list any **former** officer, director or trustee, key employee, or highest compensated employee on line 1a? *If "Yes," complete Schedule J for such individual*	**3**		No
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? *If "Yes," complete Schedule J for such individual*	**4**		No
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? *If "Yes," complete Schedule J for such person*	**5**		No

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 ▶

Part VIII Statement of Revenue

Check 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 199,950			
	g Noncash contributions included in lines 1a-1f $ _____				
	h Total. Add lines 1a-1f . . . . . ▶	199,950			

Program Service Revenue	Business Code				
2a PATIENT SUPPORT FEES		3,750	3,750		
b OTHER		308	308		
c					
d					
e					
f All other program service revenue					
g Total. Add lines 2a–2f . . . . ▶		4,058			

Other Revenue					
3 Investment income (including dividends, interest, and other similar amounts) . . . . . ▶		34,420			34,420
4 Income from investment of tax-exempt bond proceeds ▶					
5 Royalties . . . . . ▶					
	(i) Real	(ii) Personal			
6a Gross rents					
b Less rental expenses					
c Rental income or (loss)					
d Net rental income or (loss) . . . . . ▶					
	(i) Securities	(ii) Other			
7a Gross amount from sales of assets other than inventory	232,715				
b Less cost or other basis and sales expenses	212,851				
c Gain or (loss)	19,864				
d Net gain or (loss) . . . . . ▶		19,864	19,241		623
8a Gross income from fundraising events (not including $ _____ of contributions reported on line 1c) See Part IV, line 18 . . . . a					
b Less direct expenses . . . b					
c Net income or (loss) from fundraising events . . ▶					
9a Gross income from gaming activities See Part IV, line 19 . . . a					
b Less direct expenses . . . b					
c Net income or (loss) from gaming activities . . ▶					
10a Gross sales of inventory, less returns and allowances . . a					
b Less cost of goods sold . . b					
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 . . . . . ▶		258,292	23,299		35,043

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) Fundraisingexpenses
1 Grants and other assistance to domestic organizations and domestic governments See Part IV, line 21				
2 Grants and other assistance to domestic individuals See Part IV, line 22				
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals See Part IV, line 15 and 16	61,936	61,936		
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	46,833	42,149	3,747	937
8 Pension plan accruals and contributions (include section 401 (k) and 403(b) employer contributions)				
9 Other employee benefits	3,675	3,307	294	74
10 Payroll taxes	3,583	3,224	287	72
11 Fees for services (non-employees)				
a Management				
b Legal				
c Accounting	8,076		8,076	
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)	63,665	56,891	6,475	299
12 Advertising and promotion				
13 Office expenses	10,078	7,373	953	1,752
14 Information technology	21,851	16,682	4,659	510
15 Royalties				
16 Occupancy	12,297	11,067	984	246
17 Travel	42,802	42,747	40	15
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	500	500		
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	615	554	49	12
23 Insurance	550		550	
24 Other expenses Itemize expenses not covered above (List miscellaneous expenses in line 24e If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O)				
a CATERING	27,145	27,145		
b LICENSE AND DUES	8,713		35	8,678
c INVESTMENT FEES	8,712		8,712	
d BANK AND MERCHANT FEES	755	214	328	213
e All other expenses	617	56	561	
25 **Total functional expenses.** Add lines 1 through 24e	322,403	273,845	35,750	12,808
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 Sheet

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

			(A) Beginning of year		(B) End of year
Assets	1	Cash–non-interest-bearing	268,181	1	340,906
	2	Savings and temporary cash investments		2	
	3	Pledges and grants receivable, net		3	
	4	Accounts receivable, net		4	
	5	Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L		5	
	6	Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions) Complete Part II of Schedule L		6	
	7	Notes and loans receivable, net		7	
	8	Inventories for sale or use		8	
	9	Prepaid expenses and deferred charges		9	10,195
	10a	Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D — 10a: 14,821			
	b	Less accumulated depreciation — 10b: 13,964	1,472	10c	857
	11	Investments—publicly traded securities	1,150,482	11	1,071,751
	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 34)	1,420,135	16	1,423,709
Liabilities	17	Accounts payable and accrued expenses	8,731	17	653
	18	Grants payable		18	
	19	Deferred revenue		19	
	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 current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons Complete Part II of Schedule L		22	
	23	Secured mortgages and notes payable to unrelated third parties		23	
	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	8,731	26	653
Net Assets or Fund Balances		**Organizations that follow SFAS 117 (ASC 958), check here ▶ ☑ and complete lines 27 through 29, and lines 33 and 34.**			
	27	Unrestricted net assets	1,411,404	27	1,423,056
	28	Temporarily restricted net assets		28	
	29	Permanently restricted net assets		29	
		Organizations that do not follow SFAS 117 (ASC 958), check here ▶ ☐ and complete lines 30 through 34.			
	30	Capital stock or trust principal, or current funds		30	
	31	Paid-in or capital surplus, or land, building or equipment fund		31	
	32	Retained earnings, endowment, accumulated income, or other funds		32	
	33	Total net assets or fund balances	1,411,404	33	1,423,056
	34	Total liabilities and net assets/fund balances	1,420,135	34	1,423,709

Part XI Reconcilliation 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	258,292
2	Total expenses (must equal Part IX, column (A), line 25)	2	322,403
3	Revenue less expenses Subtract line 2 from line 1	3	-64,111
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	1,411,404
5	Net unrealized gains (losses) on investments	5	75,763
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	1,423,056

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 in Schedule O			
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?	2a		No
	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			
b	Were the organization's financial statements audited by an independent accountant?	2b	Yes	
	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			
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?	2c	Yes	
	If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O			
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?	3a		No
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits	3b		

Additional Data

Software ID:

Software Version:

EIN: 68-0567493

Name: PACHYONYCHIA CONGENITA FUND

Form 990 (2017)

Form 990, Part III, Line 4a:

PROVIDED FUNDING FOR RESEARCH IN FINDING A CURE FOR PACHYONYCHIA CONGENITA MAINTAINED A WEB SITE TO PROVIDE INFORMATION ABOUT AND ASSIST RESEARCH EFFORTS PROVIDED SUPPORT MEETINGS TO INDIVIDUALS AFFECTED BY PACHYONYCHIA CONGENITA PROVIDED INDIVIDUAL SUPPORT AS NEEDED FOR PATIENTS VIA EMAILS, TELEPHONE CALLS, OR THROUGH THE HELP OF PC PATIENT ADVOCATES OR MEMBERS OF THE PC SCIENTIFIC AND MEDICAL ADVISORY BOARD MORE SUPPORT IS OUTLINED NEXT IN THE RESOURCES AND BENEFITS THROUGH MEMBERSHIP IN THE IPCRR

Form 990, Part III, Line 4b:

MAINTAINED THE INTERNATIONAL PACHYONYCHIA CONGENITY RESEARCH REGISTRY (IPCRR) SINCE 2004, AND WITH IRB APPROVAL, THE IPCRR HAS PROVIDED OVER 1,900 PATIENTS FREE GENETIC TESTING, PHYSICIAN CONSULTATIONS, PATIENT MEETINGS, CHAT GROUPS, SPECIAL WEB MEETINGS, AND MONTHLY PATIENT NEWSLETTERS THROUGH THE IPCRR, PATIENTS ALSO HAVE OPPORTUNITIES TO PARTICIPATE IN CLINICAL TRIALS AND STUDIES

Form 990, Part III, Line 4c:

HOSTED THE INTERNATIONAL PACHYONYCHIA CONGENITA CONSORTIUM (IPCC) IN PORTLAND, OREGON SINCE 2004, THE IPCC HAS HELD ANNUAL SCIENTIFIC MEETINGS, AWARDED RESEARCH GRANTS, COORDINATED RESEARCH WITH BOTH ACADEMIC AND PRIVATE INSTITUTIONS,CONDUCTED MONTHLY WEB MEETINGS WITH THE IPCC GENETICS TEAM, ESTABLISHED AND MET ANNUAL RESEARCH GOALS, AND DISTRIBUTED QUARTERLY NEWSLETTERS TO OVER 200 PHYSICIANS AND SCIENTISTS WORKING WITH LEADERS IN THE IPCC,CLINICAL TRIALS HAVE BEEN COMPLETED AND NUMEROUS CLINICAL AND RESEARCH STUDIES HAVE BEEN CONDUCTED IT IS ESTIMATED THAT NEARLY 100 ARTICLES HAVE BEEN PUBLISHED IN LEADING SCIENTIFIC JOURNALS BY THE ORGANIZATION OR ITS IPCC MEMBERS, A NUMBER OF WHICH CITED IPCRR DATA AND RESEARCH AND CLINICAL STUDIES DONE THROUGH IPCC

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SCHEDULE A (Form 990 or 990EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

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

▶ **Attach to Form 990 or Form 990-EZ.**

▶ **Information about Schedule A (Form 990 or 990-EZ) and its instructions is at *www.irs.gov/form990*.**

OMB No 1545-0047

2017

Open to Public Inspection

Name of the organization
PACHYONYCHIA CONGENITA FUND

Employer identification number
68-0567493

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 or 990-EZ))

3 ☐ A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**

4 ☐ A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state _____

5 ☐ An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170 (b)(1)(A)(iv).** (Complete Part II)

6 ☐ A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**

7 ☑ 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 **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 in 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? Yes	(iv) No	(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
Total						

Part II **Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv), 170(b)(1)(A)(vi), and 170 (b)(1)(A)(ix)**

(Complete only if you checked the box on line 5, 7, 8, or 9 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) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grant ")	466,491	815,694	340,139	719,507	199,950	2,541,781
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	466,491	815,694	340,139	719,507	199,950	2,541,781
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)						1,951,235
6 **Public support.** Subtract line 5 from line 4						590,546

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a)2013	(b)2014	(c)2015	(d)2016	(e)2017	(f)Total
7 Amounts from line 4	466,491	815,694	340,139	719,507	199,950	2,541,781
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	127	28,970	33,464	25,645	34,420	122,626
9 Net income from unrelated business activities, whether or not the business is regularly carried on				2,302		2,302
10 Other income Do not include gain or loss from the sale of capital assets (Explain in Part VI)		2,427				2,427
11 **Total support.** Add lines 7 through 10						2,669,136

12	Gross receipts from related activities, etc (see instructions)	12	11,339

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

Section C. Computation of Public Support Percentage

14	Public support percentage for 2017 (line 6, column (f) divided by line 11, column (f))	14	22 120 %
15	Public support percentage for 2016 Schedule A, Part II, line 14	15	23 510 %

16a **33 1/3% support test—2017.** If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization ▶ ☐

b **33 1/3% support test—2016.** If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization ▶ ☐

17a **10%-facts-and-circumstances test—2017.** If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test The organization qualifies as a publicly supported organization ▶ ☑

b **10%-facts-and-circumstances test—2016.** If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 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) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants ")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
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) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(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 in line 10b, whether or not the business is regularly carried on						
12 Other income Do not include gain or loss from the sale of capital assets (Explain in Part VI)						
13 **Total support.** (Add lines 9, 10c, 11, and 12)						

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

Section C. Computation of Public Support Percentage

15 Public support percentage for 2017 (line 8, column (f) divided by line 13, column (f))	15	
16 Public support percentage from 2016 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17 Investment income percentage for **2017** (line 10c, column (f) divided by line 13, column (f))	17	
18 Investment income percentage from **2016** Schedule A, Part III, line 17	18	

19a **33 1/3% support tests—2017.** 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—2016.** 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 of Part I If you checked 12a of Part I, complete Sections A and B If you checked 12b of Part I, complete Sections A and C If you checked 12c of Part I, complete Sections A, D, and E If you checked 12d of Part I, complete Sections A and D, and complete Part V)

Section A. All Supporting Organizations

			Yes	No
1	Are all of the organization's supported organizations listed by name in the organization's governing documents? *If "No," describe in* ***Part VI*** *how the supported organizations are designated If designated by class or purpose, describe the designation If historic and continuing relationship, explain*	1		
2	Did the organization have any supported organization that does not have an IRS determination of status under section 509 (a)(1) or (2)? *If "Yes," explain in* ***Part VI*** *how the organization determined that the supported organization was described in section 509(a)(1) or (2)*	2		
3a	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? *If "Yes," answer (b) and (c) below*	3a		
b	Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? *If "Yes," describe in* ***Part VI*** *when and how the organization made the determination*	3b		
c	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? *If "Yes," explain in* ***Part VI*** *what controls the organization put in place to ensure such use*	3c		
4a	Was any supported organization not organized in the United States ("foreign supported organization")? *If "Yes" and if you checked 12a or 12b in Part I, answer (b) and (c) below*	4a		
b	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? *If "Yes," describe in* ***Part VI*** *how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations*	4b		
c	Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? *If "Yes," explain in* ***Part VI*** *what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes*	4c		
5a	Did the organization add, substitute, or remove any supported organizations during the tax year? *If "Yes," answer (b) and (c) below (if applicable) Also, provide detail in* ***Part VI,*** *including (i) the names and EIN numbers of the supported organizations added, substituted, or removed, (ii) the reasons for each such action, (iii) the authority under the organization's organizing document authorizing such action, and (iv) how the action was accomplished (such as by amendment to the organizing document)*	5a		
b	**Type I or Type II only.** Was any added or substituted supported organization part of a class already designated in the organization's organizing document?	5b		
c	**Substitutions only.** Was the substitution the result of an event beyond the organization's control?	5c		
6	Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? *If "Yes," provide detail in* ***Part VI.***	6		
7	Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? *If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ)*	7		
8	Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? *If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ)*	8		
9a	Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? *If "Yes," provide detail in* ***Part VI.***	9a		
b	Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? *If "Yes," provide detail in* ***Part VI.***	9b		
c	Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? *If "Yes," provide detail in* ***Part VI.***	9c		
10a	Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? *If "Yes," answer line 10b below*	10a		
b	Did the organization have any excess business holdings in the tax year? *(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings)*	10b		

Part IV Supporting Organizations (continued)

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

Section B. Type I Supporting Organizations

			Yes	No
1	Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? *If "No," describe in* ***Part VI*** *how the supported organization(s) effectively operated, supervised, or controlled the organization's activities If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year*	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 in (2), did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? *If "Yes," describe in* ***Part VI*** *the role the organization's supported organizations played 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 government entity (see instructions)

			Yes	No
2	Activities Test **Answer (a) and (b) below.**			
a	Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? *If "Yes," then in* ***Part VI identify those supported organizations and explain*** *how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities*	2a		
b	Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? *If "Yes," explain in* ***Part VI*** *the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement*	2b		
3	Parent of Supported Organizations **Answer (a) and (b) below.**			
a	Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? *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)	1		
a	Average monthly value of securities	1a		
b	Average monthly cash balances	1b		
c	Fair market value of other non-exempt-use assets	1c		
d	**Total** (add lines 1a, 1b, and 1c)	1d		
e	**Discount** claimed for blockage or other factors (explain in detail in Part VI)			
2	Acquisition indebtedness applicable to non-exempt use assets	2		
3	Subtract line 2 from line 1d	3		
4	Cash deemed held for exempt use Enter 1-1/2% of line 3 (for greater amount, see instructions)	4		
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5		
6	Multiply line 5 by 035	6		
7	Recoveries of prior-year distributions	7		
8	**Minimum Asset Amount** (add line 7 to line 6)	8		

	Section C - Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	1		
2	Enter 85% of line 1	2		
3	Minimum asset amount for prior year (from Section B, line 8, Column A)	3		
4	Enter greater of line 2 or line 3	4		
5	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	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	
4 Amounts paid to acquire exempt-use assets	
5 Qualified set-aside amounts (prior IRS approval required)	
6 Other distributions (describe in **Part VI**) See instructions	
7 **Total annual distributions.** Add lines 1 through 6	
8 Distributions to attentive supported organizations to which the organization is responsive (provide details in **Part VI**) See instructions	
9 Distributable amount for 2017 from Section C, line 6	
10 Line 8 amount divided by Line 9 amount	

Section E - Distribution Allocations (see instructions)	**(i) Excess Distributions**	**(ii) Underdistributions Pre-2017**	**(iii) Distributable Amount for 2017**
1 Distributable amount for 2017 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2017 (reasonable cause required-- explain in Part VI) See instructions			
3 Excess distributions carryover, if any, to 2017			
a			
b From 2013.			
c From 2014.			
d From 2015.			
e From 2016.			
f **Total** of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2017 distributable amount			
i Carryover from 2012 not applied (see instructions)			
j Remainder Subtract lines 3g, 3h, and 3i from 3f			
4 Distributions for 2017 from Section D, line 7 $			
a Applied to underdistributions of prior years			
b Applied to 2017 distributable amount			
c Remainder Subtract lines 4a and 4b from 4			
5 Remaining underdistributions for years prior to 2017, if any Subtract lines 3g and 4a from line 2 If the amount is greater than zero, explain in Part VI See instructions			
6 Remaining underdistributions for 2017 Subtract lines 3h and 4b from line 1 If the amount is greater than zero, explain in Part VI See instructions			
7 **Excess distributions carryover to 2018.** Add lines 3j and 4c			
8 Breakdown of line 7			
a Excess from 2013.			
b Excess from 2014.			
c Excess from 2015.			
d Excess from 2016.			
e Excess from 2017.			

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)

Facts And Circumstances Test

THE FOLLOWING FACTS AND CIRCUMSTANCES ALSO WERE REPORTED TO COME TO A FINAL DETERMINATION THAT THE ORGANIZATION IS A PUBLIC CHARITY 1 170A-9(E)(3)(II) ATTRACTION OF PUBLIC SUPPORT PACHYONYCHIA CONGENITA (PC) IS AN ULTRA-RARE SKIN DISORDER WHICH CAUSES PAINFUL BLISTERS AND CALLUSES ON FEET AS WELL AS THICKENED NAILS, CYSTS, AND OTHER PAINFUL SYMPTOMS THE ORGANIZATION'S PRIMARY GOALS HAVE BEEN (1) TO INTEREST LEADING SCIENTISTS AND PHYSICIANS WHO SPECIALIZE IN KERATIN DISORDERS IN RESEARCH FOR THE ULTRA-RARE DISORDER, PC, AND TO ESTABLISH COLLABORATION AMONG RESEARCHERS, (2) TO ESTABLISH AND MAINTAIN AN INTERNATIONAL PC PATIENT REGISTRY (IPCRR) AS A RESOURCE FOR SCIENTIFIC RESEARCH, AND (3) TO PROVIDE EDUCATION AND SUPPORT FOR PHYSICIANS, SCIENTISTS, AND PC PATIENTS AND THEIR FAMILIES WORLDWIDE BY THEIR VERY NATURE, THESE TYPES OF ACTIVITIES HAVE THE POTENTIAL TO ATTRACT SUPPORT FROM GOVERNMENTAL UNITS AND PUBLIC CHARITIES ON A CONTINUOUS BASIS AT NO TIME HAS THE ORGANIZATION CONDUCTED ACTIVITIES WHICH SERVE THE PERSONAL OR PRIVATE INTERESTS OF ITS FOUNDERS OR RELATED PARTIES THE ORGANIZATION MAINTAINS A CONTINUOUS AND BONA FIDE PROGRAM FOR SOLICITATION OF FUNDS BROCHURES REQUESTING DONATIONS ARE WIDELY DISTRIBUTED AT SCIENTIFIC, PATIENT SUPPORT, AND PUBLIC EVENTS THESE BROCHURES ARE ALSO DISTRIBUTED THROUGH DIRECT MAILINGS TO PERSONAL AND PROFESSIONAL CONTACTS GRANT APPLICATIONS HAVE BEEN MADE TO FOUNDATIONS AND OTHERS 1 170A-9(E)(III) PERCENTAGE OF FINANCIAL SUPPORT THE ORGANIZATION RECEIVED 22 12% OF ITS SUPPORT FROM PUBLIC SOURCES FROM 2013 TO 2017 1 170A-9(E)(3)(IV) SOURCES OF SUPPORT THE ORGANIZATION HAS RECEIVED ITS SUPPORT FROM INDIVIDUALS, BUSINESSES, AND FOUNDATIONS NOT RELATED TO THE ORGANIZATION THROUGH EITHER BUSINESS OR FAMILY RELATIONS IN ADDITION TO DIRECT DONATIONS, MANY INDIVIDUALS HAVE DONATED TIME AND SERVICES TO ASSIST THE ORGANIZATION IN ITS EXEMPT PURPOSE 1 170A-9(E)(3)(V) REPRESENTATIVE GOVERNING BODY THE ORGANIZATION HAS THREE BOARDS THAT GOVERN ITS ACTIVITIES 1 THE BOARD OF TRUSTEES DOES NOT REPRESENT THE PERSONAL OR PRIVATE INTERESTS OF A LIMITED NUMBER OF DONORS OR RELATED PERSONS ALL BOARD MEMBERS SERVE WITHOUT COMPENSATION MEMBERS OF THE BOARD HAVE SPECIAL KNOWLEDGE OR EXPERTISE TO ASSIST IN FULFILLING ITS EXEMPT PURPOSE 2 THE MEDICAL AND SCIENTIFIC ADVISORY BOARD IS A VOLUNTEER BOARD CONSISTING OF 21 PHYSICIANS AND SCIENTISTS WHO HAVE A SPECIALTY IN DERMATOLOGICAL RESEARCH AND GENETICS, WITH AN EMPHASIS IN KERATIN DISORDERS SOME MEMBERS OF THIS BOARD ARE IN CONTACT DAILY WITH THE ORGANIZATION REGARDING RESEARCH AND PATIENT CARE MANY ARE IN CONTACT SEVERAL TIMES EACH MONTH CONFERENCE CALLS ARE REGULARLY SCHEDULED WITH THE ENTIRE GROUP AND WITH SPECIAL SUB-GROUPS FOR PLANNING THIS BOARD IS AVAILABLE FOR CONSULTATION REGARDING PATIENT CARE AND PATIENT NEEDS 3 VOLUNTARY PATIENT ADVOCATES WORK THROUGH VARIOUS SOCIAL MEDIA, SUCH AS FACEBOOK, TO PROVIDE PATIENT OUTREACH AND PATIENT-TO-PATIENT SUPPORT 1 170A-9(E)(3)(VI) AVAILABILITY OF PUBLIC FACILITIES OR SERVICES, PUBLIC PARTICIPATION IN PROGRAMS OR POLICIES (A) THE FACT THAT AN ORGANIZATION IS THE TYPE WHICH GENERALLY PROVIDES FACILITIES OR SERVICES DIRECTLY FOR THE BENEFIT OF THE GENERAL PUBLIC WILL BE CONSIDERED EVIDENCE THAT SUCH ORGANIZATION IS "PUBLICLY SUPPORTED " IN FEBRUARY 2004, THE ORGANIZATION ORGANIZED THE FIRST INTERNATIONAL PC CONFERENCE IN WHICH 23 OF THE LEADING KERATIN SPECIALISTS ATTENDED, INCLUDING MARIO CAPECCHI (WINNER OF THE 2007 NOBEL PRIZE FOR MEDICINE) AT THE MEETING, THE GROUP FORMED THE INTERNATIONAL PC CONSORTIUM (IPCC) TO ENCOURAGE COLLABORATION FOR PC RESEARCH THERE ARE NOW SEVERAL HUNDRED EXPERTS WHO ARE ACTIVE MEMBERS OF THE IPCC AND EACH HAS AGREED TO COLLABORATE AND SHARE REAGENTS AND EXPERTISE TO ASSIST OTHER IPCC MEMBERS IN REGARD TO PC RESEARCH AND PATIENT CARE THE MAJORITY OF THESE PARTICIPANTS REPRESENT NON-GOVERNMENTAL ORGANIZATIONS THAT SERVE MEMBERS OF A CHARITABLE CLASS IN THEIR HOME COUNTRIES A LIST OF PARTICIPANTS CAN BE PROVIDED IF NEEDED BEGINNING WITH THE 2004 SYMPOSIUM, THE ORGANIZATION HAS SPONSORED AN ANNUAL SCIENTIFIC MEETING EACH YEAR THE ORGANIZATION ALSO PROVIDES EXPERTISE DIRECTLY FOR THE BENEFIT OF THE GENERAL PUBLIC BY RESPONDING TO DOZENS OF TELEPHONE, MAIL, AND INTERNET INQUIRIES EACH WEEK AT NO CHARGE FROM PUBLIC HEALTH OFFICIALS, PRACTITIONERS, AND MEMBERS OF THE GENERAL PUBLIC IN MANY CASES, MEMBERS OF THE MEDICAL AND SCIENTIFIC ADVISORY BOARD WILL PROVIDE RESPONSES WHEN SPECIFIC SCIENTIFIC OR MEDICAL OPINIONS ARE NEEDED THE IPCC HAS ORGANIZED A STEERING COMMITTEE TO DIRECT EFFORTS OF THE IPCC AND THREE WORKING TEAMS, INCLUDING (1) A RESEARCH TEAM CONDUCTING BASIC AND TRANSLATIONAL RESEARCH, (2) A DIAGNOSTICS AND GENETICS TEAM, AND (3) A PHYSICIANS NETWORK EACH OF THESE TEAMS ACTIVELY PROVIDE PUBLIC SERVICE TO THOSE WITH PC AND MANY OTHER RELATED SKIN DISORDERS (B) THE FACT THAT AN ORGANIZATION IS AN EDUCATION OR RESEARCH INSTITUTION WHICH REGULARLY PUBLISHES SCHOLARLY STUDIES WILL ALSO BE CONSIDERED EVIDENCE THAT SUCH ORGANIZATION IS "PUBLICLY SUPPORTED " FROM 2004 TO 2016, THE ORGANIZATION'S BOARD MEMBERS AND VOLUNTEERS HAVE CONTRIBUTED TO OVER 80 SCHOLARLY STUDIES RELATED TO PC AND PC RESEARCH PUBLICATIONS CAN BE PROVIDED FOR REVIEW IF NEEDED MANY ARE AVAILABLE ONLINE AT HTTP //WWW PACHYONYCHIA ORG/RESEARCH-ARTICLES/ ALSO, IPCC NEWSLETTERS HAVE BEEN PUBLISHED EVERY QUARTER SINCE 2004 IN ADDITION, NUMEROUS PRESENTATIONS ON PC HAVE BEEN MADE BY BOARD MEMBERS AND VOLUNTEERS IN SCIENTIFIC MEETINGS AROUND THE WORLD (C) SIMILARLY, THE FOLLOWING FACTORS WILL ALSO BE CONSIDERED EVIDENCE THAT AN ORGANIZATION IS "PUBLICLY SUPPORTED" (1) THE PARTICIPATION IN, OR SPONSORSHIP OF, PROGRAMS OF THE ORGANIZATION BY MEMBERS OF THE PUBLIC HAVING SPECIAL KNOWLEDGE OR EXPERTISE, PUBLIC OFFICIALS, OR CIVIC OR COMMUNITY LEADERS SEE (A) ABOVE FOR A DESCRIPTION OF THE ORGANIZATION'S INTERNATIONAL SCIENTIFIC CONFERENCE FOR EXAMPLES OF PARTICIPATION IN, AND SPONSORSHIP OF, PROGRAMS OF THE ORGANIZATION BY MEMBERS OF THE PUBLIC HAVING SPECIAL KNOWLEDGE OR EXPERTISE, PUBLIC OFFICIALS, OR CIVIC OR COMMUNITY LEADERS IN ADDITION, THE ORGANIZATION HAS SEVERAL OTHER ACTIVITIES WHICH DEMONSTRATE THIS BROAD PUBLIC SUPPORT 1 PATIENT MEETINGS HAVE BEEN HELD IN THE FOLLOWING LOCATIONS SALT LAKE CITY, UT (2004 & 2009, 2017) - HOSTED BY UNIVERSITY OF UTAH KANSAS CITY, MO (2004) - HOSTED BY F I R S T DUNDEE, SCOTLAND (2004 AND 2006) - HOSTED BY UNIVERSITY OF DUNDEE NIAGRA FALLS, ONTARIO (2005) PARK CITY, UT (2007) PITLOCHRY, SCOTLAND (2008) EDINBURGH, SCOTLAND (2010, 2012, 2014, 2016) PARIS, FRANCE (2010, 2012, 2014) PHILADELPHIA, PA (2011) SANTA CRUZ, CA (2013) NEWARK, NJ (2015) MORE THAN A DOZEN PHYSICIANS AND SCIENTISTS VOLUNTEER THEIR TIME AND PAY THEIR OWN EXPENSES TO ATTEND THE PATIENT SUPPORT MEETINGS PATIENTS AND MANY OF THEIR FAMILY MEMBER ATTEND SUPPORT MEETINGS THE MEETING LOCATION ALTERNATES EACH YEAR BETWEEN EUROPE AND THE UNITED STATES TO GIVE PATIENTS BROAD ACCESS TO INFORMATION AND SUPPORT 2 THE INTERNATIONAL PC RESEARCH REGISTRY HAS RECEIVED INSTITUTIONAL REVIEW BOARD APPROVAL THROUGH THE WESTERN INSTITUTIONAL REVIEW BOARD (STUDY 2004/0468/1057496) IRB APPROVAL HAS BEEN RENEWED EACH YEAR THIS IS THE ONLY ACTIVE REGISTRY FOR PC PATIENTS IN THE WORLD THERE ARE NEARLY 2,000 PATIENTS REGISTERED PC PATIENTS ARE REGISTERED FROM OVER 60 COUNTRIES 1 170A-9(E)(3)(VII) ADDITIONAL FACTORS PERTINENT TO MEMBERSHIP THE ORGANIZATION IS NOT A MEMBERSHIP ORGANIZATION

990 Schedule A, Supplemental Information

Return Reference	Explanation
PART II, LINE 10	OTHER INCOME 2,427

990 Schedule A, Supplemental Information

Return Reference	Explanation
PART II, LINE 17A	THE FOLLOWING FACTS AND CIRCUMSTANCES ALSO WERE REPORTED TO COME TO A FINAL DETERMINATION THAT THE ORGANIZATION IS A PUBLIC CHARITY 1 170A-9(E)(3)(II) ATTRACTION OF PUBLIC SUPPORT PACHYONYCHIA CONGENITA (PC) IS AN ULTRA-RARE SKIN DISORDER WHICH CAUSES PAINFUL BLISTERS AND CALLUSES ON FEET AS WELL AS THICKENED NAILS, CYSTS, AND OTHER PAINFUL SYMPTOMS THE O RGANIZATION'S PRIMARY GOALS HAVE BEEN (1) TO INTEREST LEADING SCIENTISTS AND PHYSICIANS WH O SPECIALIZE IN KERATIN DISORDERS IN RESEARCH FOR THE ULTRA-RARE DISORDER, PC, AND TO ESTA BLISH COLLABORATION AMONG RESEARCHERS, (2) TO ESTABLISH AND MAINTAIN AN INTERNATIONAL PC P ATIENT REGISTRY (IPCRR) AS A RESOURCE FOR SCIENTIFIC RESEARCH, AND (3) TO PROVIDE EDUCATIO N AND SUPPORT FOR PHYSICIANS, SCIENTISTS, AND PC PATIENTS AND THEIR FAMILIES WORLDWIDE BY THEIR VERY NATURE, THESE TYPES OF ACTIVITIES HAVE THE POTENTIAL TO ATTRACT SUPPORT FROM G OVERNMENTAL UNITS AND PUBLIC CHARITIES ON A CONTINUOUS BASIS AT NO TIME HAS THE ORGANIZAT ION CONDUCTED ACTIVITIES WHICH SERVE THE PERSONAL OR PRIVATE INTERESTS OF ITS FOUNDERS OR RELATED PARTIES THE ORGANIZATION MAINTAINS A CONTINUOUS AND BONA FIDE PROGRAM FOR SOLICIT ATION OF FUNDS BROCHURES REQUESTING DONATIONS ARE WIDELY DISTRIBUTED AT SCIENTIFIC, PATIE NT SUPPORT, AND PUBLIC EVENTS THESE BROCHURES ARE ALSO DISTRIBUTED THROUGH DIRECT MAILING S TO PERSONAL AND PROFESSIONAL CONTACTS GRANT APPLICATIONS HAVE BEEN MADE TO FOUNDATIONS AND OTHERS 1 170A-9(E)(III) PERCENTAGE OF FINANCIAL SUPPORT THE ORGANIZATION RECEIVED 22 12% OF ITS SUPPORT FROM PUBLIC SOURCES FROM 2013 TO 2017 1 170A-9(E)(3)(IV) SOURCES OF S UPPORT THE ORGANIZATION HAS RECEIVED ITS SUPPORT FROM INDIVIDUALS, BUSINESSES, AND FOUNDA TIONS NOT RELATED TO THE ORGANIZATION THROUGH EITHER BUSINESS OR FAMILY RELATIONS IN ADDI TION TO DIRECT DONATIONS, MANY INDIVIDUALS HAVE DONATED TIME AND SERVICES TO ASSIST THE OR GANIZATION IN ITS EXEMPT PURPOSE 1 170A-9(E)(3)(V) REPRESENTATIVE GOVERNING BODY THE ORG ANIZATION HAS THREE BOARDS THAT GOVERN ITS ACTIVITIES 1 THE BOARD OF TRUSTEES DOES NOT R EPRESENT THE PERSONAL OR PRIVATE INTERESTS OF A LIMITED NUMBER OF DONORS OR RELATED PERSON S ALL BOARD MEMBERS SERVE WITHOUT COMPENSATION MEMBERS OF THE BOARD HAVE SPECIAL KNOWLED GE OR EXPERTISE TO ASSIST IN FULFILLING ITS EXEMPT PURPOSE 2 THE MEDICAL AND SCIENTIFIC ADVISORY BOARD IS A VOLUNTEER BOARD CONSISTING OF 21 PHYSICIANS AND SCIENTISTS WHO HAVE A SPECIALTY IN DERMATOLOGICAL RESEARCH AND GENETICS, WITH AN EMPHASIS IN KERATIN DISORDERS SOME MEMBERS OF THIS BOARD ARE IN CONTACT DAILY WITH THE ORGANIZATION REGARDING RESEARCH A ND PATIENT CARE MANY ARE IN CONTACT SEVERAL TIMES EACH MONTH CONFERENCE CALLS ARE REGULA RLY SCHEDULED WITH THE ENTIRE GROUP AND WITH SPECIAL SUB-GROUPS FOR PLANNING THIS BOARD I S AVAILABLE FOR CONSULTATION REGARDING PATIENT CARE AND PATIENT NEEDS 3 VOLUNTARY PATIEN T ADVOCATES WORK THROUGH VARIOUS SOCIAL MEDIA, SUCH AS FACEBOOK, TO PROVIDE PATIENT OUTREA CH AND PATIENT-TO-PATIENT SUPP

990 Schedule A, Supplemental Information

Return Reference	Explanation
PART II, LINE 17A	ORT 1 170A-9(E)(3)(VI) AVAILABILITY OF PUBLIC FACILITIES OR SERVICES, PUBLIC PARTICIPATIO N IN PROGRAMS OR POLICIES (A) THE FACT THAT AN ORGANIZATION IS THE TYPE WHICH GENERALLY P ROVIDES FACILITIES OR SERVICES DIRECTLY FOR THE BENEFIT OF THE GENERAL PUBLIC WILL BE CO NSIDERED EVIDENCE THAT SUCH ORGANIZATION IS "PUBLICLY SUPPORTED " IN FEBRUARY 2004, THE OR GANIZATION ORGANIZED THE FIRST INTERNATIONAL PC CONFERENCE IN WHICH 23 OF THE LEADING KERA TIN SPECIALISTS ATTENDED, INCLUDING MARIO CAPECCHI (WINNER OF THE 2007 NOBEL PRIZE FOR MED ICINE) AT THE MEETING, THE GROUP FORMED THE INTERNATIONAL PC CONSORTIUM (IPCC) TO ENCOURA GE COLLABORATION FOR PC RESEARCH THERE ARE NOW SEVERAL HUNDRED EXPERTS WHO ARE ACTIVE MEM BERS OF THE IPCC AND EACH HAS AGREED TO COLLABORATE AND SHARE REAGENTS AND EXPERTISE TO AS SIST OTHER IPCC MEMBERS IN REGARD TO PC RESEARCH AND PATIENT CARE THE MAJORITY OF THESE P ARTICIPANTS REPRESENT NON-GOVERNMENTAL ORGANIZATIONS THAT SERVE MEMBERS OF A CHARITABLE CL ASS IN THEIR HOME COUNTRIES A LIST OF PARTICIPANTS CAN BE PROVIDED IF NEEDED BEGINNING W ITH THE 2004 SYMPOSIUM, THE ORGANIZATION HAS SPONSORED AN ANNUAL SCIENTIFIC MEETING EACH Y EAR THE ORGANIZATION ALSO PROVIDES EXPERTISE DIRECTLY FOR THE BENEFIT OF THE GENERAL PUBL IC BY RESPONDING TO DOZENS OF TELEPHONE, MAIL, AND INTERNET INQUIRIES EACH WEEK AT NO CHAR GE FROM PUBLIC HEALTH OFFICIALS, PRACTITIONERS, AND MEMBERS OF THE GENERAL PUBLIC IN MANY CASES, MEMBERS OF THE MEDICAL AND SCIENTIFIC ADVISORY BOARD WILL PROVIDE RESPONSES WHEN S PECIFIC SCIENTIFIC OR MEDICAL OPINIONS ARE NEEDED THE IPCC HAS ORGANIZED A STEERING COMMI TTEE TO DIRECT EFFORTS OF THE IPCC AND THREE WORKING TEAMS, INCLUDING (1) A RESEARCH TEAM CONDUCTING BASIC AND TRANSLATIONAL RESEARCH, (2) A DIAGNOSTICS AND GENETICS TEAM, AND (3) A PHYSICIANS NETWORK EACH OF THESE TEAMS ACTIVELY PROVIDE PUBLIC SERVICE TO THOSE WITH PC AND MANY OTHER RELATED SKIN DISORDERS (B) THE FACT THAT AN ORGANIZATION IS AN EDUCATION OR RESEARCH INSTITUTION WHICH REGULARLY PUBLISHES SCHOLARLY STUDIES WILL ALSO BE CONSIDE RED EVIDENCE THAT SUCH ORGANIZATION IS "PUBLICLY SUPPORTED " FROM 2004 TO 2016, THE ORGANI ZATION'S BOARD MEMBERS AND VOLUNTEERS HAVE CONTRIBUTED TO OVER 80 SCHOLARLY STUDIES RELATE D TO PC AND PC RESEARCH PUBLICATIONS CAN BE PROVIDED FOR REVIEW IF NEEDED MANY ARE AVAIL ABLE ONLINE AT HTTP //WWW PACHYONYCHIA ORG/RESEARCH-ARTICLES/ ALSO, IPCC NEWSLETTERS HAVE BEEN PUBLISHED EVERY QUARTER SINCE 2004 IN ADDITION, NUMEROUS PRESENTATIONS ON PC HAVE B EEN MADE BY BOARD MEMBERS AND VOLUNTEERS IN SCIENTIFIC MEETINGS AROUND THE WORLD (C) SIMI LARLY, THE FOLLOWING FACTORS WILL ALSO BE CONSIDERED EVIDENCE THAT AN ORGANIZATION IS "PUB LICLY SUPPORTED" (1) THE PARTICIPATION IN, OR SPONSORSHIP OF, PROGRAMS OF THE ORGANIZATIO N BY MEMBERS OF THE PUBLIC HAVING SPECIAL KNOWLEDGE OR EXPERTISE, PUBLIC OFFICIALS, OR CIV IC OR COMMUNITY LEADERS SEE (A) ABOVE FOR A DESCRIPTION OF THE ORGANIZATION'S INTERNATION AL SCIENTIFIC CONFERENCE FOR E

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Return Reference	Explanation
PART II, LINE 17B	THE FOLLOWING FACTS AND CIRCUMSTANCES ALSO WERE REPORTED TO COME TO A FINAL DETERMINATION THAT THE ORGANIZATION IS A PUBLIC CHARITY 1 170A-9(E)(3)(II) ATTRACTION OF PUBLIC SUPPORT PACHYONYCHIA CONGENITA (PC) IS AN ULTRA-RARE SKIN DISORDER WHICH CAUSES PAINFUL BLISTERS AND CALLUSES ON FEET AS WELL AS THICKENED NAILS, CYSTS, AND OTHER PAINFUL SYMPTOMS THE O RGANIZATION'S PRIMARY GOALS HAVE BEEN (1) TO INTEREST LEADING SCIENTISTS AND PHYSICIANS WH O SPECIALIZE IN KERATIN DISORDERS IN RESEARCH FOR THE ULTRA-RARE DISORDER, PC, AND TO ESTA BLISH COLLABORATION AMONG RESEARCHERS, (2) TO ESTABLISH AND MAINTAIN AN INTERNATIONAL PC P ATIENT REGISTRY (IPCRR) AS A RESOURCE FOR SCIENTIFIC RESEARCH, AND (3) TO PROVIDE EDUCATIO N AND SUPPORT FOR PHYSICIANS, SCIENTISTS, AND PC PATIENTS AND THEIR FAMILIES WORLDWIDE BY THEIR VERY NATURE, THESE TYPES OF ACTIVITIES HAVE THE POTENTIAL TO ATTRACT SUPPORT FROM G OVERNMENTAL UNITS AND PUBLIC CHARITIES ON A CONTINUOUS BASIS AT NO TIME HAS THE ORGANIZAT ION CONDUCTED ACTIVITIES WHICH SERVE THE PERSONAL OR PRIVATE INTERESTS OF ITS FOUNDERS OR RELATED PARTIES THE ORGANIZATION MAINTAINS A CONTINUOUS AND BONA FIDE PROGRAM FOR SOLICIT ATION OF FUNDS BROCHURES REQUESTING DONATIONS ARE WIDELY DISTRIBUTED AT SCIENTIFIC, PATIE NT SUPPORT, AND PUBLIC EVENTS THESE BROCHURES ARE ALSO DISTRIBUTED THROUGH DIRECT MAILING S TO PERSONAL AND PROFESSIONAL CONTACTS GRANT APPLICATIONS HAVE BEEN MADE TO FOUNDATIONS AND OTHERS 1 170A-9(E)(III) PERCENTAGE OF FINANCIAL SUPPORT THE ORGANIZATION RECEIVED 23 51% OF ITS SUPPORT FROM PUBLIC SOURCES FROM 2012 TO 2016 1 170A-9(E)(3)(IV) SOURCES OF S UPPORT THE ORGANIZATION HAS RECEIVED ITS SUPPORT FROM INDIVIDUALS, BUSINESSES, AND FOUNDA TIONS NOT RELATED TO THE ORGANIZATION THROUGH EITHER BUSINESS OR FAMILY RELATIONS IN ADDI TION TO DIRECT DONATIONS, MANY INDIVIDUALS HAVE DONATED TIME AND SERVICES TO ASSIST THE OR GANIZATION IN ITS EXEMPT PURPOSE 1 170A-9(E)(3)(V) REPRESENTATIVE GOVERNING BODY THE ORG ANIZATION HAS THREE BOARDS THAT GOVERN ITS ACTIVITIES 1 THE BOARD OF TRUSTEES DOES NOT R EPRESENT THE PERSONAL OR PRIVATE INTERESTS OF A LIMITED NUMBER OF DONORS OR RELATED PERSON S ALL BOARD MEMBERS SERVE WITHOUT COMPENSATION MEMBERS OF THE BOARD HAVE SPECIAL KNOWLED GE OR EXPERTISE TO ASSIST IN FULFILLING ITS EXEMPT PURPOSE 2 THE MEDICAL AND SCIENTIFIC ADVISORY BOARD IS A VOLUNTEER BOARD CONSISTING OF 18 PHYSICIANS AND SCIENTISTS WHO HAVE A SPECIALTY IN DERMATOLOGICAL RESEARCH AND GENETICS, WITH AN EMPHASIS IN KERATIN DISORDERS SOME MEMBERS OF THIS BOARD ARE IN CONTACT DAILY WITH THE ORGANIZATION REGARDING RESEARCH A ND PATIENT CARE MANY ARE IN CONTACT SEVERAL TIMES EACH MONTH CONFERENCE CALLS ARE REGULA RLY SCHEDULED WITH THE ENTIRE GROUP AND WITH SPECIAL SUB-GROUPS FOR PLANNING THIS BOARD I S AVAILABLE FOR CONSULTATION REGARDING PATIENT CARE AND PATIENT NEEDS 3 VOLUNTARY PATIEN T ADVOCATES WORK THROUGH VARIOUS SOCIAL MEDIA, SUCH AS FACEBOOK, TO PROVIDE PATIENT OUTREA CH AND PATIENT-TO-PATIENT SUPP

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PART II, LINE 17B	ORT 1 170A-9(E)(3)(VI) AVAILABILITY OF PUBLIC FACILITIES OR SERVICES, PUBLIC PARTICIPATIO N IN PROGRAMS OR POLICIES (A) THE FACT THAT AN ORGANIZATION IS THE TYPE WHICH GENERALLY P ROVIDES FACILITIES OR SERVICES DIRECTLY FOR THE BENEFIT OF THE GENERAL PUBLIC WILL BE CO NSIDERED EVIDENCE THAT SUCH ORGANIZATION IS "PUBLICLY SUPPORTED " IN FEBRUARY 2004, THE OR GANIZATION ORGANIZED THE FIRST INTERNATIONAL PC CONFERENCE IN WHICH 23 OF THE LEADING KERA TIN SPECIALISTS ATTENDED, INCLUDING MARIO CAPECCHI (WINNER OF THE 2007 NOBEL PRIZE FOR MED ICINE) AT THE MEETING, THE GROUP FORMED THE INTERNATIONAL PC CONSORTIUM (IPCC) TO ENCOURA GE COLLABORATION FOR PC RESEARCH THERE ARE NOW SEVERAL HUNDRED EXPERTS WHO ARE ACTIVE MEM BERS OF THE IPCC AND EACH HAS AGREED TO COLLABORATE AND SHARE REAGENTS AND EXPERTISE TO AS SIST OTHER IPCC MEMBERS IN REGARD TO PC RESEARCH AND PATIENT CARE THE MAJORITY OF THESE P ARTICIPANTS REPRESENT NON-GOVERNMENTAL ORGANIZATIONS THAT SERVE MEMBERS OF A CHARITABLE CL ASS IN THEIR HOME COUNTRIES A LIST OF PARTICIPANTS CAN BE PROVIDED IF NEEDED BEGINNING W ITH THE 2004 SYMPOSIUM, THE ORGANIZATION HAS SPONSORED AN ANNUAL SCIENTIFIC MEETING EACH Y EAR THE ORGANIZATION ALSO PROVIDES EXPERTISE DIRECTLY FOR THE BENEFIT OF THE GENERAL PUBL IC BY RESPONDING TO DOZENS OF TELEPHONE, MAIL, AND INTERNET INQUIRIES EACH WEEK AT NO CHAR GE FROM PUBLIC HEALTH OFFICIALS, PRACTITIONERS, AND MEMBERS OF THE GENERAL PUBLIC IN MANY CASES, MEMBERS OF THE MEDICAL AND SCIENTIFIC ADVISORY BOARD WILL PROVIDE RESPONSES WHEN S PECIFIC SCIENTIFIC OR MEDICAL OPINIONS ARE NEEDED THE IPCC HAS ORGANIZED A STEERING COMMI TTEE TO DIRECT EFFORTS OF THE IPCC AND THREE WORKING TEAMS, INCLUDING (1) A RESEARCH TEAM CONDUCTING BASIC AND TRANSLATIONAL RESEARCH, (2) A DIAGNOSTICS AND GENETICS TEAM, AND (3) A PHYSICIANS NETWORK EACH OF THESE TEAMS ACTIVELY PROVIDE PUBLIC SERVICE TO THOSE WITH PC AND MANY OTHER RELATED SKIN DISORDERS (B) THE FACT THAT AN ORGANIZATION IS AN EDUCATION OR RESEARCH INSTITUTION WHICH REGULARLY PUBLISHES SCHOLARLY STUDIES WILL ALSO BE CONSIDE RED EVIDENCE THAT SUCH ORGANIZATION IS "PUBLICLY SUPPORTED " FROM 2004 TO 2016, THE ORGANI ZATION'S BOARD MEMBERS AND VOLUNTEERS HAVE CONTRIBUTED TO OVER 80 SCHOLARLY STUDIES RELATE D TO PC AND PC RESEARCH PUBLICATIONS CAN BE PROVIDED FOR REVIEW IF NEEDED MANY ARE AVAIL ABLE ONLINE AT HTTP //WWW PACHYONYCHIA ORG/RESEARCH-ARTICLES/ ALSO, IPCC NEWSLETTERS HAVE BEEN PUBLISHED EVERY QUARTER SINCE 2004 IN ADDITION, NUMEROUS PRESENTATIONS ON PC HAVE B EEN MADE BY BOARD MEMBERS AND VOLUNTEERS IN SCIENTIFIC MEETINGS AROUND THE WORLD (C) SIMI LARLY, THE FOLLOWING FACTORS WILL ALSO BE CONSIDERED EVIDENCE THAT AN ORGANIZATION IS "PUB LICLY SUPPORTED" (1) THE PARTICIPATION IN, OR SPONSORSHIP OF, PROGRAMS OF THE ORGANIZATIO N BY MEMBERS OF THE PUBLIC HAVING SPECIAL KNOWLEDGE OR EXPERTISE, PUBLIC OFFICIALS, OR CIV IC OR COMMUNITY LEADERS SEE (A) ABOVE FOR A DESCRIPTION OF THE ORGANIZATION'S INTERNATION AL SCIENTIFIC CONFERENCE FOR E

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SCHEDULE D (Form 990)

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.
Information about Schedule D (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2017

Open to Public Inspection

Name of the organization
PACHYONYCHIA CONGENITA FUND

Employer identification number
68-0567493

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 (e g , recreation or education)
☐ Preservation of an historically important land area
☐ Protection of natural habitat
☐ Preservation of a certified historic structure
☐ Preservation of open space

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

		Held at the End of the 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 in (a)	2c
d	Number of conservation easements included in (c) acquired after 8/17/06, 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 conservation 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 2(d) 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 SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items

b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items

(i) 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 SFAS 116 (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 are a 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 programs
- 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
c Beginning balance	1c
d Additions during the year	1d
e Distributions during the year	1e
f Ending balance	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 Temporarily restricted 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

	Yes	No
(i) unrelated organizations	3a(i)	
(ii) related organizations	3a(ii)	
b If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R?	3b	

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		14,821	13,964	857
e Other				
Total. Add lines 1a through 1e *(Column (d) must equal Form 990, Part X, column (B), line 10(c))* ▶				857

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, col (B) line 12)* ▶		

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, col (B) line 13)* ▶		

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, col (B) line 15)* ▶	

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, col (B) line 25)* ▶	

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 FIN 48 (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	548,688
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12				
a	Net unrealized gains (losses) on investments	2a	75,763		
b	Donated services and use of facilities	2b	214,633		
c	Recoveries of prior year grants	2c			
d	Other (Describe in Part XIII)	2d			
e	Add lines **2a** through **2d**			2e	290,396
3	Subtract line **2e** from line **1**			3	258,292
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	258,292

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	537,036
2	Amounts included on line 1 but not on Form 990, Part IX, line 25				
a	Donated services and use of facilities	2a	214,633		
b	Prior year adjustments	2b			
c	Other losses	2c			
d	Other (Describe in Part XIII)	2d			
e	Add lines **2a** through **2d**			2e	214,633
3	Subtract line **2e** from line **1**			3	322,403
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	322,403

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

Return Reference	Explanation
See Additional Data Table	

Part XIII Supplemental Information *(continued)*

Return Reference	Explanation

Additional Data

Software ID:
Software Version:
EIN: 68-0567493
Name: PACHYONYCHIA CONGENITA FUND

Supplemental Information

Return Reference	Explanation
SCHEDULE D, PAGE 3, PART X	THE ORGANIZATION IS EXEMPT FROM FEDERAL INCOME TAXES UNDER SECTION 501(C) (3) OF THE INTER NAL REVENUE CODE AND THEREFORE HAS MADE NO PROVISION FOR FEDERAL INCOME TAXES IN THE ACCOM PANYING FINANCIAL STATEMENTS IN ADDITION, THE ORGANIZATION HAS BEEN DETERMINED BY THE INT ERNAL REVENUE SERVICE NOT TO BE A "PRIVATE FOUNDATION" WITHIN THE MEANING OF SECTION 509 (A) OF THE INTERNAL REVENUE CODE THERE WAS NO UNRELATED BUSINESS INCOME FOR THE YEAR ENDED DECEMBER 31, 2017 THE ORGANIZATION'S FORMS 990, RETURN OF ORGANIZATION EXEMPT FROM INCOM E TAX, FOR THE YEARS ENDING DECEMBER 31, 2017, 2016, 2015, AND 2014 ARE SUBJECT TO EXAMINA TION BY THE IRS, GENERALLY FOR THREE YEARS AFTER THEY WERE FILED GENERALLY ACCEPTED ACCOU NTING PRINCIPLES REQUIRE TAX EFFECTS FROM AN UNCERTAIN TAX POSITION TO BE RECOGNIZED IN TH E FINANCIAL STATEMENTS ONLY IF THE POSITION IS MORE LIKELY THAN NOT TO BE SUSTAINED IF THE POSITION WERE TO BE CHALLENGED BY A TAXING AUTHORITY THE ASSESSMENT OF THE TAX POSITION IS BASED SOLELY ON THE TECHNICAL MERITS OF THE POSITION, WITHOUT REGARD TO THE LIKELIHOOD THAT THE TAX POSITION MAY BE CHALLENGED IF AN UNCERTAIN TAX POSITION MEETS THE MORE-LIKEL Y-THAN-NOT THRESHOLD, THE LARGEST AMOUNT OF TAX BENEFIT THAT IS GREATER THAN 50% LIKELY TO BE RECOGNIZED UPON ULTIMATE SETTLEMENT WITH THE TAXING AUTHORITY IS RECORDED THE ORGANIZ ATION'S PRIMARY TAX POSITIONS RELATE TO ITS STATUS AS A NOT- FOR-PROFIT ENTITY EXEMPT FROM INCOME TAXES AND CLASSIFICATION OF ACTIVITIES RELATED TO ITS EXEMPT PURPOSE MANAGEMENT H AS EVALUATED THE TAX POSITIONS REFLECTED IN THE ORGANIZATION'S TAX FILINGS AND DOES NOT BE LIEVE THAT ANY MATERIAL UNCERTAIN TAX POSITIONS EXIST

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SCHEDULE F (Form 990)

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

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

► Attach to Form 990.

► Information about Schedule F (Form 990) and its instructions is at *www.irs.gov/form990*.

OMB No 1545-0047

2017

Open to Public Inspection

Name of the organization
PACHYONYCHIA CONGENITA FUND

Employer identification number
68-0567493

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

1 **For grantmakers.** Does the organization maintain records to substantiate the amount of 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 Activites 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 region	**(d)** Activities conducted in region (by type) (e g , fundraising, program services, investments, grants to recipients located in the region)	**(e)** If activity listed in (d) is a program service, describe specific type of service(s) in region	**(f)** Total expenditures for and investments in region
3a Sub-total					
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" to 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 non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			PC SUPPORT, RESEARCH	61,936	WIRE			

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter . . . . . ▶ 1

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" to 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 non-cash assistance	(g) Description of non-cash assistance	(h) Method of valuation (book, FMV, appraisal, other)

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 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 Instructions for Forms 3520 and 3520-A, do not file with Form 990)*	☐ Yes	☑ No
3	Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U S Persons with Respect to Certain Foreign Corporations (see Instructions for Form 5471)*	☐ 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 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 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 Instructions for Form 5713, do not 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).

Return Reference	Explanation
SCHEDULE F, PAGE 1, PART I, LINE 2	THE PURPOSE OF THE GRANT TO PC EUROPE WAS TO SUPPORT PC STUDIES AND EVENTS IN EUROPE AND TO FUND THE GENETIC TESTING WORK OF FRANCES SMITH FRANCES SMITH PROVIDES FREQUENT REPORTS ABOUT THE GENETIC TESTING WORK

Return Reference	Explanation
SCHEDULE F, PAGE 5, PART V	DURING 2017, THE ORGANIZATION TRANSFERED PC PROJECT EUROPE 145,137 AS A GRANT TO PURSUE RESEARCH AND ADVOCACY EFFORTS FOR PACHYONYCHIA CONGENITA IN EUROPE DURING 2017, PC PROJECT EUROPE IDENTIFIED THAT IT DID NOT NEED ALL OF THESE FUNDS, AS SOME ALTERNATIVE FUNDING SOURCES WERE IDENTIFIED THEREFORE, PC PROJECT EUROPE REFUNDED THE ORGANIZATION 83,201 OF THE GRANT GRANTS REPORTED REPRESENT GRANTS AWARDED LESS GRANTS REFUNDED, TOTALING 61,936

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Schedule L (Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Transactions with Interested Persons

▶ **Complete if the organization answered "Yes" on Form 990, Part IV, lines 25a, 25b, 26, 27, 28a, 28b, or 28c, or Form 990-EZ, Part V, line 38a or 40b.**
▶ **Attach to Form 990 or Form 990-EZ.**
▶ **Information about Schedule L (Form 990 or 990-EZ) and its instructions is at *www.irs.gov/form990*.**

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Employer identification number
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Part I Excess Benefit Transactions (section 501(c)(3), section 501(c)(4), and 501(c)(29) organizations only)

Complete if the organization answered "Yes" on Form 990, Part IV, line 25a or 25b, or Form 990-EZ, Part V, line 40b

1	(a) Name of disqualified person	(b) Relationship between disqualified person and organization	(c) Description of transaction	(d) Corrected? Yes	(d) Corrected? No

2 Enter the amount of tax incurred by organization managers or disqualified persons during the year under section 4958 . . . . . ▶ $

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

Part II Loans to and/or From Interested Persons.

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

(a) Name of interested person	(b) Relationship with organization	(c) Purpose of loan	(d) Loan to or from the organization? To	(d) Loan to or from the organization? From	(e) Original principal amount	(f) Balance due	(g) In default? Yes	(g) In default? No	(h) Approved by board or committee? Yes	(h) Approved by board or committee? No	(i) Written agreement? Yes	(i) Written agreement? No
Total				▶ $								

Part III Grants or Assistance Benefiting Interested Persons.

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

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of assistance	(d) Type of assistance	(e) Purpose of assistance

Part IV Business Transactions Involving Interested Persons.

Complete if the organization answered "Yes" on Form 990, Part IV, line 28a, 28b, or 28c.

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of transaction	(d) Description of transaction	(e) Sharing of organization's revenues?	
				Yes	No
(1) AMERICAN RESEARCH BUREAU	SEE PART V	850	SUBLEASE OFFICE		No
(2) AMERICAN RESEARCH BUREAU	SEE PART V	20,422	EMPLOYEE LEASING		No

Part V Supplemental Information

Provide additional information for responses to questions on Schedule L (see instructions)

Return Reference	Explanation
SCHEDULE L, PART V	AMERICAN RESEARCH BUREAU IS A COMPANY THAT IS OWNED BY THE FORMER EXECUTIVE DIRECTOR'S SONS AMERICAN RESEARCH BUREAU LEASES ITS OFFICE SPACE FROM A COMPANY THAT IS OWNED 50% BY THE FORMER EXECUTIVE DIRECTOR AMERICAN RESEARCH BUREAU SUBLEASED A PORTION OF THAT OFFICE SPACE TO THE ORGANIZATION FOR A FEW MONTHS OF THE YEAR IN ADDITION, AMERICAN RESEARCH BUREAU PROVIDED EMPLOYEE LEASING SERVICES TO THE ORGANIZATION FOR A FEW MONTHS OF THE YEAR

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SCHEDULE O (Form 990 or 990-EZ)

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 990-EZ.
▶ Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2017

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Name of the organization
PACHYONYCHIA CONGENITA FUND

Employer identification number
68-0567493

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PAGE 6, PART VI, LINE 2	JANICE SCHWARTZ MARY SCHWARTZ BOARD CHAIR FORMER ED DAUGHTER-IN-LAW/MOTHER-IN-LAW

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PAGE 6, PART VI, LINE 11B	THE BOARD OF DIRECTORS REVIEWS A DRAFT OF THE FORM 990 BEFORE THE FORM IS FILED A COPY OF THE FINALIZED TAX RETURN IS PROVIDED TO THE BOARD OF DIRECTORS EACH YEAR AFTER THE RETURN IS FILED

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PAGE 6, PART VI, LINE 12C	THE ORGANIZATION HAS A FORMAL CONFLICT OF INTEREST POLICY THIS POLICY REQUIRES ANNUAL WRI TTEN DISCLOSURE OF POTENTIAL CONFLICTS OF INTEREST BY ALL BOARD MEMBERS AND MANAGEMENT CO NFLICT OF INTEREST FORMS ARE REVIEWED ANNUALLY AT LEAST ANNUALLY BY THE EXECUTIVE DIRECTOR AND BOARD CHAIR IF A CONFLICT IS DETERMINED TO EXIST, BOARD MEMBERS ARE RECUSED FROM VOT ING ON TOPICS RELATED TO THE CONFLICT

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PAGE 6, PART VI, LINE 17	MINNESOTA, MISSOURI, NEW JERSEY, NEW MEXICO, NEW YORK, NORTH CAROLINA, OHIO, OREGON, PENNSYLVANIA, RHODE ISLAND, SOUTH CAROLINA, TENNESSEE, UTAH, VIRGINIA, WASHINGTON, WEST VIRGINIA, WISCONSIN

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PAGE 6, PART VI, LINE 19	THE ORGANIZATION'S GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY, AND FINANCIAL STATEME NTS ARE AVAILABLE TO THE PUBLIC UPON WRITTEN REQUEST

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART IX, LINE 11G	PROFESSIONAL SERVICES 33,698 4,188 0 EMPLOYEE LEASING 17,836 2,287 299 CONTRACT LABOR 5,357 0 0 TOTAL 56,891 6,475 299