Form **990**

Department of the Treasury
Internal Revenue Service

Return of Organization Exempt From Income Tax

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

Do not enter social security numbers on this form as it may be made public.

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

OMB No. 1545-0047

2022

Open to Public Inspection

A For the 2022 calendar year, or tax year beginning , and ending

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

C Name of organization
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$ **1,448,737**

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

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

J Website: **www.pachyonychia.org**

H(c) Group exemption number

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	7
4	Number of independent voting members of the governing body (Part VI, line 1b)	4	7
5	Total number of individuals employed in calendar year 2022 (Part V, line 2a)	5	1
6	Total number of volunteers (estimate if necessary)	6	10
7a	Total unrelated business revenue from Part VIII, column (C), line 12	7a	0
b	Net unrelated business taxable income from Form 990-T, Part I, line 11	7b	0

		Prior Year	Current Year
8	Contributions and grants (Part VIII, line 1h)	512,628	567,482
9	Program service revenue (Part VIII, line 2g)		0
10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	172,240	87,130
11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	18	207
12	Total revenue – add lines 8 through 11 (must equal Part VIII, column (A), line 12)	684,886	654,819
13	Grants and similar amounts paid (Part IX, column (A), lines 1–3)	100,000	125,776
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)	77,723	80,092
16a	Professional fundraising fees (Part IX, column (A), line 11e)	240	840
b	Total fundraising expenses (Part IX, column (D), line 25) **19,063**		
17	Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)	163,682	172,725
18	Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25)	341,645	379,433
19	Revenue less expenses. Subtract line 18 from line 12	343,241	275,386

		Beginning of Current Year	End of Year
20	Total assets (Part X, line 16)	3,157,668	3,057,177
21	Total liabilities (Part X, line 26)	2,485	136,398
22	Net assets or fund balances. Subtract line 21 from line 20	3,155,183	2,920,779

Part II Signature Block

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

Sign Here

Signature of officer — Date

Jason Hunter, CPA **Treasurer**

Type or print name and title

Paid Preparer Use Only

Print/Type preparer's name	Preparer's signature	Date	Check ☐ if self-employed	PTIN
Shalaun T. Howell, CPA	Shalaun T. Howell, CPA	09/27/23		P00969274

Firm's name: **BOUNTIFUL PEAK ADVISORS** Firm's EIN: **46-0952065**

Firm's address: **1564 SOUTH 500 WEST, SUITE 201 BOUNTIFUL, UT 84010-7400** Phone no. **801-294-3155**

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

For Paperwork Reduction Act Notice, see the separate instructions.

DAA

Form **990** (2022)

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 $ **182,604** including grants of$ **125,776**) (Revenue $)

Patient Support

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.

4b (Code:) (Expenses $ **99,233** including grants of$) (Revenue $)

IPCRR

Maintained the International Pachyonychia Congenita Research Registry (IPCRR). Since 2004, and with IRB approval, the IPCRR has provided over 2,000 patients with 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.

4c (Code:) (Expenses $ **42,774** including grants of$) (Revenue $)

IPCC

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 400 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.

4d Other program services (Describe on Schedule O.)

(Expenses $ including grants of$) (Revenue $)

4e Total program service expenses **324,611**

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**	X	
2	Is the organization required to complete *Schedule B, Schedule of Contributors?* See instructions	**2**	X	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? *If "Yes," complete Schedule C, Part I*	**3**		X
4	**Section 501(c)(3) organizations.** Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? *If "Yes," complete Schedule C, Part II*	**4**	X	
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Rev. Proc. 98-19? *If "Yes," complete Schedule C, Part III*	**5**		X
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? *If "Yes," complete Schedule D, Part I*	**6**		X
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? *If "Yes," complete Schedule D, Part II*	**7**		X
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? *If "Yes," complete Schedule D, Part III*	**8**		X
9	Did the organization report an amount in Part X, line 21, 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**		X
10	Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi endowments? *If "Yes," complete Schedule D, Part V*	**10**		X
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X, as applicable.			
a	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? *If "Yes," complete Schedule D, Part VI*	**11a**	X	
b	Did the organization report an amount for investments—other securities in Part X, line 12, that is 5% or more of its total assets reported in Part X, line 16? *If "Yes," complete Schedule D, Part VII*	**11b**		X
c	Did the organization report an amount for investments—program related in Part X, line 13, that is 5% or more of its total assets reported in Part X, line 16? *If "Yes," complete Schedule D, Part VIII*	**11c**		X
d	Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? *If "Yes," complete Schedule D, Part IX*	**11d**		X
e	Did the organization report an amount for other liabilities in Part X, line 25? *If "Yes," complete Schedule D, Part X*	**11e**	X	
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? *If "Yes," complete Schedule D, Part X*	**11f**	X	
12a	Did the organization obtain separate, independent audited financial statements for the tax year? *If "Yes," complete Schedule D, Parts XI and XII*	**12a**	X	
b	Was the organization included in consolidated, independent audited financial statements for the tax year? *If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional*	**12b**		X
13	Is the organization a school described in section 170(b)(1)(A)(ii)? *If "Yes," complete Schedule E*	**13**		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?	**14a**		X
b	Did the organization have aggregate revenues or expenses of more than $10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at $100,000 or more? *If "Yes," complete Schedule F, Parts I and IV*	**14b**	X	
15	Did the organization report on Part IX, column (A), line 3, more than $5,000 of grants or other assistance to or for any foreign organization? *If "Yes," complete Schedule F, Parts II and IV*	**15**	X	
16	Did the organization report on Part IX, column (A), line 3, more than $5,000 of aggregate grants or other assistance to or for foreign individuals? *If "Yes," complete Schedule F, Parts III and IV*	**16**		X
17	Did the organization report a total of more than $15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? *If "Yes," complete Schedule G, Part I.* See instructions	**17**		X
18	Did the organization report more than $15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? *If "Yes," complete Schedule G, Part II*	**18**		X
19	Did the organization report more than $15,000 of gross income from gaming activities on Part VIII, line 9a? *If "Yes," complete Schedule G, Part III*	**19**		X
20a	Did the organization operate one or more hospital facilities? *If "Yes," complete Schedule H*	**20a**		X
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**	X	

Part IV Checklist of Required Schedules *(continued)*

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

Part V Statements Regarding Other IRS Filings and Tax 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 on line 1a. Enter -0- if not applicable	1b	0		
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c			

Part V **Statements Regarding Other IRS Filings and Tax Compliance** *(continued)*

			Yes	No
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return **2a** **1**			
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	**2b**	X	
3a	Did the organization have unrelated business gross income of $1,000 or more during the year?	**3a**		X
b	If "Yes," has it filed a Form 990-T for this year? *If "No" to line 3b, provide an explanation on Schedule O*	**3b**		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?	**4a**		X
b	If "Yes," enter the name of the foreign country See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).			
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	**5a**		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	**5b**		X
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	**5c**		
6a	Does the organization have annual gross receipts that are normally greater than $100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?	**6a**		X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	**6b**		
7	**Organizations that may receive deductible contributions under section 170(c).**			
a	Did the organization receive a payment in excess of $75 made partly as a contribution and partly for goods and services provided to the payor?	**7a**		X
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**		X
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**		X
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	**7f**		X
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	**7g**		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	**7h**		
8	**Sponsoring organizations maintaining donor advised funds.** Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?	**8**		
9	**Sponsoring organizations maintaining donor advised funds.**			
a	Did the sponsoring organization make any taxable distributions under section 4966?	**9a**		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	**9b**		
10	**Section 501(c)(7) organizations.** Enter:			
a	Initiation fees and capital contributions included on Part VIII, line 12 **10a**			
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities **10b**			
11	**Section 501(c)(12) organizations.** Enter:			
a	Gross income from members or shareholders **11a**			
b	Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.) **11b**			
12a	**Section 4947(a)(1) non-exempt charitable trusts.** Is the organization filing Form 990 in lieu of Form 1041?	**12a**		
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year **12b**			
13	**Section 501(c)(29) qualified nonprofit health insurance issuers.**			
a	Is the organization licensed to issue qualified health plans in more than one state? **Note:** See the instructions for additional information the organization must report on Schedule O.	**13a**		
b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans **13b**			
c	Enter the amount of reserves on hand **13c**			
14a	Did the organization receive any payments for indoor tanning services during the tax year?	**14a**		X
b	If "Yes," has it filed a Form 720 to report these payments? *If "No," provide an explanation on Schedule O*	**14b**		
15	Is the organization subject to the section 4960 tax on payment(s) of more than $1,000,000 in remuneration or excess parachute payment(s) during the year? If "Yes," see instructions and file Form 4720, Schedule N.	**15**		X
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.	**16**		X
17	**Section 501(c)(21) organizations.** Did the trust, any disqualified or other person engage in any activities that would result in the imposition of an excise tax under section 4951, 4952 or 4953? If "Yes," complete Form 6069.	**17**		

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

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

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

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

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

Section C. Disclosure

17 List the states with which a copy of this Form 990 is required to be filed **AR,CA,CO,CT,DC,FL,GA,IL,KS,LA,MD,MA,MI**

18 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.

[X] Own website [X] Another's website [X] Upon request [ ] Other *(explain on Schedule O)*

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

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

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, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than $100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than $100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than $10,000 of reportable compensation from the organization and any related organizations.

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

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/ 1099-MISC/ 1099-NEC)	(E) Reportable compensation from related organizations (W-2/ 1099-MISC/ 1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) **Janice N. Schwartz**	40.00									
Executive Director	0.00	X		X				0	0	0
(2) **Jack Padovano**	4.00									
Chair	0.00	X		X				0	0	0
(3) **Jason Hunter, CPA**	0.50									
Treasurer	0.00	X		X				0	0	0
(4) **Barbara Feinstein**	0.00									
Secretary	0.00	X		X				0	0	0
(5) **Kay Dee Holmes**	0.50									
Secretary	0.00	X		X				0	0	0
(6) **C. David Hansen, MD**	8.00									
Board Member	0.00	X						0	0	0
(7) **James Rittle**	0.50									
Board Member	0.00	X						0	0	0
(8) **Aaron Klein**	0.50									
Board Member	0.00	X						0	0	0
(9)										
(10)										
(11)										

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/ 1099-MISC/ 1099-NEC)	(E) Reportable compensation from related organizations (W-2/ 1099-MISC/ 1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
1b Subtotal										
c Total from continuation sheets to Part VII, Section A										
d Total (add lines 1b and 1c)										

2 Total number of individuals (including but not limited to those listed above) who received more than $100,000 of reportable compensation from the organization **0**

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

Section B. Independent Contractors

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

(A) Name and business address	(B) Description of services	(C) Compensation

2 Total number of independent contractors (including but not limited to those listed above) who received more than $100,000 of compensation from the organization **0**

Part VIII **Statement of 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	567,482				
	g Noncash contributions included in lines 1a-1f	1g	$				
	h **Total.** Add lines 1a–1f			567,482			
Program Service Revenue			Business Code				
	2a						
	b						
	c						
	d						
	e						
	f All other program service revenue						
	g **Total.** Add lines 2a–2f						
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)			86,721			86,721
	4 Income from investment of tax-exempt bond proceeds						
	5 Royalties						
			(i) Real	(ii) Personal			
	6a Gross rents	6a					
	b Less: rental expenses	6b					
	c Rental inc. or (loss)	6c					
	d Net rental income or (loss)						
			(i) Securities	(ii) Other			
	7a Gross amount from sales of assets other than inventory	7a	794,327				
	b Less: cost or other basis and sales exps.	7b	793,918				
	c Gain or (loss)	7c	409				
	d Net gain or (loss)			409			409
	8a Gross income from fundraising events (not including $ ____ of contributions reported on line 1c). See Part IV, line 18	8a					
	b Less: direct expenses	8b					
	c Net income or (loss) from fundraising events						
	9a Gross income from gaming activities. See Part IV, line 19	9a					
	b Less: direct expenses	9b					
	c Net income or (loss) from gaming activities						
	10a Gross sales of inventory, less returns and allowances	10a					
	b Less: cost of goods sold	10b					
	c Net income or (loss) from sales of inventory						
Miscellaneous Revenue			Business Code				
	11a Other		900099	207	207		
	b						
	c						
	d All other revenue						
	e **Total.** Add lines 11a–11d			207			
	12 **Total revenue.** See instructions			654,819	207	0	87,130

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 X

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	25,000	25,000		
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, lines 15 and 16	100,776	100,776		
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	74,410	72,375	153	1,882
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits				
10 Payroll taxes	5,682	5,526	12	144
11 Fees for services (nonemployees):				
a Management				
b Legal				
c Accounting	6,250		6,250	
d Lobbying				
e Professional fundraising services. See Part IV, line 17	840			840
f Investment management fees	17,506		17,506	
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O.)	64,235	57,489	6,739	7
12 Advertising and promotion				
13 Office expenses	11,447	6,261	966	4,220
14 Information technology	23,622	22,880	568	174
15 Royalties				
16 Occupancy	5,983	3,290	1,257	1,436
17 Travel	16,660	16,660		
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	5,250	5,250		
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	960	934	2	24
23 Insurance	1,976		1,976	
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a License and dues	9,260	580	60	8,620
b Catering	7,681	7,481	200	
c Bank and merchant fees	1,895	109	70	1,716
d				
e All other expenses				
25 **Total functional expenses.** Add lines 1 through 24e	379,433	324,611	35,759	19,063
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 X ☐

				(A) Beginning of year		(B) End of year
Assets	1	Cash—non-interest-bearing		258,128	1	556,088
	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 any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons			5	
	6	Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)			6	
	7	Notes and loans receivable, net			7	
	8	Inventories for sale or use			8	
	9	Prepaid expenses and deferred charges		2,965	9	28,150
	10a	Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 21,259			
	b	Less: accumulated depreciation	10b 17,746	2,689	10c	3,513
	11	Investments—publicly traded securities		2,893,886	11	2,453,587
	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	15,839
	16	**Total assets.** Add lines 1 through 15 (must equal line 33)		3,157,668	16	3,057,177
Liabilities	17	Accounts payable and accrued expenses		2,485	17	18,920
	18	Grants payable			18	100,776
	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 any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons			22	
	23	Secured mortgages and notes payable to unrelated third parties			23	
	24	Unsecured notes and loans payable to unrelated third parties			24	
	25	Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D			25	16,702
	26	**Total liabilities.** Add lines 17 through 25		2,485	26	136,398
Net Assets or Fund Balances		**Organizations that follow FASB ASC 958, check here ☒ and complete lines 27, 28, 32, and 33.**				
	27	Net assets without donor restrictions		3,155,183	27	2,920,779
	28	Net assets with donor restrictions			28	
		Organizations that do not follow FASB ASC 958, check he ☐ and complete lines 29 through 33.				
	29	Capital stock or trust principal, or current funds			29	
	30	Paid-in or capital surplus, or land, building, or equipment fund			30	
	31	Retained earnings, endowment, accumulated income, or other funds			31	
	32	Total net assets or fund balances		3,155,183	32	2,920,779
	33	Total liabilities and net assets/fund balances		3,157,668	33	3,057,177

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	654,819
2	Total expenses (must equal Part IX, column (A), line 25)	2	379,433
3	Revenue less expenses. Subtract line 2 from line 1	3	275,386
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	3,155,183
5	Net unrealized gains (losses) on investments	5	-509,790
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	2,920,779

Part XII Financial Statements and Reporting

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

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

SCHEDULE A (Form 990)

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.

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

OMB No. 1545-0047

2022

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).)
3 ☐ A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**
4 ☐ A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state:
5 ☐ An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv).** (Complete Part II.)
6 ☐ A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**
7 ☒ An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi).** (Complete Part II.)
8 ☐ A community trust described in **section 170(b)(1)(A)(vi).** (Complete Part II.)
9 ☐ An agricultural research organization described in **section 170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university:
10 ☐ An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions, subject to certain exceptions; and (2) no more than 331/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2).** (Complete Part III.)
11 ☐ An organization organized and operated exclusively to test for public safety. See **section 509(a)(4).**
12 ☐ An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2).** See **section 509(a)(3).** Check the box on lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.

a ☐ **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
b ☐ **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
c ☐ **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
d ☐ **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
e ☐ Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
f Enter the number of supported organizations
g Provide the following information about the supported organization(s).

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

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

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	800,723	419,420	557,174	512,628	567,482	2,857,427
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	800,723	419,420	557,174	512,628	567,482	2,857,427
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)						1,943,108
6 **Public support.** Subtract line 5 from line 4.						914,319

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
7 Amounts from line 4	800,723	419,420	557,174	512,628	567,482	2,857,427
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	39,054	44,883	71,463	98,363	86,721	340,484
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)			218	18		236
11 **Total support.** Add lines 7 through 10						3,198,147
12 Gross receipts from related activities, etc. (see instructions)					12	7,241

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

Section C. Computation of Public Support Percentage

14	Public support percentage for 2022 (line 6, column (f) divided by line 11, column (f))	14	28.59 %
15	Public support percentage from 2021 Schedule A, Part II, line 14	15	28.98 %

16a **33 1/3% support test—2022.** 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—2021.** 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—2022.** 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—2021.** 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) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(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) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 **Total support.** (Add lines 9, 10c, 11, and 12.)						

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

Section C. Computation of Public Support Percentage

15 Public support percentage for 2022 (line 8, column (f), divided by line 13, column (f))	**15**	%
16 Public support percentage from 2021 Schedule A, Part III, line 15	**16**	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for **2022** (line 10c, column (f), divided by line 13, column (f))	**17**	%
18 Investment income percentage from **2021** Schedule A, Part III, line 17	**18**	%

19a **33 1/3% support tests—2022.** 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—2021.** If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization ☐

20 **Private foundation.** If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions ☐

Part IV Supporting Organizations

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

Section A. All Supporting Organizations

			Yes	No
1	Are all of the organization's supported organizations listed by name in the organization's governing documents? *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 lines 3b and 3c below.*	**3a**		
b	Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? *If "Yes," describe in Part VI when and how the organization made the determination.*	**3b**		
c	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? *If "Yes," explain in Part VI what controls the organization put in place to ensure such use.*	**3c**		
4a	Was any supported organization not organized in the United States ("foreign supported organization")? *If "Yes," and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.*	**4a**		
b	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? *If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.*	**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 lines 5b and 5c below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).*	**5a**		
b	**Type I or Type II only.** Was any added or substituted supported organization part of a class already designated in the organization's organizing document?	**5b**		
c	**Substitutions only.** Was the substitution the result of an event beyond the organization's control?	**5c**		
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 (as defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? *If "Yes," complete Part I of Schedule L (Form 990).*	**7**		
8	Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? *If "Yes," complete Part I of Schedule L (Form 990).*	**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 on 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 on 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 on lines 11b and 11c below, the governing body of a supported organization?	**11a**		
b	A family member of a person described on line 11a above?	**11b**		
c	A 35% controlled entity of a person described on line 11a or 11b above? *If "Yes" to line 11a, 11b, or 11c, provide detail in Part VI.*	**11c**		

Section B. Type I Supporting Organizations

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

Section C. Type II Supporting Organizations

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

Section D. All Type III Supporting Organizations

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

Section E. Type III Functionally Integrated Supporting Organizations

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

- **a** ☐ The organization satisfied the Activities Test. *Complete line 2 below.*
- **b** ☐ The organization is the parent of each of its supported organizations. *Complete line 3 below.*
- **c** ☐ The organization supported a governmental entity. *Describe in Part VI how you supported a governmental entity (see instructions).*

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

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

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

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

Section B – Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):			
a Average monthly value of securities	**1a**		
b Average monthly cash balances	**1b**		
c Fair market value of other non-exempt-use assets	**1c**		
d **Total** (add lines 1a, 1b, and 1c)	**1d**		
e **Discount** claimed for blockage or other factors *(explain in detail in Part VI)*:			
2 Acquisition indebtedness applicable to non-exempt-use assets	**2**		
3 Subtract line 2 from line 1d.	**3**		
4 Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).	**4**		
5 Net value of non-exempt-use assets (subtract line 4 from line 3)	**5**		
6 Multiply line 5 by 0.035.	**6**		
7 Recoveries of prior-year distributions	**7**		
8 **Minimum Asset Amount** (add line 7 to line 6)	**8**		

Section C – Distributable Amount			Current Year
1 Adjusted net income for prior year (from Section A, line 8, column A)	**1**		
2 Enter 0.85 of line 1.	**2**		
3 Minimum asset amount for prior year (from Section B, line 8, column A)	**3**		
4 Enter greater of line 2 or line 3.	**4**		
5 Income tax imposed in prior year	**5**		
6 **Distributable Amount.** Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	**6**		

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

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

Section D – Distributions			Current Year
1	Amounts paid to supported organizations to accomplish exempt purposes	1	
2	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2	
3	Administrative expenses paid to accomplish exempt purposes of supported organizations	3	
4	Amounts paid to acquire exempt-use assets	4	
5	Qualified set-aside amounts (prior IRS approval required—*provide details in Part VI*)	5	
6	Other distributions (*describe in Part VI*). See instructions.	6	
7	**Total annual distributions.** Add lines 1 through 6.	7	
8	Distributions to attentive supported organizations to which the organization is responsive (*provide details in Part VI*). See instructions.	8	
9	Distributable amount for 2022 from Section C, line 6	9	
10	Line 8 amount divided by line 9 amount	10	

Section E – Distribution Allocations (see instructions)		(i) Excess Distributions	(ii) Underdistributions Pre-2022	(iii) Distributable Amount for 2022
1	Distributable amount for 2022 from Section C, line 6			
2	Underdistributions, if any, for years prior to 2022 (reasonable cause required–*explain in Part VI*). See instructions.			
3	Excess distributions carryover, if any, to 2022			
a	From 2017			
b	From 2018			
c	From 2019			
d	From 2020			
e	From 2021			
f	**Total** of lines 3a through 3e			
g	Applied to underdistributions of prior years			
h	Applied to 2022 distributable amount			
i	Carryover from 2017 not applied (see instructions)			
j	Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4	Distributions for 2022 from Section D, line 7: $			
a	Applied to underdistributions of prior years			
b	Applied to 2022 distributable amount			
c	Remainder. Subtract lines 4a and 4b from line 4.			
5	Remaining underdistributions for years prior to 2022, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, *explain in Part VI.* See instructions.			
6	Remaining underdistributions for 2022. Subtract lines 3h and 4b from line 1. For result greater than zero, *explain in Part VI.* See instructions.			
7	**Excess distributions carryover to 2023.** Add lines 3j and 4c.			
8	Breakdown of line 7:			
a	Excess from 2018			
b	Excess from 2019			
c	Excess from 2020			
d	Excess from 2021			
e	Excess from 2022			

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.)

Part II, Line 10 - Other Income Detail

Other Income	**$ 236**

Part II, Line 17a - 10% Facts and Circumstance Test - 2022

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 28.59% of its support from public sources from

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.)

2017 to 2022.

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 technologies and 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

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.)

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 2022, the Organization's board members and volunteers have contributed to over 120

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.)

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:

Boston, MA (2019)

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

Niagara Falls, Ontario (2005)

Park City, UT (2007)

Pitlochry, Scotland (2008)

Edinburgh, Scotland (2010, 2012, 2014, 2016)

Paris, France (2010, 2012, 2014)

Philadelphia, PA (2011)

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.)

Santa Cruz, CA (2013)

Newark, NJ (2015)

London, England (2018) (Co-sponsored by PC Project Europe)

Boston, MA (2019)

Virtually (2020, 2021, 2022)

Amsterdam, The Netherlands (2022)

New Orleans, LA (2023)

Approximately 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 members 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 (IPCRR) has Received Institutional Review Board Approval through the WCG Institutional Review Board (Study #20040468/1057496). IRB approval has been renewed each year. This is the only active registry for PC patients in the world. There are nearly 2,600 patients in contact with PC Project from over 60 countries.

1.170A-9(E)(3)(VII) Additional factors pertinent to membership.

The Organization is not a membership Organization.

Schedule B (Form 990)

Department of the Treasury
Internal Revenue Service

Schedule of Contributors

Attach to Form 990 or Form 990-PF.
Go to *www.irs.gov/Form990* for the latest information.

OMB No. 1545-0047

2022

Name of the organization

Pachyonychia Congenita Fund

Employer identification number

68-0567493

Organization type (check one):

Filers of:	Section:
Form 990 or 990-EZ	☒ 501(c)(**3**) (enter number) organization
	☐ 4947(a)(1) nonexempt charitable trust **not** treated as a private foundation
	☐ 527 political organization
Form 990-PF	☐ 501(c)(3) exempt private foundation
	☐ 4947(a)(1) nonexempt charitable trust treated as a private foundation
	☐ 501(c)(3) taxable private foundation

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

General Rule

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

Special Rules

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

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

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

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

Name of organization
Pachyonychia Congenita Fund

Employer identification number
68-0567493

Part I **Contributors** (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1		$ 200,000	Person [X] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
2		$ 145,930	Person [X] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
3		$ 6,200	Person [X] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
4		$ 60,000	Person [X] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
5		$ 10,000	Person [X] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
6		$ 30,000	Person [X] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)

Name of organization
Pachyonychia Congenita Fund

Employer identification number
68-0567493

Part I **Contributors** (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
7		$ 25,000	Person [X] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		$	Person [ ] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		$	Person [ ] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		$	Person [ ] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		$	Person [ ] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		$	Person [ ] Payroll [ ] Noncash [ ] (Complete Part II for noncash contributions.)

SCHEDULE C (Form 990)

Department of the Treasury
Internal Revenue Service

Political Campaign and Lobbying Activities

For Organizations Exempt From Income Tax Under section 501(c) and section 527

Complete if the organization is described below. Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

2022

Open to Public Inspection

If the organization answered "Yes," on Form 990, Part IV, line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then

- Section 501(c)(3) organizations: Complete Parts I-A and B. Do not complete Part I-C.
- Section 501(c) (other than section 501(c)(3)) organizations: Complete Parts I-A and C below. Do not complete Part I-B.
- Section 527 organizations: Complete Part I-A only.

If the organization answered "Yes," on Form 990, Part IV, line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then

- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)): Complete Part II-A. Do not complete Part II-B.
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)): Complete Part II-B. Do not complete Part II-A.

If the organization answered "Yes," on Form 990, Part IV, line 5 (Proxy Tax) (See separate instructions) or Form 990-EZ, Part V, line 35c (Proxy Tax) (See separate instructions), then

- Section 501(c)(4), (5), or (6) organizations: Complete Part III.

Name of organization	Employer identification number
Pachyonychia Congenita Fund	68-0567493

Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

1 Provide a description of the organization's direct and indirect political campaign activities in Part IV. See instructions for definition of "political campaign activities."

2 Political campaign activity expenditures. See instructions ..... $

3 Volunteer hours for political campaign activities. See instructions .....

Part I-B Complete if the organization is exempt under section 501(c)(3).

1 Enter the amount of any excise tax incurred by the organization under section 4955 ..... $

2 Enter the amount of any excise tax incurred by organization managers under section 4955 ..... $

3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? ..... ☐ Yes ☐ No

4a Was a correction made? ..... ☐ Yes ☐ No

b If "Yes," describe in Part IV.

Part I-C Complete if the organization is exempt under section 501(c), except section 501(c)(3).

1 Enter the amount directly expended by the filing organization for section 527 exempt function activities ..... $

2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities ..... $

3 Total exempt function expenditures. Add lines 1 and 2. Enter here and on Form 1120-POL, line 17b ..... $

4 Did the filing organization file **Form 1120-POL** for this year? ..... ☐ Yes ☐ No

5 Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to which the filing organization made payments. For each organization listed, enter the amount paid from the filing organization's funds. Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC). If additional space is needed, provide information in Part IV.

	(a) Name	**(b)** Address	**(c)** EIN	**(d)** Amount paid from filing organization's funds. If none, enter -0-.	**(e)** Amount of political contributions received and promptly and directly delivered to a separate political organization. If none, enter -0-.
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					

Part II-A **Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).**

A Check ☐ if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures).

B Check ☐ if the filing organization checked box A and "limited control" provisions apply.

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)	**(a)** Filing organization's totals	**(b)** Affiliated group totals
1a Total lobbying expenditures to influence public opinion (grassroots lobbying)		
b Total lobbying expenditures to influence a legislative body (direct lobbying)		
c Total lobbying expenditures (add lines 1a and 1b)		
d Other exempt purpose expenditures		
e Total exempt purpose expenditures (add lines 1c and 1d)		
f Lobbying nontaxable amount. Enter the amount from the following table in both columns.		
g Grassroots nontaxable amount (enter 25% of line 1f)		
h Subtract line 1g from line 1a. If zero or less, enter -0-		
i Subtract line 1f from line 1c. If zero or less, enter -0-		

If the amount on line 1e, column (a) or (b) is:	**The lobbying nontaxable amount is:**
Not over $500,000	20% of the amount on line 1e.
Over $500,000 but not over $1,000,000	$100,000 plus 15% of the excess over $500,000.
Over $1,000,000 but not over $1,500,000	$175,000 plus 10% of the excess over $1,000,000.
Over $1,500,000 but not over $17,000,000	$225,000 plus 5% of the excess over $1,500,000.
Over $17,000,000	$1,000,000.

j If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year? ☐ **Yes** ☐ **No**

4-Year Averaging Period Under Section 501(h)

(Some organizations that made a section 501(h) election do not have to complete all of the five columns below. See the separate instructions for lines 2a through 2f.)

Lobbying Expenditures During 4-Year Averaging Period

Calendar year (or fiscal year beginning in)	**(a)** 2019	**(b)** 2020	**(c)** 2021	**(d)** 2022	**(e)** Total
2a Lobbying nontaxable amount					
b Lobbying ceiling amount (150% of line 2a, column (e))					
c Total lobbying expenditures					
d Grassroots nontaxable amount					
e Grassroots ceiling amount (150% of line 2d, column (e))					
f Grassroots lobbying expenditures					

Part II-B Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

For each "Yes," response on lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.	(a) Yes	(a) No	(b) Amount
1 During the year, did the filing organization attempt to influence foreign, national, state, or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:			
a Volunteers?		X	
b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?		X	
c Media advertisements?		X	
d Mailings to members, legislators, or the public?		X	
e Publications, or published or broadcast statements?		X	
f Grants to other organizations for lobbying purposes?		X	
g Direct contact with legislators, their staffs, government officials, or a legislative body?		X	
h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?		X	
i Other activities?		X	
j Total. Add lines 1c through 1i			
2a Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?		X	
b If "Yes," enter the amount of any tax incurred under section 4912			
c If "Yes," enter the amount of any tax incurred by organization managers under section 4912			
d If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

Part III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

		Yes	No
1 Were substantially all (90% or more) dues received nondeductible by members?	**1**		
2 Did the organization make only in-house lobbying expenditures of $2,000 or less?	**2**		
3 Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year?	**3**		

Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes."

1 Dues, assessments and similar amounts from members	**1**	
2 Section 162(e) nondeductible lobbying and political expenditures **(do not include amounts of political expenses for which the section 527(f) tax was paid).**		
a Current year	**2a**	
b Carryover from last year	**2b**	
c Total	**2c**	
3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues	**3**	
4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year?	**4**	
5 Taxable amount of lobbying and political expenditures. See instructions	**5**	

Part IV Supplemental Information

Provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A (affiliated group list); Part II-A, lines 1 and 2 (See instructions); and Part II-B, line 1. Also, complete this part for any additional information.

Part IV **Supplemental Information** *(continued)*

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

OMB No. 1545-0047

2022

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 (for example, recreation or education)
- ☐ Preservation of a historically important land area
- ☐ Protection of natural habitat
- ☐ Preservation of a certified historic structure
- ☐ Preservation of open space

2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.

			Held at the End of the Tax Year
a	Total number of conservation easements	2a	
b	Total acreage restricted by conservation easements	2b	
c	Number of conservation easements on a certified historic structure included in (a)	2c	
d	Number of conservation easements included in (c) acquired after July 25, 2006, and not on a historic structure listed in the National Register	2d	

3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year

4 Number of states where property subject to conservation easement is located

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? ☐ Yes ☐ No

6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing 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 FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide in Part XIII the text of the footnote to its financial statements that describes these items.

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

(i) Revenue included on Form 990, Part VIII, line 1 $

(ii) Assets included in Form 990, Part X $

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items:

a Revenue included on Form 990, Part VIII, line 1 $

b Assets included in Form 990, Part X $

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

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

- **a** ☐ Public exhibition
- **b** ☐ Scholarly research
- **c** ☐ Preservation for future generations
- **d** ☐ Loan or exchange program
- **e** ☐ Other

4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.

5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? ☐ **Yes** ☐ **No**

Part IV Escrow and Custodial Arrangements.

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

1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? ☐ **Yes** ☐ **No**

b If "Yes," explain the arrangement in Part XIII and complete the following table:

		Amount
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 on Part XIII ☐

Part V Endowment Funds.

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance					
b Contributions					
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					

2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:

- **a** Board designated or quasi-endowment ____ %
- **b** Permanent endowment ____ %
- **c** Term endowment ____ %

The percentages on lines 2a, 2b, and 2c should equal 100%.

3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:

		Yes	No
(i) Unrelated organizations	**3a(i)**		
(ii) Related organizations	**3a(ii)**		
b If "Yes" on line 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		**21,259**	**17,746**	**3,513**
e Other				
Total. Add lines 1a through 1e. *(Column (d) must equal Form 990, Part X, column (B), line 10c.)*				**3,513**

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) **Lease liability**	**16,702**
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. *(Column (b) must equal Form 990, Part X, col. (B) line 25.)*	**16,702**

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

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	367,123
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:				
a	Net unrealized gains (losses) on investments	2a	-509,790		
b	Donated services and use of facilities	2b	239,600		
c	Recoveries of prior year grants	2c			
d	Other (Describe in Part XIII.)	2d			
e	Add lines **2a** through **2d**			2e	-270,190
3	Subtract line **2e** from line **1**			3	637,313
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	17,506		
b	Other (Describe in Part XIII.)	4b			
c	Add lines **4a** and **4b**			4c	17,506
5	Total revenue. Add lines **3** and **4c.** *(This must equal Form 990, Part I, line 12.)*			5	654,819

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	601,527
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:				
a	Donated services and use of facilities	2a	239,600		
b	Prior year adjustments	2b			
c	Other losses	2c			
d	Other (Describe in Part XIII.)	2d			
e	Add lines **2a** through **2d**			2e	239,600
3	Subtract line **2e** from line **1**			3	361,927
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	17,506		
b	Other (Describe in Part XIII.)	4b			
c	Add lines **4a** and **4b**			4c	17,506
5	Total expenses. Add lines **3** and **4c.** *(This must equal Form 990, Part I, line 18.)*			5	379,433

Part XIII Supplemental Information.

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

Part X - FIN 48 Footnote

The Organization has been recognized by the Internal Revenue Service (IRS) as exempt from federal income taxes under Section 501(c)(3), qualifying for the charitable contribution deduction under section 170(b)(1)(A)(vi), and has been determined not to be a private foundation under Section 509(a). The Organization is annually required to file a Return of Organization Exempt from Income Tax (Form 990) and is subject to income tax on net income that is derived from business activities that are unrelated to their exempt purposes. Management has determined that the Organization is not subject to unrelated business income tax. Management believes that the Organization has appropriate support for any tax positions taken in its annual filing and does not have any uncertain tax

Part XIII Supplemental Information *(continued)*

positions that are material to the financial statements. The Organization's Forms 990 are no longer subject to tax examination for years before 2019.

SCHEDULE F (Form 990)

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.
Attach to Form 990.
Go to *www.irs.gov/Form990* for instructions and the latest information.

OMB No. 1545-0047

2022

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" on Form 990, Part IV, line 14b.

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

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

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

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
Europe (1)			Grantmaking		100,776
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
3a Subtotal					100,776
b Total from continuation sheets to Part I . .					
c **Totals** (add lines 3a and 3b)					100,776

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

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
(1)			Europe	PC research	100,776	Wire transfer			
(2)									
(3)									
(4)									
(5)									
(6)									
(7)									
(8)									
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									

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

3 Enter total number of other organizations or entities . . . . . u 1

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

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

Part IV Foreign Forms

1	Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see 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; don't file with Form 990)*	☐ **Yes**	☒ **No**
3	Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Corporations (see Instructions for Form 5471)*	☐ **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; don't file with Form 990)*	☐ **Yes**	☒ **No**

Part V **Supplemental Information**

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

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

The use of grant funds are overseen by members of our International Pachyonychia Congenita Consortium (IPCC) and Medical and Scientific Advisory Board (MSAB). We receive regular updates from the awardees/researchers about the progress of the grant project. The end product of a grant is normally a publication, presentation at our annual IPCC symposium, and/or a scientific poster with results of the grant project--all is shared with PC Project.

Part I, Line 3 - Activities per Region

Region	Expenditures	Investments
Europe	$ 100,776	$ 0

SCHEDULE I (Form 990)

Department of the Treasury
Internal Revenue Service

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

Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.

Attach to Form 990.

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

OMB No. 1545-0047

2022

Open to Public Inspection

Name of the organization

Pachyonychia Congenita Fund

Employer identification number

68-0567493

Part I General Information on Grants and Assistance

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

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

Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments.

Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than $5,000. Part II can be duplicated if additional space is needed.

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1) Anyi Therapeutics, Inc. 2161 Delaware Avenue Ste A2 Santa Cruz CA 95060	83-3508993		25,000				PC research
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							

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

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

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

	(a) Type of grant or assistance	**(b)** Number of recipients	**(c)** Amount of cash grant	**(d)** Amount of noncash assistance	**(e)** Method of valuation (book, FMV, appraisal, other)	**(f)** Description of noncash assistance
1						
2						
3						
4						
5						
6						
7						

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

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

The use of grant funds are overseen by members of our International Pachyonychia Congenita Consortium (IPCC) and Medical and Scientific Advisory Board (MSAB). We receive regular updates from the awardees/researchers about the progress of the grant project. The end product of a grant is normally a publication, presentation at our annual IPCC symposium, and/or a scientific poster with results of the grant project--all is shared with PC Project

SCHEDULE O (Form 990)	Supplemental Information to Form 990 or 990-EZ	OMB No. 1545-0047
Department of the Treasury Internal Revenue Service	Complete to provide information for responses to specific questions on Form 990 or 990-EZ or to provide any additional information. Attach to Form 990 or Form 990-EZ. Go to *www.irs.gov/Form990* for the latest information.	2022 Open to Public Inspection

Name of the organization	Employer identification number
Pachyonychia Congenita Fund	68-0567493

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

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.

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

The organization has a formal conflict of interest policy. This policy requires annual written disclosure of potential conflicts of interest by all board members and management. Conflict 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 voting on topics related to the conflict.

Form 990, Part VI, Line 17 - Other States Where Copy of Return is Filed

Minnesota, Missouri, New Jersey, New Mexico, New York, North Carolina, Ohio, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, Utah, Virginia, Washington, West Virginia, Wisconsin

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

The organization's governing documents, conflict of interest policy, and financial statements are available to the public upon written request.

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

Description	Tot/Prog Service	Mgt & General	Fundraising

Name of the organization: Pachyonychia Congenita Fund

Employer identification number: 68-0567493

Clerican and administrative			
$ 7,574	$ 6,739	$ 0	
Genetic Testing			
$ 40,600	$ 0	$ 0	
Research writing			
$ 8,000	$ 0	$ 0	
Other			
$ 1,315	$ 0	$ 7	
Total			
$ 57,489	$ 6,739	$ 7	

Federal Statements

Taxable Interest on Investments

Description	Amount	Unrelated Business	Exclusion Code	Postal Code	Acquired after 6/30/75	US Obs ($ or %)
Interest and dividends	$ 132		14			
Total	$ 132					

Taxable Dividends from Securities

Description	Amount	Unrelated Business	Exclusion Code	Postal Code	Acquired after 6/30/75	US Obs ($ or %)
Interest and Dividends	$ 86,589		14			
Total	$ 86,589					

Federal Statements

Form 990, Part IX, Line 11g - Other Fees for Service (Non-employee)

Description	Total Expenses	Program Service	Management & General	Fund Raising
Clerican and administrative	$ 14,313	$ 7,574	$ 6,739	$
Genetic Testing	40,600	40,600		
Research writing	8,000	8,000		
Other	1,322	1,315		7
Total	$ 64,235	$ 57,489	$ 6,739	$ 7

Federal Statements

Schedule A, Part II, Line 12 - Current year

Description	Amount
Other	$ 207
Total	$ 207