

990EZ

Short Form

Return of Organization Exempt From Income Tax

OMB No. 1545-

1150

2020

Open to Public Inspection

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/Form990EZ for instructions and the latest information.

Department of the Treasury Internal Revenue Service

- 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 ADVOCACY AND RESOURCE N. Address: PO 551, STANTON, KY 40380

D Employer identification number: 83-1084501. E Telephone number: (414) 331-3316. F Group Exemption Number

G Accounting Method: Accrual

H Check if the organization is not required to attach Schedule B (Form 990, 990-EZ, or 990-PF).

I Website: N/A

J Tax-exempt status: 501(c)(3)

K Form of organization: Corporation

L Add lines 5b, 6c, and 7b to line 9 to determine gross receipts. If gross receipts are \$200,000 or more, or if total assets (Part II, column (B) below) are \$500,000 or more, file Form 990 instead of Form 990-EZ.

Part I Revenue, Expenses, and Changes in Net Assets or Fund Balances

Check if the organization used Schedule O to respond to any question in this Part I

Table with 9 rows for Revenue. Line 1: 101,541. Line 9: 101,541.

Table with 7 rows for Expenses. Line 17: 77,107.

Table with 3 rows for Net Assets. Line 21: 96,186.

**Part II Balance Sheets** (see the instructions for Part II)

Check if the organization used Schedule O to respond to any question in this Part II

	(A) Beginning of year	(B) End of year
<b>22</b> Cash, savings, and investments . . . . .	71,752	<b>22</b> 99,034
<b>23</b> Land and buildings . . . . .		<b>23</b>
<b>24</b> Other assets (describe in Schedule O) . . . . .		<b>24</b>
<b>25 Total assets</b> . . . . .	71,752	<b>25</b> 99,034
<b>26 Total liabilities</b> (describe in Schedule O). . . . .		<b>26</b> 2,848
<b>27 Net assets or fund balances</b> (line 27 of column (B) <b>must</b> agree with line 21)	71,752	<b>27</b> 96,186

**Part III Statement of Program Service Accomplishments** (see the instructions for Part III)

Check if the organization used Schedule O to respond to any question in this Part III

What is the organization's primary exempt purpose?  
 TO IMPROVE THE LIVES OF PATIENTS AND FAMILIES WORLDWIDE AFFECTED BY PROGRESSIVE FAMILIAL INTRAHEPATIC CHOLESTASIS, PFIC.

Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. In a clear and concise manner, describe the services provided, the number of persons benefited, and other relevant information for each program title.

**28** PROGRESSIVE FAMILIAL INTRAHEPATIC CHOLESTASIS (PFIC) IS A GENERAL TERM THAT REPRESENTS A GROUP OF RARE GENETIC DISORDERS THAT CAUSE A PROGRESSIVE LIVER DISEASE AND CAN LEAD TO CIRRHOSIS AND END-STATE LIVER DISEASE. THE ORGANIZATION IS RUN BY PFIC PATIENTS AND CAREGIVERS WHO WORK WITH A TEAM OF PHYSICIANS THAT SPECIALIZE IN PFIC TO HELP IDENTIFY THE NEEDS OF THE PFIC COMMUNITY. ADDITIONALLY, WE BRING PFIC FAMILIES TOGETHER TO DEVELOP A GREATER VOICE IN THE RARE DISEASE COMMUNITY, ADVOCATE FOR MORE MEDICAL RESEARCH, AND CREATE OPPORTUNITIES TO HELP FAMILIES CONNECT ACROSS THE WORLD AND RECEIVE THE SUPPORT THEY NEED.

(Grants \$ 2,669) If this amount includes foreign grants, check here

**29**

(Grants \$ ) If this amount includes foreign grants, check here

**30**

(Grants \$ ) If this amount includes foreign grants, check here

**31** Other program services (describe in Schedule O)

(Grants \$ ) If this amount includes foreign grants, check here

**32 Total program service expenses** (add lines 28a through 31a)

**Part IV List of Officers, Directors, Trustees, and Key Employees** (list each one even if not compensated — see the instructions for Part IV)

Check if the organization used Schedule O to respond to any question in this Part IV.

(a) Name and title	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	(d) Health benefits, contributions to employee benefit plans, and deferred compensation	(e) Estimated amount of other compensation
EMILY VENTURA	40.00	0		
EXECUTIVE DI				
TARA KEARNS	2.00	0		
VICE PRESIDE				
ERIN HOVEY	2.00	0		
SECRETARY				
HAYLEY WATTS	2.00	0		
TREASURER				
WALTER PEREZ	2.00	0		
PRESIDENT				

Part V Other Information (Note the Schedule A and personal benefit contract statement requirements in the

instructions for Part V.) Check if the organization used Schedule O to respond to any question in this Part V. . . . .

Main form area containing questions 33 through 45b with corresponding Yes/No columns and input fields.

	Yes	No
46		No

46 Did the organization engage, directly or indirectly, in political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I.

Part VI Section 501(c)(3) Organizations Only

All section 501(c)(3) organizations must answer questions 47- 49b and 52, and complete the tables for lines 50 and 51.

Check if the organization used Schedule O to respond to any question in this Part VI.

	Yes	No
47		No
48		No
49a		No
49b		

47 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

48 Is the organization a school as described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E

49a Did the organization make any transfers to an exempt non-charitable related organization?

b If "Yes," was the related organization a section 527 organization?

50 Complete this table for the organization's five highest compensated employees (other than officers, directors, trustees and key employees) who each received more than \$100,000 of compensation from the organization. If there is none, enter "None."

(a) Name and title of each employee	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC)	(d) Health benefits, contributions to employee benefit plans, and deferred compensation	(e) Estimated amount of other compensation
NONE				

f Total number of other employees paid over \$100,000

51 Complete this table for the organization's five highest compensated independent contractors who each received more than \$100,000 of compensation from the organization. If there is none, enter "None."

(a) Name and business address of each independent contractor	(b) Type of service	(c) Compensation
NONE		

d Total number of other independent contractors each receiving over \$100,000.

52 Did the organization complete Schedule A? NOTE. All section 501(c)(3) organizations must attach a completed Schedule A

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.

<b>Sign Here</b>	Signature of officer	2021-11-15
	EMILY VENTURA EXECUTIVE DIRECTOR	Date
	Type or print name and title	

<b>Paid Preparer Use Only</b>	Print/Type preparer's name DERRICK ROGERS	Preparer's signature	Date 2021-11-11	Check <input type="checkbox"/> if self-employed	PTIN P01316040
	Firm's name	BREEDING HENDERSON & HORD PLLC		Firm's EIN	
	Firm's address	1050 MONARCH ST STE 300 LEXINGTON, KY 405131877		80-0874573	
				Phone no. (859) 278-0112	

May the IRS discuss this return with the preparer shown above? See instructions

Yes No

## **Additional Data**

**Return to Form**

**Software ID:**

**Software Version:**

**Form 990-EZ, Special Condition Description:**

**Special Condition Description**

**SCHEDULE A**  
**(Form 990 or 990-EZ)**

**Public Charity Status and Public Support**

OMB No. 1545-0047

**2020**

**Open to Public Inspection**

**Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.**  
**▶ Attach to Form 990 or Form 990-EZ.**

**▶ Go to [www.irs.gov/Form990](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 ADVOCACY AND RESOURCE N

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

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 10 above (see instructions))	(iv) Is the organization listed in your governing document?		(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**

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grant.") . . .				130,613	101,541	232,154
<b>2</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . . .						
<b>3</b> The value of services or facilities furnished by a governmental unit to the organization without charge..						
<b>4 Total.</b> Add lines 1 through 3				130,613	101,541	232,154
<b>5</b> 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) . . . . .						161,071
<b>6 Public support.</b> Subtract line 5 from line 4.						71,083

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
<b>7</b> Amounts from line 4. . . . .				130,613	101,541	232,154
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources . . . . .						
<b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on . . . . .						
<b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . . . .						
<b>11 Total support.</b> Add lines 7 through 10						232,154

**12** Gross receipts from related activities, etc. (see instructions) . . . . . **12**

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

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

<b>14</b> Public support percentage for 2020 (line 6, column (f) divided by line 11, column (f)) . . . . .	<b>14</b>	30.620 %
<b>15</b> Public support percentage for 2019 Schedule A, Part II, line 14 . . . . .	<b>15</b>	

**16a 33 1/3% support test—2020.** 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—2019.** 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—2020.** 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—2019.** 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) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(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) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(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 in 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 2020 (line 8, column (f) divided by line 13, column (f)) . . . . .	<b>15</b>	
<b>16</b> Public support percentage from 2019 Schedule A, Part III, line 15 . . . . .	<b>16</b>	

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

<b>17</b> Investment income percentage for <b>2020</b> (line 10c, column (f) divided by line 13, column (f)) . . . . .	<b>17</b>	
<b>18</b> Investment income percentage from <b>2019</b> Schedule A, Part III, line 17 . . . . .	<b>18</b>	

**19a 33 1/3% support tests—2020.** 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—2019.** 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**

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

**Part IV Supporting Organizations** (continued)

- 11** Has the organization accepted a gift or contribution from any of the following persons?
  - a** A person who directly or indirectly controls, either alone or together with persons described in lines 11b and 11c below, the governing body of a supported organization?
  - b** A family member of a person described in 11a above?
  - c** A 35% controlled entity of a person described in line 11a or 11b above? *If "Yes" to 11a, 11b, or 11c, provide detail in Part VI.*

	Yes	No
<b>11a</b>		
<b>11b</b>		
<b>11c</b>		

**Section B. Type I Supporting Organizations**

- 1** Did the officers, directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? *If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.*
- 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.*

	Yes	No
<b>1</b>		
<b>2</b>		

**Section C. Type II Supporting Organizations**

- 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).*

	Yes	No
<b>1</b>		

**Section D. All Type III Supporting Organizations**

- 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?
- 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).*
- 3** By reason of the relationship described in 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.*

	Yes	No
<b>1</b>		
<b>2</b>		
<b>3</b>		

**Section E. Type III Functionally-Integrated Supporting Organizations**

- 1** Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (**see instructions**):
  - a** The organization satisfied the Activities Test. Complete **line 2** below.
  - b** The organization is the parent of each of its supported organizations. Complete **line 3** below.
  - c** The organization supported a governmental entity. Describe in **Part VI** how you supported a government entity (see instructions)

**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.*
- b** Did the activities described in line 2a 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.*

	Yes	No
<b>2a</b>		
<b>2b</b>		
<b>3a</b>		
<b>3b</b>		

**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.*
- 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.*

**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 (explain in detail in <b>Part VI</b> ):			
<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 2020 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-2020	(iii) Distributable Amount for 2020
<b>1</b> Distributable amount for 2020 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2020 (reasonable cause required-- explain in <b>Part VI</b> ). See instructions.			
<b>3</b> Excess distributions carryover, if any, to 2020:			
<b>a</b> From 2015. . . . .			
<b>b</b> From 2016. . . . .			
<b>c</b> From 2017. . . . .			
<b>d</b> From 2018. . . . .			
<b>e</b> From 2019. . . . .			
<b>f Total</b> of lines 3a through e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2020 distributable amount			
<b>i</b> Carryover from 2015 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
<b>4</b> Distributions for 2020 from Section D, line 7: \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2020 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from line 4.			
<b>5</b> Remaining underdistributions for years prior to 2020, 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 2020. 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 2021.</b> Add lines 3j and 4c.			
<b>8</b> Breakdown of line 7:			
<b>a</b> Excess from 2016. . . . .			
<b>b</b> Excess from 2017. . . . .			
<b>c</b> Excess from 2018. . . . .			
<b>d</b> Excess from 2019. . . . .			
<b>e</b> Excess from 2020. . . . .			

**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**

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**Schedule B**

(Form 990, 990-EZ, or 990-PF)

Department of the Treasury  
Internal Revenue Service

**Schedule of Contributors**

▶ Attach to Form 990, 990-EZ, or 990-PF.  
▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2020**

Name of the organization PROGRESSIVE FAMILIAL INTRAHEPATIC CHOLESTASIS ADVOCACY AND RESOURCE N	Employer identification number 83-1084501
--	--

Organization type (check one):

Filers of:

Section:

Form 990 or 990-EZ

- 501(c)( ) (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 other 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<sup>1</sup>/<sub>3</sub>% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), 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, 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, 990-EZ, or 990-PF), 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 990PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

Name of organization  
PROGRESSIVE FAMILIAL INTRAHEPATIC  
CHOLESTASIS ADVOCACY AND RESOURCE N

Employer identification number  
83-1084501

**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
RESTRICTED		\$ RESTRICTED	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
-		\$	<input type="checkbox"/> Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash (Complete Part II for noncash contributions.)

Name of organization  
 PROGRESSIVE FAMILIAL INTRAHEPATIC  
 CHOLESTASIS ADVOCACY AND RESOURCE N

**Employer identification number**  
 83-1084501

**Part II** **Noncash Property** (see instructions). Use duplicate copies of Part II if additional space is needed.

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____
-	_____ _____ _____	_____ \$	_____

Name of organization PROGRESSIVE FAMILIAL INTRAHEPATIC CHOLESTASIS ADVOCACY AND RESOURCE N	Employer identification number 83-1084501
--	--

**Part III** Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of exclusively religious, charitable, etc., contributions of \$1,000 or less for the year. (Enter this information once. See instructions.) ► \$ \_\_\_\_\_

Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	_____ _____	_____ _____	_____ _____
(e) Transfer of gift			
Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	
_____ _____		_____ _____	
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	_____ _____	_____ _____	_____ _____
(e) Transfer of gift			
Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	
_____ _____		_____ _____	
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	_____ _____	_____ _____	_____ _____
(e) Transfer of gift			
Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	
_____ _____		_____ _____	
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	_____ _____	_____ _____	_____ _____
(e) Transfer of gift			
Transferee's name, address, and ZIP 4		Relationship of transferor to transferee	
_____ _____		_____ _____	

## **Additional Data**

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**SCHEDULE O**  
**(Form 990 or 990-EZ)****Supplemental Information to Form 990 or 990-EZ**

OMB No. 1545-0047

**2020****Open to Public Inspection**

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.

Department of the Treasury

Name of the organization

PROGRESSIVE FAMILIAL INTRAHEPATIC  
CHOLESTASIS ADVOCACY AND RESOURCE N

Employer identification number

83-1084501

Return Reference	Explanation
FORM 990-EZ	ORGANIZATION FULL LEGAL NAME: PROGRESSIVE FAMILIAL INTRAHEPATIC CHOLESTASIS ADVOCACY AND RESOURCE NETWORK, INC DOING BUSINESS AS: PFIC ADVOCACY AND RESOURCE NETWORK
FORM 990-EZ, PART I, LINE 16	EXPENSES ADVERTISING AND PROMOTION 9,856 OFFICE 2,356 INFORMATION TECHNOLOGY 14,220 CONFERENCES/MEETINGS 5,375 INSURANCE 565 BANK FEES 252 CARE PACKAGES 1,703 LICENSES 3,533 TOTAL 37,860
FORM 990-EZ, PART II, LINE 26	UNSECURED NOTES AND LOANS PAYABLE 0 2,848
FORM 990-EZ, PART III	TO IMPROVE THE LIVES OF PATIENTS AND FAMILIES WORLDWIDE AFFECTED BY PROGRESSIVE FAMILIAL INTRAHEPATIC CHOLESTASIS, PFIC.
FORM 990-EZ, PART III, LINE 28	PROGRESSIVE FAMILIAL INTRAHEPATIC CHOLESTASIS (PFIC) IS A GENERAL TERM THAT REPRESENTS A GROUP OF RARE GENETIC DISORDERS THAT CAUSE A PROGRESSIVE LIVER DISEASE AND CAN LEAD TO CIRRHOSIS AND END-STATE LIVER DISEASE. THE ORGANIZATION IS RUN BY PFIC PATIENTS AND CAREGIVERS WHO WORK WITH A TEAM OF PHYSICIANS THAT SPECIALIZE IN PFIC TO HELP IDENTIFY THE NEEDS OF THE PFIC COMMUNITY. ADDITIONALLY, WE BRING PFIC FAMILIES TOGETHER TO DEVELOP A GREATER VOICE IN THE RARE DISEASE COMMUNITY, ADVOCATE FOR MORE MEDICAL RESEARCH, AND CREATE OPPORTUNITIES TO HELP FAMILIES CONNECT ACROSS THE WORLD AND RECEIVE THE SUPPORT THEY NEED.

## **Additional Data**

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## TY 2020 IRS 990 e-File Render

**Name:** PROGRESSIVE FAMILIAL INTRAHEPATIC  
CHOLESTASIS ADVOCACY AND RESOURCE N

**EIN:** 83-1084501

Person Name	Explanation
EMILY VENTURA	
TARA KEARNS	
ERIN HOVEY	
HAYLEY WATTS	
WALTER PEREZ	