

990

Return of Organization Exempt From Income Tax

OMB No. 1545-

0047 2021

Open to Public Inspection

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

Department of the Treasury Internal Revenue Service

A For the 2021 calendar year, or tax year beginning 01-01-2021, and ending 12-31-2021

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

C Name of organization: Progressive Familial Intrahepatic Cholestasis. Doing business as: contd Advocacy and Resource Ne. Number and street (or P.O. box if mail is not delivered to street address): PO Box 551. Room/suite: . City or town, state or province, country, and ZIP or foreign postal code: Stanton, KY 40380

D Employer identification number: 83-1084501. E Telephone number: . G Gross receipts \$ 814,932

F Name and address of principal officer: Emily Ventura

H(a) Is this a group return for subordinates? Yes No. H(b) Are all subordinates included? Yes No. H(c) Group exemption number

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

J Website: www.pfic.org

K Form of organization: Corporation, Trust, Association, Other

L Year of formation: 2018. M State of legal domicile: KY

Part I Summary

Table with 3 main sections: Activities & Governance (lines 1-7b), Revenue (lines 8-12), Expenses (lines 13-19), and Net Assets or Fund Balances (lines 20-22). Includes columns for Prior Year and Current Year.

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.

Sign Here. Signature of officer: Emily Ventura Co-Founder Exe. Date: 2022-06-07

Paid Preparer Use Only. Print/Type preparer's name: Mullins PC. Preparer's signature. Date: 2022-06-07. Firm's name: Mullins PC. Firm's address: 7625 Wisconsin Avenue, Bethesda, MD 20814.

May the IRS discuss this return with the preparer shown above? (see instructions) Yes No

**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:

To improve the lives of patients and families worldwide affected by Progressive Familial Intrahepatic Cholestasis, PFIC.

**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 \$ **164,591** including grants of \$ **10,554**) (Revenue \$ )  
In 2021 the PFIC Network provided program services to meet our mission in the areas of Peer support, Education, Awareness, Outreach, Advocacy and Research. Through our peer support program, we provided financial assistance and care packages to patients and families in need. We hosted opportunities for gatherings and connection through community zoom calls and individual mentorship zoom calls. The education program published an educational brochure which has been translated into 19 languages upon request. We sent these brochures along with a patient information packet to hospitals that care for PFIC patients through our patient and provider outreach program. The PFIC Network hosted a virtual family conference, attended by 109 participants worldwide. New webinars were recorded during this conference and added to our online educational webinar library, available on demand. We also more than doubled our reach on social media, newsletter, through our awareness and outreach programs. Through our advocacy program, the PFIC Network hosted an FDA Listening Session where 5 PFIC caregivers shared their stories with the FDA to better understand the urgent need for treatment development in PFIC. Our research program continues to house and grow the PFIC patient registry, and expanded with the addition of a PFIC research grant program. The grant program allowed us to open up a \$30,000 Funding Opportunity for patient centered research initiatives, in which applications will be accepted through March, 2022.

**4b** (Code: ) (Expenses \$ including grants of \$ ) (Revenue \$ )

**4c** (Code: ) (Expenses \$ including grants of \$ ) (Revenue \$ )

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

**4e** Total program service expenses **164,591**

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Question Text, Yes, No. Rows include questions 1 through 21 regarding organizational requirements, such as political activities, lobbying, and financial reporting.

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

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

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

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

		Yes	No
<b>1a</b>	Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable	<b>1a</b>	9
<b>b</b>	Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable	<b>1b</b>	0
<b>c</b>	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? . . . . .	<b>1c</b>	Yes

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

<p><b>2a</b> 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 . . . . .</p>	<p><b>2a</b> <span style="float: right;">2</span></p>			
<p><b>b</b> If at least one is reported on line 2a, did the organization file all required federal employment tax returns? <b>Note.</b> If the sum of lines 1a and 2a is greater than 250, you may be required to e-file. See instructions.</p>		<p><b>2b</b> Yes</p>		
<p><b>3a</b> Did the organization have unrelated business gross income of \$1,000 or more during the year? . . . . .</p>		<p><b>3a</b></p>	<p>No</p>	
<p><b>b</b> If "Yes," has it filed a Form 990-T for this year? <i>If "No" to line 3b, provide an explanation in Schedule O . . . . .</i></p>		<p><b>3b</b></p>		
<p><b>4a</b> At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?</p>		<p><b>4a</b></p>	<p>No</p>	
<p><b>b</b> <i>Enter the name of the foreign country: _____</i> See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).</p>				
<p><b>5a</b> Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? . . . . .</p>		<p><b>5a</b></p>	<p>No</p>	
<p><b>b</b> Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?</p>		<p><b>5b</b></p>	<p>No</p>	
<p><b>c</b> If "Yes," to line 5a or 5b, did the organization file Form 8886-T? . . . . .</p>		<p><b>5c</b></p>		
<p><b>6a</b> 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? . . . . .</p>		<p><b>6a</b></p>	<p>No</p>	
<p><b>b</b> If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible? . . . . .</p>		<p><b>6b</b></p>		
<p><b>7 Organizations that may receive deductible contributions under section 170(c).</b></p>				
<p><b>a</b> 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? . . . . .</p>		<p><b>7a</b></p>	<p>No</p>	
<p><b>b</b> If "Yes," did the organization notify the donor of the value of the goods or services provided? . . . . .</p>		<p><b>7b</b></p>		
<p><b>c</b> Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282? . . . . .</p>		<p><b>7c</b></p>	<p>No</p>	
<p><b>d</b> If "Yes," indicate the number of Forms 8282 filed during the year . . . . .</p>	<p><b>7d</b></p>			
<p><b>e</b> Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?</p>		<p><b>7e</b></p>	<p>No</p>	
<p><b>f</b> Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?</p>		<p><b>7f</b></p>	<p>No</p>	
<p><b>g</b> If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required? . . . . .</p>		<p><b>7g</b></p>		
<p><b>h</b> If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C? . . . . .</p>		<p><b>7h</b></p>		
<p><b>8 Sponsoring organizations maintaining donor advised funds.</b> Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?</p>		<p><b>8</b></p>		
<p><b>9 Sponsoring organizations maintaining donor advised funds.</b></p>				
<p><b>a</b> Did the sponsoring organization make any taxable distributions under section 4966?</p>		<p><b>9a</b></p>		
<p><b>b</b> Did the sponsoring organization make a distribution to a donor, donor advisor, or related person? . . . . .</p>		<p><b>9b</b></p>		
<p><b>10 Section 501(c)(7) organizations.</b> Enter:</p>				
<p><b>a</b> Initiation fees and capital contributions included on Part VIII, line 12 . . . . .</p>	<p><b>10a</b></p>			
<p><b>b</b> Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities</p>	<p><b>10b</b></p>			
<p><b>11 Section 501(c)(12) organizations.</b> Enter:</p>				
<p><b>a</b> Gross income from members or shareholders . . . . .</p>	<p><b>11a</b></p>			
<p><b>b</b> Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.)</p>	<p><b>11b</b></p>			
<p><b>12a Section 4947(a)(1) non-exempt charitable trusts.</b> Is the organization filing Form 990 in lieu of Form 1041?</p>				
<p><b>b</b> If "Yes," enter the amount of tax-exempt interest received or accrued during the year.</p>	<p><b>12b</b></p>			
<p><b>13 Section 501(c)(29) qualified nonprofit health insurance issuers.</b></p>				
<p><b>a</b> Is the organization licensed to issue qualified health plans in more than one state? . . . . . <b>Note.</b> See the instructions for additional information the organization must report on Schedule O.</p>		<p><b>13a</b></p>	<p>No</p>	
<p><b>b</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 . . . . .</p>	<p><b>13b</b></p>			
<p><b>c</b> Enter the amount of reserves on hand . . . . .</p>	<p><b>13c</b></p>			
<p><b>14a</b> Did the organization receive any payments for indoor tanning services during the tax year? . . . . .</p>		<p><b>14a</b></p>	<p>No</p>	
<p><b>b</b> If "Yes," has it filed a Form 720 to report these payments? <i>If "No," provide an explanation in Schedule O . . . . .</i></p>		<p><b>14b</b></p>		
<p><b>15</b> 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? . . . . .</p>		<p><b>15</b></p>	<p>No</p>	
<p><b>16</b> If the organization is a trust, did it file Form 720, Schedule E, to report the section 4968 excise tax on net investment income? . . . . . <i>If "Yes," complete Form 4720, Schedule O.</i></p>		<p><b>16</b></p>	<p>No</p>	
<p><b>17 Section 501(c)(21) organizations.</b> Did the trust, any disqualified person, or mine operator engage in any activities that would result in the imposition of an excise tax under section 4951, 4952, or 4953? . . . . . <i>If "Yes," complete Form 6069.</i></p>		<p><b>17</b></p>		

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



Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members... 1b Enter the number of voting members included... 2 Did any officer, director, trustee, or key employee have a family relationship... 3 Did the organization delegate control over management duties... 4 Did the organization make any significant changes to its governing documents... 5 Did the organization become aware during the year of a significant diversion of the organization's assets... 6 Did the organization have members or stockholders... 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? 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? 8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: 8a The governing body? 8b Each committee with authority to act on behalf of the governing body? 9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O.

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

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters, branches, or affiliates? 10b 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? 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? 11b 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 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe on Schedule O how this was done 13 Did the organization have a written whistleblower policy? 14 Did the organization have a written document retention and destruction policy? 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? 15a The organization's CEO, Executive Director, or top management official 15b Other officers or key employees of the organization 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? 16b 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?

Section C. Disclosure

Table with 3 columns: Question, Yes, No. Rows include: 17 List the states with which a copy of this Form 990 is required to be filed CA, CO, CT, FL, GA, HI, IL, KS, KY, MA, MD, MI, NC, NJ, OH, PA, SC, TN, UT, VA, WI, WV 18 Section 6104 requires an organization to make its Form 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply. Own website Another's website Upon request Other (explain in Schedule O) 19 Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year. 20 State the name, address, and telephone number of the person who possesses the organization's books and records: Organization PO Box 551 Stanton, KY 40380 (414) 331-3316





Part VIII Statement of Revenue

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

Table with 5 columns: (A) Total revenue, (B) Related or exempt function revenue, (C) Unrelated business revenue, (D) Revenue excluded from tax under sections 512 - 514. Rows include 1a-f (Contributions, Gifts, Grants, and Other) and 1g (Total).

Table for Program Service Revenue with columns for Business Code and rows 2a-f (All other program service revenue) and 9 (Total).

Main table for Other Revenue with columns for Business Code and rows 3-12 (Investment income, Royalties, Rents, Fundraising events, Gaming activities, Sales of inventory, Miscellaneous Revenue, and Total revenue).

**Part IX Statement of Functional Expenses**

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

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

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

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
<b>1</b> Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	3,000	3,000		
<b>2</b> Grants and other assistance to domestic individuals. See Part IV, line 22	2,554	2,554		
<b>3</b> Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.	5,000	5,000		
<b>4</b> Benefits paid to or for members				
<b>5</b> Compensation of current officers, directors, trustees, and key employees	64,527	35,928	24,822	3,777
<b>6</b> Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
<b>7</b> Other salaries and wages	20,000	17,833	667	1,500
<b>8</b> Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
<b>9</b> Other employee benefits				
<b>10</b> Payroll taxes	6,449	4,100	1,946	403
<b>11</b> Fees for services (non-employees):				
<b>a</b> Management	1,240	400	840	
<b>b</b> Legal	8,870		1,380	7,490
<b>c</b> Accounting	3,133		3,133	
<b>d</b> Lobbying				
<b>e</b> Professional fundraising services. See Part IV, line 17				
<b>f</b> Investment management fees				
<b>g</b> Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)	78,432	59,725	18,229	478
<b>12</b> Advertising and promotion	5,324	4,908		416
<b>13</b> Office expenses	21,349	19,659	1,496	194
<b>14</b> Information technology	6,720	4,765	1,423	532
<b>15</b> Royalties				
<b>16</b> Occupancy				
<b>17</b> Travel	1,084	1,084		
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials				
<b>19</b> Conferences, conventions, and meetings	5,695	5,635	60	
<b>20</b> Interest				
<b>21</b> Payments to affiliates				
<b>22</b> Depreciation, depletion, and amortization				
<b>23</b> Insurance	1,101		1,101	
<b>24</b> Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
<b>a</b> Bad Debt	726		726	
<b>b</b>				
<b>c</b>				
<b>d</b>				
<b>e</b> All other expenses				
<b>25</b> <b>Total functional expenses.</b> Add lines 1 through 24e	235,204	164,591	55,823	14,790
<b>26</b> <b>Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720).				

**Part X Balance Sheet**

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

		(A) Beginning of year		(B) End of year
<b>Assets</b>	<b>1</b> Cash-non-interest-bearing . . . . .	99,035	<b>1</b>	318,319
	<b>2</b> Savings and temporary cash investments		<b>2</b>	
	<b>3</b> Pledges and grants receivable, net . . . . .	26,136	<b>3</b>	400,000
	<b>4</b> Accounts receivable, net . . . . .		<b>4</b>	
	<b>5</b> 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		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		<b>6</b>	
	<b>7</b> Notes and loans receivable, net . . . . .		<b>7</b>	
	<b>8</b> Inventories for sale or use . . . . .		<b>8</b>	
	<b>9</b> Prepaid expenses and deferred charges . . . . .		<b>9</b>	
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D <b>10a</b>			
	<b>b</b> Less: accumulated depreciation <b>10b</b>		<b>10c</b>	
	<b>11</b> Investments—publicly traded securities . . . . .		<b>11</b>	
	<b>12</b> Investments—other securities. See Part IV, line 11 . . . . .		<b>12</b>	
	<b>13</b> Investments—program-related. See Part IV, line 11 . . . . .		<b>13</b>	
	<b>14</b> Intangible assets . . . . .		<b>14</b>	
	<b>15</b> Other assets. See Part IV, line 11		<b>15</b>	21
<b>16 Total assets:</b> Add lines 1 through 15 (must equal line 33) . . . . .	125,171	<b>16</b>	718,340	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses . . . . .	6,234	<b>17</b>	25,852
	<b>18</b> Grants payable . . . . .		<b>18</b>	
	<b>19</b> Deferred revenue . . . . .		<b>19</b>	
	<b>20</b> Tax-exempt bond liabilities . . . . .		<b>20</b>	
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D		<b>21</b>	
	<b>22</b> 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		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties . . . . .		<b>23</b>	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties . . . . .		<b>24</b>	
	<b>25</b> 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		<b>25</b>	
	<b>26 Total liabilities.</b> Add lines 17 through 25 . . . . .	6,234	<b>26</b>	25,852
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.</b>			
	<b>27</b> Net assets without donor restrictions . . . . .	118,937	<b>27</b>	92,488
	<b>28</b> Net assets with donor restrictions		<b>28</b>	600,000
	<b>Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.</b>			
	<b>29</b> Capital stock or trust principal, or current funds . . . . .		<b>29</b>	
	<b>30</b> Paid-in or capital surplus, or land, building or equipment fund . . . . .		<b>30</b>	
	<b>31</b> Retained earnings, endowment, accumulated income, or other funds		<b>31</b>	
	<b>32</b> Total net assets or fund balances	118,937	<b>32</b>	692,488
	<b>33</b> Total liabilities and net assets/fund balances	125,171	<b>33</b>	718,340

**Part XI Reconciliation of Net Assets**

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

<b>1</b>	Total revenue (must equal Part VIII, column (A), line 12)	<b>1</b>	808,755
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25)	<b>2</b>	235,204
<b>3</b>	Revenue less expenses. Subtract line 2 from line 1	<b>3</b>	573,551
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	<b>4</b>	118,937
<b>5</b>	Net unrealized gains (losses) on investments	<b>5</b>	
<b>6</b>	Donated services and use of facilities	<b>6</b>	
<b>7</b>	Investment expenses	<b>7</b>	
<b>8</b>	Prior period adjustments	<b>8</b>	
<b>9</b>	Other changes in net assets or fund balances (explain in Schedule O)	<b>9</b>	0
<b>10</b>	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (A))	<b>10</b>	692,488

**Part XII Financial Statements and Reporting**

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

		Yes	No
<b>1</b>	Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.		
<b>2a</b>	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: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		No
<b>2b</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: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	Yes	
<b>2c</b>	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 in Schedule O.	Yes	
<b>3a</b>	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		No
<b>3b</b>	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits.		

**Additional Data**

**Return to Form**

**Software ID:**

**Software Version:**

**Form 990, Special Condition Description:**

**Special Condition Description**

**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](http://www.irs.gov/Form990) for instructions and the latest information.**

**Name of the organization**  
Progressive Familial Intrahepatic Cholestasis

**Employer identification number**  
83-1084501

**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:

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

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
<b>Total</b>						

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 failed to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Table with 7 columns: (a) 2017, (b) 2018, (c) 2019, (d) 2020, (e) 2021, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Tax revenues levied for the organization's benefit; 3 The value of services or facilities furnished; 4 Total; 5 The portion of total contributions by each person; 6 Public support.

Section B. Total Support

Table with 7 columns: (a) 2017, (b) 2018, (c) 2019, (d) 2020, (e) 2021, (f) Total. Rows include: 7 Amounts from line 4; 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources; 9 Net income from unrelated business activities; 10 Other income; 11 Total support; 12 Gross receipts from related activities; 13 First 5 years.

Section C. Computation of Public Support Percentage

Table with 2 columns: Line number, Description. Rows include: 14 Public support percentage for 2021; 15 Public support percentage for 2020; 16a 33 1/3% support test-2021; b 33 1/3% support test-2020; 17a 10%-facts-and-circumstances test-2021; b 10%-facts-and-circumstances test-2020; 18 Private foundation.

**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) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .						
<b>2</b> 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						
<b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513 . . . . .						
<b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . . .						
<b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge						
<b>6 Total.</b> Add lines 1 through 5						
<b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons						
<b>b</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.						
<b>c</b> Add lines 7a and 7b. .						
<b>8 Public support.</b> (Subtract line 7c from line 6.)						

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
<b>9</b> Amounts from line 6. . . . .						
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources . . . . .						
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975.						
<b>c</b> Add lines 10a and 10b.						
<b>11</b> Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on.						
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . . . .						
<b>13 Total support.</b> (Add lines 9, 10c, 11, and 12.) . . . . .						
<b>14 First 5 years.</b> 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 <b>stop here.</b> . . . . . <input type="checkbox"/>						

**Section C. Computation of Public Support Percentage**

<b>15</b> Public support percentage for 2021 (line 8, column (f) divided by line 13, column (f)) . . . . .	<b>15</b>	
<b>16</b> Public support percentage from 2020 Schedule A, Part III, line 15 . . . . .	<b>16</b>	

**Section D. Computation of Investment Income Percentage**

<b>17</b> Investment income percentage for <b>2021</b> (line 10c, column (f) divided by line 13, column (f)) . . . . .	<b>17</b>	
<b>18</b> Investment income percentage from <b>2020</b> Schedule A, Part III, line 17 . . . . .	<b>18</b>	

**19a 33 1/3% support tests—2021.** 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—2020.** If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization . . . . .

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

Part IV Supporting Organizations

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

Section A. All Supporting Organizations

Table with 3 columns: Question, Yes, No. Rows include questions 1 through 10b regarding supported organizations, including their status, control, and reporting requirements.



**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)

- |   |          |  |  |
|---|----------|--|--|
| <b>1</b> Net short-term capital gain  | <b>1</b> |  |  |
| <b>2</b> Recoveries of prior-year distributions   | <b>2</b> |  |  |
| <b>3</b> Other gross income (see instructions)  | <b>3</b> |  |  |
| <b>4</b> Add lines 1 through 3  | <b>4</b> |  |  |
| <b>5</b> Depreciation and depletion   | <b>5</b> |  |  |
| <b>6</b> 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) | <b>6</b> |  |  |
| <b>7</b> Other expenses (see instructions)  | <b>7</b> |  |  |
| <b>8 Adjusted Net Income</b> (subtract lines 5, 6 and 7 from line 4)  | <b>8</b> |  |  |

**Section B - Minimum Asset Amount**

(A) Prior Year

(B) Current Year  
(optional)

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

**Section C - Distributable Amount**

Current Year

- |  |          |  |
|--|----------|--|
| <b>1</b> Adjusted net income for prior year (from Section A, line 8, Column A)   | <b>1</b> |  |
| <b>2</b> Enter 85% of line 1   | <b>2</b> |  |
| <b>3</b> Minimum asset amount for prior year (from Section B, line 8, Column A)  | <b>3</b> |  |
| <b>4</b> Enter greater of line 2 or line 3   | <b>4</b> |  |
| <b>5</b> Income tax imposed in prior year  | <b>5</b> |  |
| <b>6 Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions) | <b>6</b> |  |

- 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
<b>1</b> Amounts paid to supported organizations to accomplish exempt purposes	<b>1</b>	
<b>2</b> Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	<b>2</b>	
<b>3</b> Administrative expenses paid to accomplish exempt purposes of supported organizations	<b>3</b>	
<b>4</b> Amounts paid to acquire exempt-use assets	<b>4</b>	
<b>5</b> Qualified set-aside amounts (prior IRS approval required - provide details in <b>Part VI</b> )	<b>5</b>	
<b>6</b> Other distributions (describe in <b>Part VI</b> ). See instructions	<b>6</b>	
<b>7 Total annual distributions.</b> Add lines 1 through 6.	<b>7</b>	
<b>8</b> Distributions to attentive supported organizations to which the organization is responsive (provide details in <b>Part VI</b> ). See instructions	<b>8</b>	
<b>9</b> Distributable amount for 2021 from Section C, line 6	<b>9</b>	
<b>10</b> Line 8 amount divided by Line 9 amount	<b>10</b>	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2021	(iii) Distributable Amount for 2021
<b>1</b> Distributable amount for 2021 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2021 (reasonable cause required-- explain in <b>Part VI</b> ). See instructions.			
<b>3</b> Excess distributions carryover, if any, to 2021:			
<b>a</b> From 2016. . . . .			
<b>b</b> From 2017. . . . .			
<b>c</b> From 2018. . . . .			
<b>d</b> From 2019. . . . .			
<b>e</b> From 2020. . . . .			
<b>f Total</b> of lines 3a through e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2021 distributable amount			
<b>i</b> Carryover from 2016 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
<b>4</b> Distributions for 2021 from Section D, line 7: \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2021 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from line 4.			
<b>5</b> Remaining underdistributions for years prior to 2021, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>6</b> Remaining underdistributions for 2021. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>7 Excess distributions carryover to 2022.</b> Add lines 3j and 4c.			
<b>8</b> Breakdown of line 7:			
<b>a</b> Excess from 2017. . . . .			
<b>b</b> Excess from 2018. . . . .			
<b>c</b> Excess from 2019. . . . .			
<b>d</b> Excess from 2020. . . . .			
<b>e</b> Excess from 2021. . . . .			

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

### Facts And Circumstances Test

Return Reference	Explanation

## **Additional Data**

**Return to Form**

**Software ID:**

**Software Version:**

# Supplemental Financial Statements

# 2021

**Open to Public Inspection**

▶ **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](http://www.irs.gov/Form990) for instructions and the latest information.**

Department of the Treasury  
Internal Revenue Service

**Name of the organization**

Progressive Familial Intrahepatic Cholestasis

**Employer identification number**

83-1084501

## **Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.**

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

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year . . . . .		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year)		
4 Aggregate value at end of year . . . . .		

- 5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? . . . . .  Yes  No
- 6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? . . . . .  Yes  No

## **Part II Conservation Easements.**

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

- 1 Purpose(s) of conservation easements held by the organization (check all that apply).  
 Preservation of land for public use (e.g., recreation or education)  Preservation of an historically important land area  
 Protection of natural habitat  Preservation of a certified historic structure  
 Preservation of open space

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

	Held at the End of the Year
a Total number of conservation easements . . . . .	2a
b Total acreage restricted by conservation easements . . . . .	2b
c Number of conservation easements on a certified historic structure included in (a) . . . . .	2c
d Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register . . . . .	2d

- 3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year ▶ \_\_\_\_\_
- 4 Number of states where property subject to conservation easement is located ▶ \_\_\_\_\_
- 5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? . . . . .  Yes  No
- 6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year  
▶ \_\_\_\_\_
- 7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year  
▶ \$ \_\_\_\_\_
- 8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? . . . . .  Yes  No
- 9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.

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

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

- 1a If the organization elected, as permitted under 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 are a significant use of its collection items (check all that apply):
- a**  Public exhibition
  - b**  Scholarly research
  - c**  Preservation for future generations
  - d**  Loan or exchange programs
  - e**  Other .....
- 4** Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5** During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? . . .  **Yes**  **No**

**Part IV Escrow and Custodial Arrangements.**

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

- 1a** Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? . . . . .  **Yes**  **No**
- b** If "Yes," explain the arrangement in Part XIII and complete the following table:
- |  | Amount    |
|--|-----------|
| <b>c</b> Beginning balance . . . . .             | <b>1c</b> |
| <b>d</b> Additions during the year . . . . .     | <b>1d</b> |
| <b>e</b> Distributions during the year . . . . . | <b>1e</b> |
| <b>f</b> Ending balance . . . . .                | <b>1f</b> |
- 2a** Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability?  **Yes**  **No**
- b** If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII . . . .

**Part V Endowment Funds.**

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

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

- 2** Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a** Board designated or quasi-endowment ▶ .....
  - b** Permanent endowment ▶ .....
  - c** Term endowment ▶ .....
- The percentages on lines 2a, 2b, and 2c should equal 100%.

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

- (i)** Unrelated organizations . . . . .
- (ii)** Related organizations . . . . .

	Yes	No
<b>3a(i)</b>		
<b>3a(ii)</b>		
<b>3b</b>		

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

**Part VI Land, Buildings, and Equipment.**

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
<b>1a</b> Land . . . . .				
<b>b</b> Buildings . . . . .				
<b>c</b> Leasehold improvements				
<b>d</b> Equipment . . . . .				
<b>e</b> Other . . . . .				

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

**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)		
<b>Total.</b> (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)		
<b>Total.</b> (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)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col.(B) line 15.)	

**Part X Other Liabilities.**

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

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

**2.** Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII

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

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

<b>1</b>	Total revenue, gains, and other support per audited financial statements . . . . .		<b>1</b>	808,755
<b>2</b>	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
<b>a</b>	Net unrealized gains (losses) on investments . . . . .	<b>2a</b>		
<b>b</b>	Donated services and use of facilities . . . . .	<b>2b</b>		
<b>c</b>	Recoveries of prior year grants . . . . .	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>		
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .		<b>2e</b>	
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .		<b>3</b>	808,755
<b>4</b>	Amounts included on Form 990, Part VIII, line 12, but not on line <b>1</b> :			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .		<b>4c</b>	
<b>5</b>	Total revenue. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 12.) . . . . .		<b>5</b>	808,755

**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.

<b>1</b>	Total expenses and losses per audited financial statements . . . . .		<b>1</b>	235,204
<b>2</b>	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
<b>a</b>	Donated services and use of facilities . . . . .	<b>2a</b>		
<b>b</b>	Prior year adjustments . . . . .	<b>2b</b>		
<b>c</b>	Other losses . . . . .	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>		
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .		<b>2e</b>	
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .		<b>3</b>	235,204
<b>4</b>	Amounts included on Form 990, Part IX, line 25, but not on line <b>1</b> :			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .		<b>4c</b>	
<b>5</b>	Total expenses. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 18.) . . . . .		<b>5</b>	235,204

**Part XIII Supplemental Information**

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

Return Reference	Explanation
Footnote for uncertain tax position under FIN 48 (Part X)	PFIC is exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code. The accounting standard on accounting for uncertainty in income taxes addresses the determination of whether tax benefits claimed or expected to be claimed on a tax return should be recorded in the financial statements. Under that guidance, PFIC may recognize the tax benefit from an uncertain tax position only if it is more likely than not that the tax position will be sustained on examination by taxing authorities based on the technical merits of the position. Examples of tax positions include the tax-exempt status of PFIC and various positions related to the potential sources of unrelated business taxable income (UBIT). The tax benefits recognized in the financial statements from such a position are measured based on the largest benefit that has a greater than 50% likelihood of being realized upon ultimate settlement. There were no unrecognized tax benefits identified or recorded as liabilities for at year end. PFICs policy would be to recognize interest and penalties, if any, on tax positions related to its unrecognized tax benefits in income tax expense in the financial statements. No interest and penalties were assessed or recorded during the year then ended. PFICs IRS Forms 990 that have been filed are subject to examination by the Internal Revenue Service, generally for three years after they were filed.

**Additional Data**

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**SCHEDULE O**  
**(Form 990)**Department of the Treasury  
Internal Revenue Service**Supplemental Information to Form 990 or 990-EZ**Complete to provide information for responses to specific questions on  
Form 990 or 990-EZ or to provide any additional information.

▶ Attach to Form 990 or 990-EZ.

▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2021****Open to Public  
Inspection**Name of the organization  
Progressive Familial Intrahepatic Cholestasis**Employer identification number**

83-1084501

Return Reference	Explanation
Form 990 governing body review Part VI line 11	The Form 990 is prepared by a Certified Public Accountant. It is reviewed by the Executive Director and full Board before being filed.
Conflict of interest policy compliance Part VI line 12c	The Organization has updated its written conflict of interest policy. Officers and directors are required to report interests that could give rise to conflicts.
CEO executive director top management comp Part VI line 15a	The compensation of the Executive Director is established by the Board, and is part of the budget process.
Governing documents etc available to public Part VI line 19	The Organization makes required documents available upon request, in accordance with IRS guidance.
List of other fees for services expenses Part IX line 11g	Other Professional Fees \$78,432

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