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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 black lung benefit trust or private foundation)	OMB No 1545-0047 2009 Open to Public Inspection
	The organization may have to use a copy of this return to satisfy state reporting requirements	

A For the 2009 calendar year, or tax year beginning 01-01-2009 and ending 12-31-2009				
B Check if applicable ☐ Address change ☐ Name change ☐ Initial return ☐ Terminated ☐ Amended return ☐ Application pending	Please use IRS label or print or type. See Specific Instructions.	C Name of organization PACHYONYCHIA CONGENITA FUND		D Employer identification number 68-0567493
		Doing Business As		E Telephone number (877) 628-7300
		Number and street (or P O box if mail is not delivered to street address) 2386 EAST HERITAGE WAY SUITE B	Room/suite	G Gross receipts \$ 233,031
		City or town, state or country, and ZIP + 4 SALT LAKE CITY, UT 84109		
	F Name and address of principal officer MARY SCHWARTZ 2386 EAST HERITAGE WAY SUITE B SALT LAKE CITY, UT 84109		H(a) Is this a group return for affiliates? ☐ Yes ☒ No H(b) Are all affiliates included? ☐ Yes ☐ No If "No," attach a list (see instructions) H(c) Group exemption number ▶	
I Tax-exempt status ☒ 501(c) (3) ◀ (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		
Activities & Governance	1	Briefly describe the organization's mission or most significant activities MEDICAL RESEARCH - PACHYONYCHIA CONGENITA 		
	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 _____	
	4	Number of independent voting members of the governing body (Part VI, line 1b)	4 _____	
	5	Total number of employees (Part V, line 2a)	5 _____	
	6	Total number of volunteers (estimate if necessary)	6 _____	
	7a	Total gross unrelated business revenue from Part VIII, column (C), line 12	7a _____	
	b	Net unrelated business taxable income from Form 990-T, line 34	7b _____	
Revenue	8	Contributions and grants (Part VIII, line 1h)	Prior Year	Current Year
	9	Program service revenue (Part VIII, line 2g)	381,317	232,702
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	1,398	329
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		0
	12	Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	382,715	233,031
	Expenses	13	Grants and similar amounts paid (Part IX, column (A), lines 1–3)	32,107
14		Benefits paid to or for members (Part IX, column (A), line 4)		0
15		Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)		0
16a		Professional fundraising fees (Part IX, column (A), line 11e)		0
b		Total fundraising expenses (Part IX, column (D), line 25) ☐ 394		
17		Other expenses (Part IX, column (A), lines 11a–11d, 11f–24f)	354,058	222,281
18		Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25)	386,165	287,239
19		Revenue less expenses Subtract line 18 from line 12	-3,450	-54,208
Net Assets or Fund Balances			Beginning of Current Year	End of Year
	20	Total assets (Part X, line 16)	233,708	183,915
	21	Total liabilities (Part X, line 26)		4,415
	22	Net assets or fund balances Subtract line 21 from line 20	233,708	179,500

Part II		Signature Block			
Sign Here	Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge				
	***** Signature of officer		2010-07-15 Date		
	MARY SCHWARTZ TRUSTEE Type or print name and title				
Paid Preparer's Use Only	Preparer's signature  DON MANTYLA CPA		Date 2010-08-24	Check if self-employed 	Preparer's identifying number (see instructions)
	Firm's name (or yours if self-employed), address, and ZIP + 4 		MANTYLA MCREYNOLDS LLC 178 S RIO GRANDE ST STE 200 SALT LAKE CITY, UT 84101		EIN 
					Phone no  (801) 269-1818

1 Briefly describe the organization's mission

MEDICAL RESEARCH - PACHYONYCHIA CONGENITA

Form **990** (2009)

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? 	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? If "Yes," complete Schedule C, Part II	4	No
5	Section 501(c)(4), 501(c)(5), and 501(c)(6) organizations. Is the organization subject to the section 6033(e) notice and reporting requirement and proxy tax? If "Yes," complete Schedule C, Part III	5	
6	Did the organization maintain any donor advised funds or any similar funds or accounts where donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I 	6	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, 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 term, permanent, or quasi-endowments? If "Yes," complete Schedule D, Part V 	10	No
11	Is the organization's answer to any of the following questions "Yes"? If so, complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable. 	11	Yes
	• Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI.		
	• 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.		
	• 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.		
	• 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.		
	• Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X.		
	• 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? If "Yes," complete Schedule D, Part X.		
12	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI, XII, and XIII 	12	Yes
12A	Was the organization included in consolidated, independent audited financial statements for the tax year?	Yes	No
	If "Yes," completing Schedule D, Parts XI, XII, and XIII is optional 	12A	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	No
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, and program service activities outside the United States? If "Yes," complete Schedule F, Part I 	14b	Yes
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization or entity located outside the U S ? If "Yes," complete Schedule F, Part II 	15	Yes
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or assistance to individuals located outside the U S ? If "Yes," complete Schedule F, Part III 	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	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
20	Did the organization operate one or more hospitals? If "Yes," complete Schedule H	20	No

Part IV

Checklist of Required Schedules (continued)

21	Did the organization report more than \$5,000 of grants and other assistance to governments and organizations in the United States on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21		No
22	Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22		No
23	Did the organization answer "Yes" to Part VII, Section A, questions 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	23		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? <i>If "Yes," answer questions 24b–24d and complete Schedule K. If "No," go to line 25</i>	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) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a		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? <i>If "Yes," complete Schedule L, Part I</i>	25b		No
26	Was a loan to or by a current or former officer, director, trustee, key employee, highly compensated employee, or disqualified person outstanding as of the end of the organization's tax year? <i>If "Yes," complete Schedule L, Part II</i>	26		No
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor, or a grant selection committee member, or to a person related to such an individual? <i>If "Yes," complete Schedule L, Part III</i>	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? <i>If "Yes," complete Schedule L, Part IV</i>	28a	Yes	
b	A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28b		No
c	An entity of which a current or former officer, director, trustee, or key employee of the organization (or a family member) was an officer, director, trustee, or owner? <i>If "Yes," complete Schedule L, Part IV</i>	28c	Yes	
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	29		No
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>	30		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31		No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>	32		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? <i>If "Yes," complete Schedule R, Part I</i>	33		No
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Parts II, III, IV, and V, line 1</i>	34		No
35	Is any related organization a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35		No
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	36		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? <i>If "Yes," complete Schedule R, Part VI</i>	37		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11 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

			Yes	No
1a	Enter the number reported in Box 3 of Form 1096, <i>Annual Summary and Transmittal of U.S. Information Returns</i> . Enter -0- if not applicable	1a	0	
		1b	0	
b Enter the number of Forms W-2G included in line 1a Enter -0- if not applicable			1c	
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?				
2a	Enter the number of employees reported on Form W-3, <i>Transmittal of Wage and Tax Statements</i> filed for the calendar year ending with or within the year covered by this return	2a	0	
	b If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file this return (see instructions)			
3a Did the organization have unrelated business gross income of \$1,000 or more during the year covered by this return?			3a	No
b If "Yes," has it filed a Form 990-T for this year? If "No," 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 the instructions for exceptions and filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts				
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, Disclosure by Tax-Exempt Entity Regarding Prohibited Tax Shelter Transaction?			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?			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	
b If "Yes," did the organization notify the donor of the value of the goods or services provided?			7b	
c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?			7c	
d If "Yes," indicate the number of Forms 8282 filed during the year			7d	
e Did the organization, during the year, receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?			7e	
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? . . .			7f	
g For all contributions of qualified intellectual property, did the organization file Form 8899 as required? . . .			7g	
h For contributions of cars, boats, airplanes, and other vehicles, did the organization file a Form 1098-C as required?			7h	
8 Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?			8	
9 Sponsoring organizations maintaining donor advised funds.				
a Did the organization make any taxable distributions under section 4966?			9a	
b Did the 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	

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.

Section A. Governing Body and Management

			Yes	No
1a	Enter the number of voting members of the governing body	1a	8	
b	Enter the number of voting members that are independent	1b	6	
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 organizational documents since the prior Form 990 was filed?	4		No
5	Did the organization become aware during the year of a material diversion of the organization's assets?	5		No
6	Does the organization have members or stockholders?	6		No
7a	Does the organization have members, stockholders, or other persons who may elect one or more members of the governing body?	7a		No
b	Are any decisions of the governing body subject to approval by members, stockholders, or other persons?	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		No
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	Does the organization have local chapters, branches, or affiliates?	10a		No
b	If "Yes," does the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with those of the organization?	10b		
11	Has the organization provided a copy of this Form 990 to all members of its governing body before filing the form?	11		No
11A	Describe in Schedule O the process, if any, used by the organization to review the Form 990			
12a	Does the organization have a written conflict of interest policy? If "No," go to line 13	12a		No
b	Are officers, directors or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b		
c	Does the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this is done	12c		
13	Does the organization have a written whistleblower policy?	13		No
14	Does the organization have a written document retention and destruction policy?	14		No
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 a or b, 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," has the organization adopted a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and taken steps to safeguard the organization's exempt status with respect to such arrangements?	16b		

Section C. Disclosure

17	List the States with which a copy of this Form 990 is required to be filed▶
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 make these available. Check all that apply. ☒ Own website ☐ Another's website ☐ Upon request
19	Describe in Schedule O whether (and if so, how), the organization makes its governing documents, conflict of interest policy, and financial statements available to the public. See Additional Data Table.
20	State the name, physical address, and telephone number of the person who possesses the books and records of the organization ▶ MARY SCHWARTZ 2386 EAST HERITAGE WAY SUITE B SALT LAKE CITY, UT 84109 (877) 628-7300

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

• 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

☒ Check this box if the organization did not compensate any current or former officer, director, trustee or key employee

[illegible]

1b	Total			
----	-----------------	--	--	--

2	Total number of individuals (including but not limited to those listed above) who received more than \$100,000 in 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? <i>If "Yes," complete Schedule J for such individual</i>		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? <i>If "Yes," complete Schedule J for such individual</i>		No
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		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		
---	---	--	--

(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 in compensation from the organization	
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Part VIII

Statement of Revenue

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 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	12,783			
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	219,919			
	g	Noncash contributions included in lines 1a-1f \$ _____					
	h	Total. Add lines 1a-1f			232,702		
Program Service Revenue	2a		Business Code				
	b						
	c						
	d						
	e						
	f	All other program service revenue					
	g	Total. Add lines 2a-2f					
	Other Revenue	3	Investment income (including dividends, interest and other similar amounts)		329	329	
4		Income from investment of tax-exempt bond proceeds . . .					
5		Royalties					
6a		Gross Rents	(i) Real	(ii) Personal			
b		Less rental expenses					
c		Rental income or (loss)					
d		Net rental income or (loss)					
7a		Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other			
b		Less cost or other basis and sales expenses					
c		Gain or (loss)					
d		Net gain or (loss)					
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			233,031	329		

Part IX

Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns.

All other organizations must complete column (A) but are not required to complete columns (B), (C), and (D).

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.		(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to governments and organizations in the U S See Part IV, line 21				
2	Grants and other assistance to individuals in the U S See Part IV, line 22				
3	Grants and other assistance to governments, organizations, and individuals outside the U S See Part IV, lines 15 and 16	64,958	64,958		
4	Benefits paid to or for members				
5	Compensation of current officers, directors, trustees, and key employees				
6	Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7	Other salaries and wages				
8	Pension plan contributions (include section 401(k) and section 403(b) employer contributions)				
9	Other employee benefits				
10	Payroll taxes				
11	Fees for services (non-employees)				
a	Management				
b	Legal				
c	Accounting	12,775		12,775	
d	Lobbying				
e	Professional fundraising See Part IV, line 17				
f	Investment management fees				
g	Other	53,419	51,062	2,357	
12	Advertising and promotion				
13	Office expenses	8,878	7,989	889	
14	Information technology	6,539	5,317	1,222	
15	Royalties				
16	Occupancy	6,000		6,000	
17	Travel				
18	Payments of travel or entertainment expenses for any federal, state, or local public officials				
19	Conferences, conventions, and meetings	95,757	95,757		
20	Interest				
21	Payments to affiliates				
22	Depreciation, depletion, and amortization	2,074		2,074	
23	Insurance				
24	Other expenses Itemize expenses not covered above (Expenses grouped together and labeled miscellaneous may not exceed 5% of total expenses shown on line 25 below)				
a	REGISTRY EXPENSES	33,192	33,192		
b	OTHER PROGRAM SERVICES	1,992	1,992		
c	MISCELLANEOUS	639	219	420	
d	FUNDRAISING EXPENSES	394			394
e	EQUIPMENT	330		330	
f	All other expenses	292	200	92	
25	Total functional expenses. Add lines 1 through 24f	287,239	260,686	26,159	394
26	Joint costs. Check here ☐ if following SOP 98-2 Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation				

Part X

Balance Sheet

					(A)		(B)
					Beginning of year		End of year
Assets	1	Cash—non-interest-bearing			180,965	1	172,205
	2	Savings and temporary cash investments				2	
	3	Pledges and grants receivable, net			48,858	3	4,026
	4	Accounts receivable, net				4	
	5	Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L				5	
	6	Receivables from other disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) Complete Part II of Schedule L				6	
	7	Notes and loans receivable, net				7	5,873
	8	Inventories for sale or use				8	
	9	Prepaid expenses and deferred charges				9	
	10a	Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	10a	17,256	3,885	10c	1,811
	b	Less accumulated depreciation	10b	15,445			
	11	Investments—publicly traded securities				11	
	12	Investments—other securities See Part IV, line 11				12	
	13	Investments—program-related See Part IV, line 11				13	
	14	Intangible assets				14	
	15	Other assets See Part IV, line 11				15	
	16	Total assets. Add lines 1 through 15 (must equal line 34)			233,708	16	183,915
Liabilities	17	Accounts payable and accrued expenses				17	4,415
	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	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 Complete Part X of Schedule D				25	
	26	Total liabilities. Add lines 17 through 25			0	26	4,415
Net Assets or Fund Balances	Organizations that follow SFAS 117, check here ☒ and complete lines 27 through 29, and lines 33 and 34.						
	27	Unrestricted net assets			233,708	27	179,500
	28	Temporarily restricted net assets				28	
	29	Permanently restricted net assets				29	
	Organizations that do not follow SFAS 117, 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			233,708	33	179,500
	34	Total liabilities and net assets/fund balances			233,708	34	183,915

Part XI **Financial Statements and Reporting**

	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? . . .		No
b Were the organization's financial statements audited by an independent accountant?	Yes	
c If "Yes," to 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O	Yes	
d If "Yes" to line 2a or 2b, check a box below to indicate whether the financial statements for the year were issued on a consolidated basis, separate basis, or both ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separated basis		
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?		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 . . .		

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. ▶ See separate instructions.

OMB No 1545-0047

2009

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 11, check only one box)

- 1

☐

A church, convention of churches, or association of churches **section 170(b)(1)(A)(i).**
- 2

☐

A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E)
- 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 organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975 See **section 509(a)(2).** (Complete Part III)
- 10

☐

An organization organized and operated exclusively to test for public safety See**section 509(a)(4).**
- 11

☐

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 that describes the type of supporting organization and complete lines 11e through 11h

a

☐

Type I

b

☐

Type II

c

☐

Type III - Functionally integrated

d

☐

Type III - Other

e

☐

By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2)

f

☐

If the organization received a written determination from the IRS that it is a Type I, Type II or Type III supporting organization, check this box

g

☐

Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?

(i)

a person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the the supported organization?

(ii)

a family member of a person described in (i) above?

(iii)

a 35% controlled entity of a person described in (i) or (ii) above?

h

☐

Provide the following information about the supported organization(s)

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 9 above or IRC section (see instructions))	(iv) Is the organization in col (i) listed in your governing document?		(v) Did you notify the organization in col (i) of your support?		(vi) Is the organization in col (i) organized in the U S ?		(vii) Amount of support?
			Yes	No	Yes	No	Yes	No	
Total									

Part II

Support Schedule for Organizations Described in IRC 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)
(Complete only if you checked the box on line 5, 7, or 8 of Part I.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")	360,742	545,137	1,035,995	381,318	232,702	2,555,894
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	360,742	545,137	1,035,995	381,318	232,702	2,555,894
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)						2,042,817
6 Public Support. Subtract line 5 from line 4						513,077

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
7 Amounts from line 4	360,742	10,100	1,035,995	381,318	232,702	2,555,894
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	5,676	10,100	1,432	1,398	329	18,935
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income (Explain in Part IV) Do not include gain or loss from the sale of capital assets						
11 Total support (Add lines 7 through 10)						2,574,829
12 Gross receipts from related activities, etc (See instructions)					12	329
13 First Five Years If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here						

Section C. Computation of Public Support Percentage

14 Public Support Percentage for 2009 (line 6 column (f) divided by line 11 column (f))	14	19 930 %
15 Public Support Percentage for 2008 Schedule A, Part II, line 14	15	17 710 %
16a 33 1/3% support test—2009. 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—2008. If the organization did not check the 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—2009. If the organization did not check a box on line 13, 16a, or 16b and line 14 is 10% or more, and if the organization meets the "facts and circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts and circumstances" test The organization qualifies as a publicly supported organization		
b 10%-facts-and-circumstances test—2008. 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 IV 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 IIISupport Schedule for Organizations Described in IRC 509(a)(2)
(Complete only if you checked the box on line 9 of Part I.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
1Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
2Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3Gross receipts from activities that are not an unrelated trade or business under section 513						
4Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5The value of services or facilities furnished by a governmental unit to the organization without charge						
6Total. Add lines 1 through 5						
7aAmounts included on lines 1, 2, and 3 received from disqualified persons						
bAmounts 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						
cAdd lines 7a and 7b						
8Public Support (Subtract line 7c from line 6)						

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
9Amounts from line 6						
10aGross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
bUnrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
cAdd lines 10a and 10b						
11Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13Total support (Add lines 9, 10c, 11 and 12.)						

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

☐

Section C. Computation of Public Support Percentage

15Public Support Percentage for 2009 (line 8 column (f) divided by line 13 column (f))	15	
16Public support percentage from 2008 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17Investment income percentage for 2009 (line 10c column (f) divided by line 13 column (f))	17	
18Investment income percentage from 2008 Schedule A, Part III, line 17	18	

19a**33 1/3% support tests—2009.** 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—2008.** 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

☐

Facts And Circumstances Test
THE FOLLOWING FACTS AND CIRCUMSTANCES ALSO WERE REPORTED TO COME TO A FINAL DETERMINATION THAT THE TAXPAYER 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 TAXPAYER'S PRIMARY GOALS HAVE BEEN (1)TO INTEREST LEADING SCIENTISTS AND PHYSICANS 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 (IPCCR) 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 CHARTIES ON A CONTINUOUS BASIS AT NO TIME HAS PC PROJECT CONDUCTED ACTIVITIES WHICH SERVE THE PERSONAL OR PRIVATE INTEREST OF ITS FOUNDERS OR OTHER INSIDERS THE TAXPAYER MAINTAINS A CONTINUOUS AND BONA FIDE PROGRAM FOR SOLICITATION OF FUNDS BROCHURES REQUESTING DONATIONS ARE WIDELY DISTRIBUTED AT BOTH SCIENTIFIC AND PATIENT SUPPORT EVENTS THESE BROCHURES WERE ALSO DISTRIBUTED THROUGH DIRECT MAILINGS TO PERSONAL AND PROFESSIONAL CONTACTS GRANT APPLICATIONS WERE MADE TO FOUNDATIONS SUCH AS NFED, NORD, FDA/OOPD, NIH/NIAMS AND OTHERS 1 170A-9(E)(3)(III) PERCENTAGE OF FINANCIAL SUPPORT THE TAXPAYER RECEIVED 10 90% OF ITS SUPPORT FROM PUBLIC SOURCES FROM 2005 TO 2009 1 170A-9(E)(3)(IV) SOURCES OF SUPPORT THE TAXPAYER 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 TAXPAYER IN ITS EXEMPT PURPOSE 1 170A-9(E)(3)(V) REPRESENTATIVE GOVERNING BODY THE TAXPAYER 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 FULFING ITS EXEMPT PURPOSE 2 THE MEDICAL AND SCIENTIFIC ADVISORY BOARD IS A VOLUNTEER BOARD CONSISTING OF NINE PHYSICIANS AND SCIENTISTS WHO HAVE A SPECIALTY IN DERMATOLOGICAL RESEARCH AND AN EMPHASIS ON KERATIN DISORDERS SOME MEMBERS OF THIS BOARD ARE IN CONTACT DAILY WITH THE TAXPAYER REGARDING RESEARCH AND PATIENT CARE MANY ARE IN CONTACT SEVERAL TIMES A MONTH QUARTERLY CONFERENCE CALLS ARE HELD WITH THE ENTIRE GROUP FOR PLANNING THIS BOARD IS AVAILABLE FOR CONSULTATION REGARDING PATIENT CARE AND PATIENT NEEDS 3 THE PATIENT ADVISORY BOARD IS A VOLUNTEER BOARD CONSISTING OF PC PATIENTS FROM AROUND THE WORLD MONTHLY CONFERENCE CALLS ARE HELD REGARDING THE WORK OF ITS THREE VOLUNTEER COMMITTEES FUND RAISING, NEWSLETTER, AND PATIENT OUTREACH A PATIENT NEWSLETTER HAS BEEN PUBLISHED REGULARLY SINCE 2004 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 WILL BE CONSIDERED EVIDENCE THAT SUCH ORGANIZATION IS "PUBLICLY SUPPORTED " IN FEBRUARY 2004, THE TAXPAYER ORGANIZED THE FIRST INTERNATIONAL PC CONFERENCE IN WHICH 23 OF THE LEADING KERATIN SPECIALISTS ATTENDED INCLUDING MARIO CAPCCHI (WINNER OF 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 83 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 FOR REVIEW IF NEEDED BEGINNING WITH THE 2004 SYMPOSIUM, THE TAXPAYER HAS SPONSORED AN ANNUAL SCIENTIFIC MEETING EACH YEAR THE TAXPAYER 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 IN THE FIELD, AND/OR MEMBERS OF THE GENERAL PUBLIC IN MANY CASES, MEMBERS OF THE MEDICAL AND SCIENTIFIC ADVISORY BOARD PROVIDED RESPONSES WHEN SPECIFIC SCIENTIFIC OR MEDICAL OPINIONS WERE NEEDED (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 2009, THE TAXPAYER'S BOARD MEMBERS AND VOLUNTEERS HAVE CONTRIBUTED TO A NUMBER OF SCHOLARLY STUDIES REGARDING PC PUBLICATIONS CAN BE PROVIDED FOR REVIEW IF NEEDED AND MANY ARE ON-LINE AND AVAILABLE AT WWW.PACHYONYCHIA.ORG/BIBLIOGRAPH.PHP ALSO, IPCC NEWSLETTERS HAVE BEEN PUBLISHED EVERY QUARTER SINCE 2004 THE LATEST EDITION WAS DISTRIBUTED TO OVER 200 VIA E-MAIL AND MAIL IN ADDITION, NUMEROUS PRESENTATIONS ON PC HAVE BEEN MADE BY BOARD MEMBERS AND VOLUNTEERS IN SCIENTIFIC MEETINGS IN ST LOUIS, MISSOURI, PHILADELPHIA, PENNSYLVANIA, LOS ANGELES, CALIFORNIA, SAN FRANCISCO, CALIFORNIA, WASHINGTON, DC, BUENOS AIRES, ARGENTINA, MAASTRICHT, THE NETHERLANDS, ETC (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 PLEASE SEE (A) ABOVE FOR A DESCRIPTION OF THE TAXPAYER'S INTERNATIONAL SCIENTIFIC CONFERENCES 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 TAXPAYER HAS SEVERAL OTHER ACTIVITIES WHICH DEMONSTRATE THIS BROAD PUBLIC SUPPORT 1 PATIENT SUPPORT MEETINGS HAVE BEEN HELD IN SALT LAKE CITY, UTAH (2004), KANSAS CITY, MISSOURI (2004), DUNDEE, SCOTLAND (2004 AND 2006), NIAGRA FALLS, ONTARIO (2005) AND PARK CITY, UTAH (2007) MORE THAN A DOZEN PHYSICIANS AND SCIENTISTS VOLUNTEERED THEIR TIME AND PAID THEIR OWN EXPENSES TO ATTEND THE 2007 MEETING AND SIMILAR NUMBERS HAVE ATTENDED EACH MEETING THERE WERE OVER 50 PC PATIENTS AND THEIR FAMILY MEMBERS AT THE 2007 MEETING, THERE WERE ONLY 9 AT THE KANSAS CITY MEETING IN 2004 THE 2004 MEETING IN KANSAS CITY WAS HOSTED BY THE FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES (FIRST) THE MEETING IN 2004 AND 2006 WERE HOSTED BY THE UNIVERSITY OF DUNDEE, SCOTLAND 2 THE INTERNATIONAL PC RESEARCH REGISTRY HAS RECEIVED INSTITUTIONAL REVIEW BOARD APPROVAL THROUGH THE WESTERN INSTITUTIONAL REVIEW BOARD (STUDY NO 2004/0468/1057496 THIS IS THE ONLY ACTIVE REGISTRY FOR PC PATIENTS IN THE WORLD THERE ARE NEARLY 550 PATIENTS REGISTERED PC PATIENTS REGISTERED ARE FROM 31 COUNTRIES AND 36 U.S. STATES 1 170A-9(E)(3)(VII) ADDITIONAL FACTORS PERTINENT TO MEMBERSHIP ORGANIZATIONS THE TAXPAYER IS NOT A MEMBERSHIP ORGANIZATION

SCHEDULE D

(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

► **Complete if the organization answered "Yes," to Form 990,
Part IV, line 6, 7, 8, 9, 10, 11, or 12.**
► **Attach to Form 990. ► See separate instructions.**

OMB No 1545-0047

2009

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" to Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1	Total number at end of year	
2	Aggregate contributions to (during year)	
3	Aggregate 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 may 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" to 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 pleasure)☐ Preservation of an historically importantly land area☐ Protection of natural habitat☐ Preservation of a certified historic structure☐ Preservation of open space											
2	Complete lines 2a–2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year											
		<table><tr><td></td><td>Held at the End of the Year</td></tr><tr><td>a</td><td>Total number of conservation easements</td></tr><tr><td>b</td><td>Total acreage restricted by conservation easements</td></tr><tr><td>c</td><td>Number of conservation easements on a certified historic structure included in (a)</td></tr><tr><td>d</td><td>Number of conservation easements included in (c) acquired after 8/17/06</td></tr></table>		Held at the End of the Year	a	Total number of conservation easements	b	Total acreage restricted by conservation easements	c	Number of conservation easements on a certified historic structure included in (a)	d	Number of conservation easements included in (c) acquired after 8/17/06
	Held at the End of the Year											
a	Total number of conservation easements											
b	Total acreage restricted by conservation easements											
c	Number of conservation easements on a certified historic structure included in (a)											
d	Number of conservation easements included in (c) acquired after 8/17/06											
3	Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the taxable 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 and enforcing conservation easements during the year ► _____											
7	Amount of expenses incurred in monitoring, inspecting, 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 170(h)(4)(B)(ii)? ☐ Yes☒ No											
9	In Part XIV, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization’s financial statements that describes the organization’s accounting for conservation easements											

Part III

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

1a	If the organization elected, as permitted under SFAS 116, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education or research in furtherance of public service, provide, in Part XIV, the text of the footnote to its financial statements that describes these items	
b	If the organization elected, as permitted under SFAS 116, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items	
	(i) Revenues included in Form 990, Part VIII, line 1	► \$ _____
	(ii) Assets included in Form 990, Part X	► \$ _____
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 relating to these items	
a	Revenues included in 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 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 XIV

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" to 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 XIV and complete the following table

	Amount
1c	
1d	
1e	
1f	

2a

Did the organization include an amount on Form 990, Part X, line 21?

☐ Yes

☒ No

b

If "Yes," explain the arrangement in Part XIV

Part V

Endowment Funds. Complete if the organization answered "Yes" to 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	Investment earnings or 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 year end balance held as

a

Board designated or quasi-endowment ▶ %

b

Permanent endowment ▶ %

c

Term endowment ▶ %

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

4

Describe in Part XIV the intended uses of the organization's endowment funds

Part VI

Investments—Land, Buildings, and Equipment. See Form 990, Part X, line 10.

Description of investment	(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		17,256	15,445	1,811
e Other				
Total. Add lines 1a-1e (Column (d) should equal Form 990, Part X, column (B), line 10(c).)				1,811

Part XI Reconciliation of Change in Net Assets from Form 990 to Financial Statements			
1	Total revenue (Form 990, Part VIII, column (A), line 12)	1	233,031
2	Total expenses (Form 990, Part IX, column (A), line 25)	2	287,239
3	Excess or (deficit) for the year Subtract line 2 from line 1	3	-54,208
4	Net unrealized gains (losses) on investments	4	
5	Donated services and use of facilities	5	
6	Investment expenses	6	
7	Prior period adjustments	7	
8	Other (Describe in Part XIV)	8	
9	Total adjustments (net) Add lines 4 - 8	9	
10	Excess or (deficit) for the year per financial statements Combine lines 3 and 9	10	-54,208

Part XII Reconciliation of Revenue per Audited Financial Statements With Revenue per Return			
1	Total revenue, gains, and other support per audited financial statements	1	233,031
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12		
a	Net unrealized gains on investments	2a	
b	Donated services and use of facilities	2b	
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIV)	2d	
e	Add lines 2a through 2d	2e	
3	Subtract line 2e from line 1	3	233,031
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 XIV)	4b	
c	Add lines 4a and 4b	4c	
5	Total Revenue Add lines 3 and 4c. (This should equal Form 990, Part I, line 12)	5	233,031

Part XIII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return			
1	Total expenses and losses per audited financial statements	1	287,239
2	Amounts included on line 1 but not on Form 990, Part IX, line 25		
a	Donated services and use of facilities	2a	
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIV)	2d	
e	Add lines 2a through 2d	2e	
3	Subtract line 2e from line 1	3	287,239
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 XIV)	4b	
c	Add lines 4a and 4b	4c	
5	Total expenses Add lines 3 and 4c. (This should equal Form 990, Part I, line 18)	5	287,239

Part XIV Supplemental Information			
Complete this part to 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, Part XI, line 8, Part XII, lines 2d and 4b, and Part XIII, lines 2d and 4b. Also complete this part to provide any additional information.			
Identifier	Return Reference	Explanation	

OMB No 1545-0047

2009

**Open to Public
Inspection**

Employer identification number
68-0567493

3 Activities per Region (Use Schedule F-1 (Form 990) if additional space is needed)

For Privacy Act and Paperwork Reduction Act Notice, see the Instructions for Form 990. Cat No 50082W Schedule F (Form 990) 2009

Part II

Grants and Other Assistance to Organizations or Entities Outside the United States.

Complete if the organization answered "Yes" to Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Check this box if no one recipient received more than \$5,000 ☐

Use Schedule F-1 (Form 990) 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)
			EUROPE	GENETIC TESTING	63,458	EFT			

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. Use Schedule F-1 (Form 990) if additional space is needed.

[illegible]

Complete this part to provide the information required in Part I, line 2, and any additional information.

Schedule F (Form 990) 2009

SCHEDULE O

(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990

Complete to provide information for responses to specific questions on
Form 990 or to provide any additional information.
▶ Attach to Form 990.

OMB No 1545-0047

2009

Open to Public
Inspection

Name of the organization PACHYONYCHIA CONGENITA FUND	Employer identification number 68-0567493
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Identifier	Return Reference	Explanation
RELATED PARTY INFORMATION AMONG OFFICERS	FORM 990, PAGE 6, PART VI, LINE 2	MARY SCHWARTZ JANICE SCHWARTZ TRUSTEE/MNGR TRUSTEE MOTHER-IN-LAW/DAUGHTER-IN-LAW
DOCUMENTATION BY COMMITTEE	FORM 990, PAGE 6, PART VI, LINE 8B	NO COMMITTEE HAS AUTHORITY TO ACT ON BEHALF OF THE GOVERNING BODY
ORGANIZATION'S PROCESS USED TO REVIEW FORM 990	FORM 990, PAGE 6, PART VI, LINE 11	NO BOARD REVIEW WILL BE CONDUCTED PRIOR TO FILING FORM 990
GOVERNING DOCUMENTS DISCLOSURE EXPLANATION	FORM 990, PAGE 6, PART VI, LINE 19	GOVERNING DOCUMENTS AVAILABLE UPON REQUEST

Form

4562

Depreciation and Amortization
(Including Information on Listed Property)

OMB No 1545-0172

2009

Attachment
Sequence No 67

Department of the Treasury
Internal Revenue Service

▶ See separate instructions. ▶ Attach to your tax return.

Name(s) shown on return PACHYONYCHIA CONGENITA FUND	Business or activity to which this form relates INDIRECT DEPRECIATION	Identifying number 68-0567493
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Part I Election To Expense Certain Property Under Section 179

Note: If you have any listed property, complete Part V before you complete Part I.

1 Maximum amount See the instructions for a higher limit for certain businesses	1	250,000
2 Total cost of section 179 property placed in service (see instructions)	2	
3 Threshold cost of section 179 property before reduction in limitation (see instructions)	3	800,000
4 Reduction in limitation Subtract line 3 from line 2 If zero or less, enter -0-	4	
5 Dollar limitation for tax year Subtract line 4 from line 1 If zero or less, enter -0- If married filing separately, see instructions	5	

6 (a) Description of property	(b) Cost (business use only)	(c) Elected cost	
6			
7 Listed property Enter the amount from line 29	7		
8 Total elected cost of section 179 property Add amounts in column (c), lines 6 and 7	8		
9 Tentative deduction Enter the smaller of line 5 or line 8	9		
10 Carryover of disallowed deduction from line 13 of your 2008 Form 4562	10		
11 Business income limitation Enter the smaller of business income (not less than zero) or line 5 (see instructions)	11		
12 Section 179 expense deduction Add lines 9 and 10, but do not enter more than line 11	12		
13 Carryover of disallowed deduction to 2010 Add lines 9 and 10, less line 12 .▶	13		

Note: Do not use Part II or Part III below for listed property. Instead, use Part V.

Part II Special Depreciation Allowance and Other Depreciation (Do not include listed property) (See instructions)		
14 Special depreciation allowance for qualified property (other than listed property) placed in service during the tax year (see instructions)	14	
15 Property subject to section 168(f)(1) election	15	
16 Other depreciation (including ACRS)	16	

Part III MACRS Depreciation (Do not include listed property.) (See instructions.)

Section A

17 MACRS deductions for assets placed in service in tax years beginning before 2009	17	2,074
18 If you are electing to group any assets placed in service during the tax year into one or more general asset accounts, check here▶		

Section B—Assets Placed in Service During 2008 Tax Year Using the General Depreciation System						
(a) Classification of property	(b) Month and year placed in service	(c) Basis for depreciation (business/investment use only—see instructions)	(d) Recovery period	(e) Convention	(f) Method	(g) Depreciation deduction
19a 3-year property						
b 5-year property						
c 7-year property						
d 10-year property						
e 15-year property						
f 20-year property						
g 25-year property			25 yrs		S/L	
h Residential rental property			27 5 yrs	MM	S/L	
			27 5 yrs	MM	S/L	
i Nonresidential real property			39 yrs	MM	S/L	
				MM	S/L	

Section C—Assets Placed in Service During 2009 Tax Year Using the Alternative Depreciation System						
20a Class life					S/L	
b 12-year			12 yrs		S/L	
c 40-year			40 yrs	MM	S/L	

Non-Res Prop Type 1 count 0 Non-Res Prop Type 2 count 0 Non-Res Prop Totals count 0

Part IV Summary (see instructions)				21 Listed property
22 Total. Add amounts from line 12, lines 14 through 17, lines 19 and 20 in column (g), and line 21 Enter here and on the appropriate lines of your return Partnerships and S corporations—see instructions	22		2,074	
23 For assets shown above and placed in service during the current year, enter the portion of the basis attributable to section 263A costs	23			

Part V

Listed Property (Include automobiles, certain other vehicles, cellular telephones, certain computers, and property used for entertainment, recreation, or amusement.)
Note: For any vehicle for which you are using the standard mileage rate or deducting lease expense, complete **only** 24a, 24b, columns (a) through (c) of Section A, all of Section B, and Section C if applicable.

Section A—Depreciation and Other Information (Caution: See the instructions for limits for passenger automobiles.)

24a Do you have evidence to support the business/investment use claimed?						Yes No			24b If "Yes," is the evidence written?			Yes No					
(a) Type of property (list vehicles first)		(b) Date placed in service		(c) Business/ investment use percentage		(d) Cost or other basis		(e) Basis for depreciation (business/investment use only)		(f) Recovery period		(g) Method/ Convention		(h) Depreciation/ deduction		(i) Elected section 179 cost	
25 Special depreciation allowance for qualified listed property placed in service during the tax year and used more than 50% in a qualified business use (see instructions)												25					
26 Property used more than 50% in a qualified business use																	
				%													
				%													
				%													
27 Property used 50% or less in a qualified business use																	
				%						S/L -							
				%						S/L -							
				%						S/L -							
28 Add amounts in column (h), lines 25 through 27 Enter here and on line 21, page 1												28					
29 Add amounts in column (i), line 26 Enter here and on line 7, page 1														29			

Section B—Information on Use of Vehicles

Complete this section for vehicles used by a sole proprietor, partner, or other "more than 5% owner," or related person
If you provided vehicles to your employees, first answer the questions in Section C to see if you meet an exception to completing this section for those vehicles

30 Total business/investment miles driven during the year (do not include commuting miles)			(a) Vehicle 1		(b) Vehicle 2		(c) Vehicle 3		(d) Vehicle 4		(e) Vehicle 5		(f) Vehicle 6	
31 Total commuting miles driven during the year														
32 Total other personal(noncommuting) miles driven														
33 Total miles driven during the year Add lines 30 through 32														
34 Was the vehicle available for personal use during off-duty hours?			Yes No		Yes No		Yes No		Yes No		Yes No		Yes No	
35 Was the vehicle used primarily by a more than 5% owner or related person?														
36 Is another vehicle available for personal use?														

Section C—Questions for Employers Who Provide Vehicles for Use by Their Employees

Answer these questions to determine if you meet an exception to completing Section B for vehicles used by employees who are not more than 5% owners or related persons (see instructions)

37 Do you maintain a written policy statement that prohibits all personal use of vehicles, including commuting, by your employees?												Yes		No	
38 Do you maintain a written policy statement that prohibits personal use of vehicles, except commuting, by your employees? See the instructions for vehicles used by corporate officers, directors, or 1% or more owners															
39 Do you treat all use of vehicles by employees as personal use?															
40 Do you provide more than five vehicles to your employees, obtain information from your employees about the use of the vehicles, and retain the information received?															
41 Do you meet the requirements concerning qualified automobile demonstration use? (See instructions)															
Note: If your answer to 37, 38, 39, 40, or 41 is "Yes," do not complete Section B for the covered vehicles															

Part VI Amortization

(a) Description of costs		(b) Date amortization begins		(c) Amortizable amount		(d) Code section		(e) A mortization period or percentage		(f) A mortization for this year	
42 A mortization of costs that begins during your 2009 tax year (see instructions)											
43 A mortization of costs that began before your 2009 tax year									43		
44 Total. Add amounts in column (f) See the instructions for where to report									44		

Additional Data

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

Form 990, Part IX - Statement of Functional Expenses - 24a - 24e Other Expenses

<i>Do not include amounts reported on line 6b, 8b, 9b, and 10b of Part VIII.</i>	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
REGISTRY EXPENSES	33,192	33,192		
OTHER PROGRAM SERVICES	1,992	1,992		
MISCELLANEOUS	639	219	420	
FUNDRAISING EXPENSES	394			394
EQUIPMENT	330		330	