

3

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

Return of Organization Exempt From Income Tax

2017

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.
▶ Information about Form 990-EZ and its instructions is at www.irs.gov/form990ez.

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

B Check if applicable

☐ Address change

☐ Name change

☐ Initial return

☐ Final return/terminated

☒ Amended return

☐ Application pending

C Name of organization
PURA Syndrome Foundation

Number and street (or P O box, if mail is not delivered to street address) 3 Little Harbor Road	Room/suite
--	------------

City or town, state or province, country, and ZIP or foreign postal code
Berwick, ME 03901

D Employer identification number

81-2235818

E Telephone number

(512) 413-2460

F Group Exemption Number	Exemption Description	Exemption Amount	Exemption Type	Exemption Status
1	...	...	...	...
2	...	...	...	...
3	...	...	...	...
4	...	...	...	...
5	...	...	...	...
6	...	...	...	...
7	...	...	...	...
8	...	...	...	...
9	...	...	...	...
10	...	...	...	...
11	...	...	...	...
12	...	...	...	...
13	...	...	...	...
14	...	...	...	...
15	...	...	...	...
16	...	...	...	...
17	...	...	...	...
18	...	...	...	...
19	...	...	...	...
20	...	...	...	...
21	...	...	...	...
22	...	...	...	...
23	...	...	...	...
24	...	...	...	...
25	...	...	...	...
26	...	...	...	...
27	...	...	...	...
28	...	...	...	...
29	...	...	...	...
30	...	...	...	...
31	...	...	...	...
32	...	...	...	...
33	...	...	...	...
34	...	...	...	...
35	...	...	...	...
36	...	...	...	...
37	...	...	...	...
38	...	...	...	...
39	...	...	...	...
40	...	...	...	...
41	...	...	...	...
42	...	...	...	...
43	...	...	...	...
44	...	...	...	...
45	...	...	...	...
46	...	...	...	...
47	...	...	...	...
48	...	...	...	...
49	...	...	...	...
50	...	...	...	...
51	...	...	...	...
52	...	...	...	...
53	...	...	...	...
54	...	...	...	...
55	...	...	...	...
56	...	...	...	...
57	...	...	...	...
58	...	...	...	...
59	...	...	...	...
60	...	...	...	...
61	...	...	...	...
62	...	...	...	...
63	...	...	...	...
64	...	...	...	...
65	...	...	...	...
66	...	...	...	...
67	...	...	...	...
68	...	...	...	...
69	...	...	...	...
70	...	...	...	...
71	...	...	...	...
72	...	...	...	...
73	...	...	...	...
74	...	...	...	...
75	...	...	...	...
76	...	...	...	...
77	...	...	...	...
78	...	...	...	...
79	...	...	...	...
80	...	...	...	...
81	...	...	...	...
82	...	...	...	...
83	...	...	...	...
84	...	...	...	...
85	...	...	...	...
86	...	...	...	...
87	...	...	...	...
88	...	...	...	...
89	...	...	...	...
90	...	...	...	...
91	...	...	...	...
92	...	...	...	...
93	...	...	...	...
94	...	...	...	...
95	...	...	...	...
96	...	...	...	...
97	...	...	...	...
98	...	...	...	...
99	...	...	...	...
100	...	...	...	...

G Accounting Method ☒ Cash ☐ Accrual Other (specify) ▶

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

I Website: ► www.purasynndrome.org

J Tax-exempt status(check only one) - ☒ 501(c)(3) ☐ 501(c)() ◀(insert no) ☐ 4947(a)(1) or ☐ 527

K Form of organization ☒ Corporation ☐ Trust ☐ Association ☐ Other

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. ▶ \$ 88,559

Part I **Revenue, Expenses, and Changes in Net Assets or Fund Balances** (see the instructions for Part I)

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

Revenue	1	Contributions, gifts, grants, and similar amounts received		81,823
	2	Program service revenue including government fees and contracts		6,734
	3	Membership dues and assessments		0
	4	Investment income		2
	5a	Gross amount from sale of assets other than inventory	5a	
	b	Less cost or other basis and sales expenses	5b	0
	c	Gain or (loss) from sale of assets other than inventory (Subtract line 5b from line 5a)	5c	0
	6	Gaming and fundraising events		
	a	Gross income from gaming (attach Schedule G if greater than \$15,000)	6a	0
	b	Gross income from fundraising events (not including \$ _____ of contributions from fundraising events reported on line 1) (attach Schedule G if the sum of such gross income and contributions exceeds \$15,000)	6b	0
	c	Less direct expenses from gaming and fundraising events	6c	0
	d	Net income or (loss) from gaming and fundraising events (add lines 6a and 6b and subtract line 6c)	6d	0
	7a	Gross sales of inventory, less returns and allowances	7a	
	b	Less cost of goods sold	7b	0
c	Gross profit or (loss) from sales of inventory (Subtract line 7b from line 7a)	7c	0	
8	Other revenue (describe in Schedule O)	8		
9	Total revenue. Add lines 1, 2, 3, 4, 5c, 6d, 7c, and 8	9	88,559	
Expenses	10	Grants and similar amounts paid (list in Schedule O)	10	
	11	Benefits paid to or for members	11	
	12	Salaries, other compensation, and employee benefits	12	
	13	Professional fees and other payments to independent contractors	13	60
	14	Occupancy, rent, utilities, and maintenance	14	
	15	Printing, publications, postage, and shipping	15	179
	16	Other expenses (describe in Schedule O)	16	39,446
	17	Total expenses. Add lines 10 through 16	17	39,685
Net Assets	18	Excess or (deficit) for the year (Subtract line 17 from line 9)	18	48,874
	19	Net assets or fund balances at beginning of year (from line 27, column (A)) (must agree with end-of-year figure reported on prior year's return)	19	23,502
	20	Other changes in net assets or fund balances (explain in Schedule O)	20	-10,153
	21	Net assets or fund balances at end of year Combine lines 18 through 20	21	62,222

For Paperwork Reduction Act Notice, see the separate instructions.

Cat No 10642I

Form **990-EZ** (2017)

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
22 Cash, savings, and investments	23,502	22 62,223
23 Land and buildings		23
24 Other assets (describe in Schedule O)		24
25 Total assets	23,502	25 62,223
26 Total liabilities (describe in Schedule O).		26
27 Net assets or fund balances (line 27 of column (B) must agree with line 21)	23,502	27 62,223

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 serve, educate, and fund research for families coping with the effects of PURA Syndrome

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

		Expenses (Required for section 501(c)(3) and 501(c)(4) organizations, optional for others)
28 See Additional Data Table		
(Grants \$) If this amount includes foreign grants, check here ☐	28a	
29	29a	
(Grants \$) If this amount includes foreign grants, check here ☐		
30	30a	
(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 ☐	31a	
32 Total program service expenses (add lines 28a through 31a) ☒	32	27,974

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
DOMINIC SPADAFORE President	15 00	0		
DAMON FISHER Treasurer	10 00	0		
CECIEL VAN HOECKEL European Parent Liason	10 00	0		
KERRY HILDRING American Parent Liason	10 00	0		
JON ERICKSON IT / Media	10 00	0		
JOANNA HORSNAIL Fundraising Liason	5 00	0		
MEL ANDERSON Medical Liason	20 00	0		

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 ☐

	Yes	No
33 Did the organization engage in any significant activity not previously reported to the IRS? If "Yes," provide a detailed description of each activity in Schedule O	33	No
34 Were any significant changes made to the organizing or governing documents? If "Yes," attach a conformed copy of the amended documents if they reflect a change to the organization's name. Otherwise, explain the change on Schedule O (see instructions)	34	No
35a Did the organization have unrelated business gross income of \$1,000 or more during the year from business activities (such as those reported on lines 2, 6a, and 7a, among others)?	35a	No
b If "Yes," to line 35a, has the organization filed a Form 990-T for the year? If "No," provide an explanation in Schedule O	35b	
c Was the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization subject to section 6033(e) notice, reporting, and proxy tax requirements during the year? If "Yes," complete Schedule C, Part III	35c	No
36 Did the organization undergo a liquidation, dissolution, termination, or significant disposition of net assets during the year? If "Yes," complete applicable parts of Schedule N	36	No
37a Enter amount of political expenditures, direct or indirect, as described in the instructions ▶ 37a		
b Did the organization file Form 1120-POL for this year?	37b	No
38a Did the organization borrow from, or make any loans to, any officer, director, trustee, or key employee or were any such loans made in a prior year and still outstanding at the end of the tax year covered by this return?	38a	No
b If "Yes," complete Schedule L, Part II and enter the total amount involved	38b	
39 Section 501(c)(7) organizations Enter		
a Initiation fees and capital contributions included on line 9	39a	
b Gross receipts, included on line 9, for public use of club facilities	39b	
40a Section 501(c)(3) organizations Enter amount of tax imposed on the organization during the year under section 4911 ▶ , section 4912 ▶ , section 4955 ▶		
b Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations Did the organization engage in any section 4958 excess benefit transaction during the year, or did it engage in an excess benefit transaction in a prior year that has not been reported on any of its prior Forms 990 or 990-EZ? If "Yes," complete Schedule L, Part I	40b	No
c Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations Enter amount of tax imposed on organization managers or disqualified persons during the year under sections 4912, 4955, and 4958 ▶		
d Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations Enter amount of tax on line 40c reimbursed by the organization ▶		
e All organizations At any time during the tax year, was the organization a party to a prohibited tax shelter transaction? If "Yes," complete Form 8886-T	40e	No
41 List the states with which a copy of this return is filed ▶		
42a The organization's books are in care of ▶ <u>DAMON FISHER</u> Telephone no ▶ <u>(512) 413-2460</u> Located at ▶ <u>129 Shelf Rock Road Driftwood, TX</u> ZIP + 4 ▶ <u>78619</u>		
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)?	42b	No
If "Yes," enter the name of the foreign country ▶		
See the instructions for exceptions and filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR)		
c At any time during the calendar year, did the organization maintain an office outside the U S ?	42c	No
If "Yes," enter the name of the foreign country ▶		
43 Section 4947(a)(1) nonexempt charitable trusts filing Form 990-EZ in lieu of Form 1041 - Check here ☐ and enter the amount of tax-exempt interest received or accrued during the tax year ▶ 43		
44a Did the organization maintain any donor advised funds during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ	44a	No
b Did the organization operate one or more hospital facilities during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ	44b	No
c Did the organization receive any payments for indoor tanning services during the year?	44c	No
d If "Yes," to line 44c, has the organization filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O	44d	
45a Did the organization have a controlled entity within the meaning of section 512(b)(13)?	45a	No
45b Did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," Form 990 and Schedule R may need to be completed instead of Form 990-EZ (see instructions)	45b	No

		Yes	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	46	No

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	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	47	No
48	Is the organization a school as described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	48	No
49a	Did the organization make any transfers to an exempt non-charitable related organization?	49a	Yes
49b	If "Yes," was the related organization a section 527 organization?	49b	No

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 ► ☒ **Yes** ☐ **No**

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

Sign Here	***** Signature of officer		2018-08-22 Date	
	DAMON FISHER, TREASURER Type or print name and title			
Paid Preparer Use Only	Print/Type preparer's name ARTURO MONTEMAYOR III	Preparer's signature	Date	Check ☐ if self-employed PTIN P01388530
	Firm's name ► Montemayor Britton Bender PC			Firm's EIN ►
	Firm's address ► 2525 Wallingwood Drive Bldg 1 Ste 2 Austin, TX 78746			Phone no. (512) 442-0380

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

Additional Data

Software ID:
Software Version:
EIN: 81-2235818
Name: PURA Syndrome Foundation

Form 990EZ, Part III - Statement of Program Service Accomplishments

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.		Expenses (Required for section 501(c)(3) and 501(c)(4) organizations; optional for others.)	
28 PURA Syndrome Foundation Global Conference - The PURA Syndrome Foundation welcomes families of individuals diagnosed with PURA Syndrome, medical and research professionals, and other interested (Grants \$) If this amount includes foreign grants, check here . . . ☐		28a	27,974

TY 2017 Reasonable Cause Explanation

Name: PURA Syndrome Foundation

EIN: 81-2235818

Explanation: 2017 WAS THE FIRST YEAR PURA SYNDROME FOUNDATION WAS REQUIRED TO FILE A FORM 990-EZ. THE ORGANIZATION HIRED A CPA TO PREPARE THE RETURN, BUT DUE TO UNFORSEEN CIRCUMSTANCES, THE CPA WAS NOT ABLE TO FILE THE RETURN. THE ORGANIZATION THEN PREPARED THE RETURN THEMSELVES AND FILED ON TIME TO AVOID PENALTIES, BUT THE RETURN WAS REJECTED. THE ORGANIZATION PROMPTLY HIRED ANOTHER FIRM TO PREPARE THIS FORM 990-EZ.

SCHEDULE A

(Form 990 or 990EZ)

Department of the Treasury

Internal Revenue Service

Name of the organization

PURA Syndrome Foundation

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.
▶ Attach to Form 990 or Form 990-EZ.
▶ Information about Schedule A (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2017

Open to Public Inspection

Employer identification number

81-2235818

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		
Total						

Part II

Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv), 170(b)(1)(A)(vi), and 170(b)(1)(A)(ix)
(Complete only if you checked the box on line 5, 7, 8, or 9 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support							
	Calendar year (or fiscal year beginning in) ►	(a) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
1	Gifts, grants, contributions, and membership fees received (Do not include any "unusual grant ")						
2	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3	The value of services or facilities furnished by a governmental unit to the organization without charge						
4	Total. Add lines 1 through 3						
5	The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						
6	Public support. Subtract line 5 from line 4						0

Section B. Total Support							
Calendar year (or fiscal year beginning in) ►		(a)2013	(b)2014	(c)2015	(d)2016	(e)2017	(f)Total
7	Amounts from line 4						
8	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						0
9	Net income from unrelated business activities, whether or not the business is regularly carried on						
10	Other income Do not include gain or loss from the sale of capital assets (Explain in Part VI)						
11	Total support. Add lines 7 through 10						
12	Gross receipts from related activities, etc (see instructions)					12	
13	First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here ► ☐						

Section C. Computation of Public Support Percentage						
14	Public support percentage for 2017 (line 6, column (f) divided by line 11, column (f))					14 0 %
15	Public support percentage for 2016 Schedule A, Part II, line 14					15
16a	33 1/3% support test—2017. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ► ☐					
b	33 1/3% support test—2016. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ► ☐					
17a	10%-facts-and-circumstances test—2017. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part VI how the organization meets the "facts-and-circumstances" test The organization qualifies as a publicly supported organization ► ☐					
b	10%-facts-and-circumstances test—2016. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part VI how the organization meets the "facts-and-circumstances" test The organization qualifies as a publicly supported organization ► ☐					
18	Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions ► ☐					

Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ►	(a) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")				23,502	81,823	105,325
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose					6,734	6,734
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5				23,502	88,557	112,059
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support. (Subtract line 7c from line 6)						112,059

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
9 Amounts from line 6				23,502	88,557	112,059
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources					2	2
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b					2	2
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						112,061

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

Section C. Computation of Public Support Percentage

15 Public support percentage for 2017 (line 8, column (f) divided by line 13, column (f))	15	100.000 %
16 Public support percentage from 2016 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2017 (line 10c, column (f) divided by line 13, column (f))	17	0 %
18 Investment income percentage from 2016 Schedule A, Part III, line 17	18	

19a 33 1/3% support tests—2017. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization ☒

b 33 1/3% support tests—2016. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization ☐

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

Part IV Supporting Organizations

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

Section A. All Supporting Organizations

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

Part IV Supporting Organizations (continued)

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

Section B. Type I Supporting Organizations

	Yes	No
1 Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>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.</i>		
	1	
2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? <i>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.</i>		
	2	

Section C. Type II Supporting Organizations

	Yes	No
1 Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <i>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).</i>		
	1	

Section D. All Type III Supporting Organizations

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

Section E. Type III Functionally-Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions)		
a ☐ The organization satisfied the Activities Test. Complete line 2 below.		
b ☐ The organization is the parent of each of its supported organizations. Complete line 3 below.		
c ☐ The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).		
2 Activities Test Answer (a) and (b) below.		
a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>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.</i>		
	2a	
b Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>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.</i>		
	2b	
3 Parent of Supported Organizations Answer (a) and (b) below.		
a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>Provide details in Part VI.</i>		
	3a	
b Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>		
	3b	

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

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

Section A - Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
1 Net short-term capital gain	1		
2 Recoveries of prior-year distributions	2		
3 Other gross income (see instructions)	3		
4 Add lines 1 through 3	4		
5 Depreciation and depletion	5		
6 Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6		
7 Other expenses (see instructions)	7		
8 Adjusted Net Income (subtract lines 5, 6 and 7 from line 4)	8		
Section B - Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year)	1		
a Average monthly value of securities	1a		
b Average monthly cash balances	1b		
c Fair market value of other non-exempt-use assets	1c		
d Total (add lines 1a, 1b, and 1c)	1d		
e Discount claimed for blockage or other factors (explain in detail in Part VI)			
2 Acquisition indebtedness applicable to non-exempt use assets	2		
3 Subtract line 2 from line 1d	3		
4 Cash deemed held for exempt use Enter 1-1/2% of line 3 (for greater amount, see instructions)	4		
5 Net value of non-exempt-use assets (subtract line 4 from line 3)	5		
6 Multiply line 5 by .035	6		
7 Recoveries of prior-year distributions	7		
8 Minimum Asset Amount (add line 7 to line 6)	8		
Section C - Distributable Amount			Current Year
1 Adjusted net income for prior year (from Section A, line 8, Column A)	1		
2 Enter 85% of line 1	2		
3 Minimum asset amount for prior year (from Section B, line 8, Column A)	3		
4 Enter greater of line 2 or line 3	4		
5 Income tax imposed in prior year	5		
6 Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions)	6		
7 ☐ Check here if the current year is the organization's first as a non-functionally-integrated Type III supporting organization (see instructions)			

Part V

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

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

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

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

Facts And Circumstances Test

SCHEDULE O (Form 990 or 990-EZ) Department of the Treasury Internal Revenue Service	Supplemental Information to Form 990 or 990-EZ Complete to provide information for responses to specific questions on Form 990 or 990-EZ or to provide any additional information. ▶ Attach to Form 990 or 990-EZ. ▶ Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990 .	OMB No 1545-0047 2017 Open to Public Inspection
---	--	--

Name of the organization PURA Syndrome Foundation	Employer identification number 81-2235818
---	---

990 Schedule O, Supplemental Information

Return Reference	Explanation
Pt III, Line 31	Line 28 continued attendees from around the world to gather together Families and medical specialists had the chance to meet each other, sharing information and ideas

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990EZ, Part I, Line 16	Conference Expense 27974

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990EZ, Part I, Line 16	Fundraising Events 5797

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990EZ, Part I, Line 16	Internet Expenses 3210

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990EZ, Part I, Line 16	Insurance 771

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990EZ, Part I, Line 16	Charitable Gifts 750

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990EZ, Part I, Line 16	Advertising 572

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990EZ, Part I, Line 16	Miscellaneous 372

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990EZ, Part I, Line 20	2017 is the first year client is required to file a Form -10153

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990EZ, Part I, Line 20	990-EZ This difference is due to adjusting the beginning

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990EZ, Part I, Line 20	net assets to reflect the correct ending net assets, which

990 Schedule O, Supplemental Information

Return Reference	Explanation
Form 990EZ, Part I, Line 20	was prepared by an external bookkeeper