

Form **990EZ**  
 Department of the Treasury  
 Internal Revenue Service

**Short Form**  
**Return of Organization Exempt From Income Tax**  
 Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

▶ Do not enter social security numbers on this form as it may be made public.  
 ▶ Go to [www.irs.gov/Form990EZ](http://www.irs.gov/Form990EZ) for the latest information.

OMB No 1545-1150  
**2018**  
**Open to Public Inspection**

**A For the 2018 calendar year, or tax year beginning 01-01-2018, and ending 12-31-2018**

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

**C** Name of organization  
 SHARE AND CARE COCKAYNE SYNDROME NETWORK

Number and street (or P O box, if mail is not delivered to street address) Room/suite  
 PO BOX 282

City or town, state or province, country, and ZIP or foreign postal code  
 WATERFORD, VA 20197

**D** Employer identification number  
 01-0557037

**E** Telephone number  
 (703) 727-0404

**F** Group Exemption Number ▶

**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.COCKAYNESYNDROME.NET](http://WWW.COCKAYNESYNDROME.NET)  
**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. ▶ \$ 106,403

**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.

		1	2	3	4	5a	5b	5c	6a	6b	6c	6d	7a	7b	7c	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Revenue	<b>1</b>	Contributions, gifts, grants, and similar amounts received . . . . .																106,096											
	<b>2</b>	Program service revenue including government fees and contracts . . . . .																											
	<b>3</b>	Membership dues and assessments . . . . .																											
	<b>4</b>	Investment income . . . . .																											
	<b>5a</b>	Gross amount from sale of assets other than inventory . . . . .																											
	<b>b</b>	Less cost or other basis and sales expenses . . . . .																											
	<b>c</b>	Gain or (loss) from sale of assets other than inventory (Subtract line 5b from line 5a) . . . . .																											
	<b>6</b>	Gaming and fundraising events																											
	<b>a</b>	Gross income from gaming (attach Schedule G if greater than \$15,000) . . . . .																											
	<b>b</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) . . . . .																											
	<b>c</b>	Less direct expenses from gaming and fundraising events . . . . .																											
	<b>d</b>	Net income or (loss) from gaming and fundraising events (add lines 6a and 6b and subtract line 6c) . . . . .																											
	<b>7a</b>	Gross sales of inventory, less returns and allowances . . . . .																											
	<b>b</b>	Less cost of goods sold . . . . .																											
	<b>c</b>	Gross profit or (loss) from sales of inventory (Subtract line 7b from line 7a) . . . . .																											
	<b>8</b>	Other revenue (describe in Schedule O) . . . . .																307											
	<b>9</b>	<b>Total revenue.</b> Add lines 1, 2, 3, 4, 5c, 6d, 7c, and 8 . . . . . ▶																106,403											
Expenses	<b>10</b>	Grants and similar amounts paid (list in Schedule O) . . . . .																											
	<b>11</b>	Benefits paid to or for members . . . . .																											
	<b>12</b>	Salaries, other compensation, and employee benefits . . . . .																											
	<b>13</b>	Professional fees and other payments to independent contractors . . . . .																220											
	<b>14</b>	Occupancy, rent, utilities, and maintenance . . . . .																5,804											
	<b>15</b>	Printing, publications, postage, and shipping . . . . .																1,115											
	<b>16</b>	Other expenses (describe in Schedule O) . . . . .																150,956											
<b>17</b>	<b>Total expenses.</b> Add lines 10 through 16 . . . . . ▶																158,095												
Net Assets	<b>18</b>	Excess or (deficit) for the year (Subtract line 17 from line 9) . . . . .																-51,692											
	<b>19</b>	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) . . . . .																95,818											
	<b>20</b>	Other changes in net assets or fund balances (explain in Schedule O) . . . . .																-619											
	<b>21</b>	Net assets or fund balances at end of year Combine lines 18 through 20 . . . . .																43,507											

**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 . . . . .	78,300	<b>22</b>	25,989
<b>23</b> Land and buildings . . . . .	17,518	<b>23</b>	17,518
<b>24</b> Other assets (describe in Schedule O) . . . . .		<b>24</b>	
<b>25 Total assets</b> . . . . .	95,818	<b>25</b>	43,507
<b>26 Total liabilities</b> (describe in Schedule O). . . . .	0	<b>26</b>	0
<b>27 Net assets or fund balances</b> (line 27 of column (B) must agree with line 21)	95,818	<b>27</b>	43,507

**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

**Expenses**  
(Required for section 501(c)(3) and 501(c)(4) organizations, optional for others )

What is the organization's primary exempt purpose?  
**SUPPORTING CHILDREN AND FAMILIES WITH COCKAYNE 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

<b>28</b> See Additional Data Table			
(Grants \$ )	If this amount includes foreign grants, check here . . . . . <input type="checkbox"/>	<b>28a</b>	
<b>29</b> See Additional Data Table			
(Grants \$ )	If this amount includes foreign grants, check here . . . . . <input type="checkbox"/>	<b>29a</b>	
<b>30</b> See Additional Data Table			
(Grants \$ )	If this amount includes foreign grants, check here . . . . . <input type="checkbox"/>	<b>30a</b>	
<b>31</b> Other program services (describe in Schedule O) . . . . .			
(Grants \$ )	If this amount includes foreign grants, check here . . . . . <input type="checkbox"/>	<b>31a</b>	
<b>32 Total program service expenses</b> (add lines 28a through 31a)		<b>32</b>	119,985

**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
JACQUELINE ARIAS CLARK EXECUTIVE DIRECTOR/PRESIDENT	30 00	0	0	0
HAYLEE CARROLL VICE PRESIDENT	25 00	0	0	0
SETH ZIMMERMAN DIRECTOR	1 00	0	0	0
BRENT SMITH DIRECTOR	1 00	0	0	0
NIKKI EBERSTEIN DIRECTOR	4 00	0	0	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 . . . . .

Table with columns for question number, question text, and Yes/No columns. Rows include 33, 34, 35a, 35b, 35c, 36, 37a, 37b, 38a, 38b, 39, 39a, 39b, 40a, 40b, 40c, 40d, 40e, 41.

42a The organization's books are in care of JACQUELINE ARIAS CLARK Telephone no (703) 727-0404 Located at 14700 NINA COURT WATERFORD, VA ZIP + 4 20197

Table with columns for question number, question text, and Yes/No columns. Rows include 42b and 42c.

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

Table with columns for question number, question text, and Yes/No columns. Rows include 44a, 44b, 44c, 44d, 45a, 45b.

	<b>Yes</b>	<b>No</b>
<b>46</b> 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 . . . . .	<b>46</b>	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 . . . . .

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

**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.

<b>Sign Here</b> ***** Signature of officer	2019-11-14 Date
JACQUELINE ARIAS CLARK EXECUTIVE DIRECTOR/PRESIDENT Type or print name and title	

<b>Paid Preparer Use Only</b>	Print/Type preparer's name CRAIG KLEIN	Preparer's signature	Date 2019-11-14	Check <input type="checkbox"/> if self-employed	PTIN P00734640
	Firm's name ▶ CBIZ MHM LLC			Firm's EIN ▶ 26-3753134	
	Firm's address ▶ 500 BOYLSTON STREET BOSTON, MA 02116			Phone no (617) 761-0600	

May the IRS discuss this return with the preparer shown above? See instructions . . . . . ▶  Yes  No

# Additional Data

**Software ID:**

**Software Version:**

**EIN:** 01-0557037

**Name:** SHARE AND CARE COCKAYNE SYNDROME NETWORK

## 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.)	
<p><b>28</b></p> <p>CS FAMILY SERVICES PROGRAM THE PURPOSE OF THE SCCS FAMILY SERVICES PROGRAM IS TO CREATE AND FOSTER A CARING COMMUNITY THAT WILL OFFER EACH CS FAMILY INFORMATION, GUIDANCE AND EMOTIONAL SUPPORT AND MAINTAIN THE MOST COMPREHENSIVE MEMBERSHIP REGISTRY OF INDIVIDUALS AFFECTED BY COCKAYNE SYNDROME SCCS MAINTAINS THE FOLLOWING RESOURCES FOR AFFECTED FAMILIES THE CS WEBSITE WWW COCKAYNESYNDROME ORG AND THE FACEBOOK PRIVATE MEDICAL FORUM FOR COCKAYNE SYNDROME AS WELL AS THE FACEBOOK FAN PAGE OUR INTERNATIONAL CS FAMILY CONFERENCE IS HELD EVERY YEAR IN WHICH THE LATEST INFORMATION IS DISCUSSED WITH FAMILIES FREE MEDICAL CONSULTS ARE ALSO HELD ENABLING FAMILIES TO CONSULT WITH MEDICAL EXPERTS FROM AROUND THE WORLD IN ADDITION THE CONSULTS OFFER FAMILIES THE OPPORTUNITY TO PARTICIPATE IN RESEARCH STUDIES, PROVIDING IMPORTANT INFORMATION AND BLOOD SAMPLES TO TEST "CS SIBS" IS A SUPPORT PROGRAM FOR KIDS WHO HAVE SIBLINGS WITH COCKAYNE SYNDROME THEY ARE SENT A BIRTHDAY PACKAGE EVERY YEAR THAT RECOGNIZES THEM AS A TERRIFIC SIBLING WE ALSO HELP LOCATE SUMMER CAMPS FOR SIBLINGS TO ATTEND THAT WILL HELP THEM TO GROW "GOOD GRIEF" IS A SUPPORT PROGRAM FOR BEREAVED PARENTS, IT IS A PRIVATE FACEBOOK GROUP FOR PARENTS TO PROVIDE PEER TO PEER SUPPORT AND THE DISCUSSION IS FACILITATED BY A BEREAVED CS PARENT WHO HAS TRAINING IN COUNSELING</p> <p>(Grants \$ 0) <span style="float: right;">If this amount includes foreign grants, check here . . . ► <input type="checkbox"/></span></p>	<b>28a</b>	111,770

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

<p><b>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.</b></p>	<p><b>Expenses (Required for section 501(c)(3) and 501(c)(4) organizations; optional for others.)</b></p>	
<p><b>29</b>            CS AWARENESS PROGRAM AWARENESS IS THE COMMON THREAD WOVEN THROUGH ALL THE SCCS PROGRAMS OUR GOAL IS TO RAISE AWARENESS AND TO REACH OUT TO THE MEDICAL AND RESEARCH COMMUNITIES FOR THEIR SUPPORT IN THE ADVANCEMENT OF RESEARCH AND CLINICAL CARE THAT WOULD BENEFIT INDIVIDUALS AFFECTED BY COCKAYNE SYNDROME SCCS IS COMMITTED TO PROVIDING INFORMATION TO HELP PEOPLE UNDERSTAND CS THROUGH THE USE OF EVENTS, PUBLICATIONS, WEBSITE, FACEBOOK, TWITTER, INSTAGRAM, THE NETWORK DISSEMINATED INFORMATION BEYOND FAMILIES, CREATING A GLOBAL COMMUNITY WITH FUNDERS, PHYSICIANS, AND RESEARCHERS WE PROVIDE BROCHURES, BALLOONS, WRISTBANDS FOR THE BUTTERFLY WALK CS FAMILY FUND RAISERS WHICH HELP TO RAISE AWARENESS AND FUNDS TO HELP SUPPORT RESEARCH, SUPPORT PROGRAMS, AND THE ANNUAL FAMILY CONFERENCE</p> <p>(Grants \$ 0) <span style="float: right;">If this amount includes foreign grants, check here . . . <input type="checkbox"/></span></p>	<p><b>29a</b></p>	<p>7,562</p>

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

<p><b>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.</b></p>	<p><b>Expenses (Required for section 501(c)(3) and 501(c)(4) organizations; optional for others.)</b></p>	
<p><b>30</b>            CS RESEARCH PROGRAM SCCS CONTINUES TO FOLLOW RESEARCH FOR CS AND CONNECTS FAMILIES WITH RESEARCHERS OUR SCIENTIFIC MEETINGS ARE HELD EVERY-OTHER-YEAR AND ARE IN CONJUNCTION WITH OUR ANNUAL FAMILY CONFERENCES SCIENTIFIC MEETINGS ARE HELD BI-ANNUALLY            (Grants \$ 0) <span style="float: right;">If this amount includes foreign grants, check here . . . <input type="checkbox"/></span></p>	<p><b>30a</b></p>	<p>653</p>

**TY 2018 Transfers Personal Benefits  
Contracts Declaration**

**Name:** SHARE AND CARE COCKAYNE SYNDROME NETWORK

**EIN:** 01-0557037

**Declaration:** THE ORGANIZATION DID NOT, DURING THE YEAR, RECEIVE ANY FUNDS, DIRECTLY, OR INDIRECTLY, TO PAY PREMIUMS ON A PERSONAL BENEFIT CONTRACT. THE ORGANIZATION, DID NOT, DURING THE YEAR, PAY ANY PREMIUMS, DIRECTLY, OR INDIRECTLY, ON A PERSONAL BENEFIT CONTRACT.



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

**Public Charity Status and Public Support**

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.  
 Attach to Form 990 or Form 990-EZ.  
 Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

**2018**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

Name of the organization

SHARE AND CARE COCKAYNE SYNDROME NETWORK

Employer identification number

01-0557037

**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), 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) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
<b>1</b>	Gifts, grants, contributions, and membership fees received (Do not include any "unusual grant.")	74,849	199,854	176,891	248,561	106,096	806,251
<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</b>	<b>Total.</b> Add lines 1 through 3	74,849	199,854	176,891	248,561	106,096	806,251
<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)						143,731
<b>6</b>	<b>Public support.</b> Subtract line 5 from line 4						662,520

**Section B. Total Support**

	Calendar year (or fiscal year beginning in) ▶	(a) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
<b>7</b>	Amounts from line 4	74,849	199,854	176,891	248,561	106,096	806,251
<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.)		6,711		166	307	7,184
<b>11</b>	<b>Total support.</b> Add lines 7 through 10						813,435
<b>12</b>	Gross receipts from related activities, etc. (see instructions)					<b>12</b>	

**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**

<b>14</b>	Public support percentage for 2018 (line 6, column (f) divided by line 11, column (f))	<b>14</b>	81.450 %
<b>15</b>	Public support percentage for 2017 Schedule A, Part II, line 14	<b>15</b>	83.190 %

**16a 33 1/3% support test—2018.** 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—2017.** 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—2018.** 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—2017.** 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) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(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</b>	<b>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</b>	<b>Public support.</b> (Subtract line 7c from line 6)						

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ►		(a) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(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</b>	<b>Total support.</b> (Add lines 9, 10c, 11, and 12.)						

**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**

<b>15</b>	Public support percentage for 2018 (line 8, column (f) divided by line 13, column (f))	<b>15</b>	
<b>16</b>	Public support percentage from 2017 Schedule A, Part III, line 15	<b>16</b>	

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

<b>17</b>	Investment income percentage for <b>2018</b> (line 10c, column (f) divided by line 13, column (f))	<b>17</b>	
<b>18</b>	Investment income percentage from <b>2017</b> Schedule A, Part III, line 17	<b>18</b>	

**19a 33 1/3% support tests—2018.** 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—2017.** 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
<b>1</b>	Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in <b>Part VI</b> how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.		
	<b>1</b>		
<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)? If "Yes," explain in <b>Part VI</b> how the organization determined that the supported organization was described in section 509(a)(1) or (2).		
	<b>2</b>		
<b>3a</b>	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer (b) and (c) below.		
	<b>3a</b>		
<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)? If "Yes," describe in <b>Part VI</b> when and how the organization made the determination.		
	<b>3b</b>		
<b>c</b>	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in <b>Part VI</b> what controls the organization put in place to ensure such use.		
	<b>3c</b>		
<b>4a</b>	Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes" and if you checked 12a or 12b in Part I, answer (b) and (c) below.		
	<b>4a</b>		
<b>b</b>	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in <b>Part VI</b> how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.		
	<b>4b</b>		
<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)? If "Yes," explain in <b>Part VI</b> 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.		
	<b>4c</b>		
<b>5a</b>	Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer (b) and (c) below (if applicable). Also, provide detail in <b>Part VI</b> , 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).		
	<b>5a</b>		
<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>5b</b>		
<b>c</b>	<b>Substitutions only.</b> Was the substitution the result of an event beyond the organization's control?		
	<b>5c</b>		
<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? If "Yes," provide detail in <b>Part VI</b> .		
	<b>6</b>		
<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? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).		
	<b>7</b>		
<b>8</b>	Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).		
	<b>8</b>		
<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))? If "Yes," provide detail in <b>Part VI</b> .		
	<b>9a</b>		
<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? If "Yes," provide detail in <b>Part VI</b> .		
	<b>9b</b>		
<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? If "Yes," provide detail in <b>Part VI</b> .		
	<b>9c</b>		
<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)? If "Yes," answer line 10b below.		
	<b>10a</b>		
<b>b</b>	Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)		
	<b>10b</b>		

**Part IV Supporting Organizations** (continued)

		Yes	No
<b>11</b>	Has the organization accepted a gift or contribution from any of the following persons?		
<b>a</b>	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>b</b>	A family member of a person described in (a) above?		
<b>c</b>	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>		

**Section B. Type I Supporting Organizations**

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

**Section C. Type II Supporting Organizations**

		Yes	No
<b>1</b>	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>		

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

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

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

<b>1</b>	Check the box next to the method that the organization used to satisfy the Integral Part Test during the year ( <b>see instructions</b> )		
<b>a</b>	<input type="checkbox"/> The organization satisfied the Activities Test. Complete <b>line 2</b> below.		
<b>b</b>	<input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete <b>line 3</b> below.		
<b>c</b>	<input type="checkbox"/> The organization supported a governmental entity. Describe in <b>Part VI</b> how you supported a government entity (see instructions).		
<b>2</b>	Activities Test <b>Answer (a) and (b) below.</b>		
<b>a</b>	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>	Yes	No
<b>b</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>		
<b>3</b>	Parent of Supported Organizations <b>Answer (a) and (b) below.</b>		
<b>a</b>	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>		
<b>b</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>		

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

- 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.

<b>Section A - Adjusted Net Income</b>		(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</b>	<b>Adjusted Net Income</b> (subtract lines 5, 6 and 7 from line 4)	<b>8</b>	
<b>Section B - Minimum Asset Amount</b>		(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</b>	<b>Total</b> (add lines 1a, 1b, and 1c)	<b>1d</b>	
<b>e</b>	<b>Discount</b> claimed for blockage or other factors (explain in detail in Part VI)		
<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 1-1/2% 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 .035	<b>6</b>	
<b>7</b>	Recoveries of prior-year distributions	<b>7</b>	
<b>8</b>	<b>Minimum Asset Amount</b> (add line 7 to line 6)	<b>8</b>	
<b>Section C - Distributable Amount</b>			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</b>	<b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions)	<b>6</b>	
<b>7</b>	<input type="checkbox"/> 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)**

<b>Section D - Distributions</b>	<b>Current Year</b>
<b>1</b> Amounts paid to supported organizations to accomplish exempt purposes	
<b>2</b> Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
<b>3</b> Administrative expenses paid to accomplish exempt purposes of supported organizations	
<b>4</b> Amounts paid to acquire exempt-use assets	
<b>5</b> Qualified set-aside amounts (prior IRS approval required)	
<b>6</b> Other distributions (describe in <b>Part VI</b> ) See instructions	
<b>7 Total annual distributions.</b> Add lines 1 through 6	
<b>8</b> Distributions to attentive supported organizations to which the organization is responsive (provide details in <b>Part VI</b> ) See instructions	
<b>9</b> Distributable amount for 2018 from Section C, line 6	
<b>10</b> Line 8 amount divided by Line 9 amount	

<b>Section E - Distribution Allocations (see instructions)</b>	<b>(i) Excess Distributions</b>	<b>(ii) Underdistributions Pre-2018</b>	<b>(iii) Distributable Amount for 2018</b>
<b>1</b> Distributable amount for 2018 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2018 (reasonable cause required-- explain in Part VI) See instructions			
<b>3</b> Excess distributions carryover, if any, to 2018			
<b>a</b> From 2013. . . . .			
<b>b</b> From 2014. . . . .			
<b>c</b> From 2015. . . . .			
<b>d</b> From 2016. . . . .			
<b>e</b> From 2017. . . . .			
<b>f Total</b> of lines 3a through e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2018 distributable amount			
<b>i</b> Carryover from 2013 not applied (see instructions)			
<b>j</b> Remainder Subtract lines 3g, 3h, and 3i from 3f			
<b>4</b> Distributions for 2018 from Section D, line 7 \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2018 distributable amount			
<b>c</b> Remainder Subtract lines 4a and 4b from 4			
<b>5</b> Remaining underdistributions for years prior to 2018, if any Subtract lines 3g and 4a from line 2 If the amount is greater than zero, explain in Part VI See instructions			
<b>6</b> Remaining underdistributions for 2018 Subtract lines 3h and 4b from line 1 If the amount is greater than zero, explain in Part VI See instructions			
<b>7 Excess distributions carryover to 2019.</b> Add lines 3j and 4c			
<b>8</b> Breakdown of line 7			
<b>a</b> Excess from 2014. . . . .			
<b>b</b> Excess from 2015. . . . .			
<b>c</b> Excess from 2016. . . . .			
<b>d</b> Excess from 2017. . . . .			
<b>e</b> Excess from 2018. . . . .			

## Additional Data

**Software ID:**

**Software Version:**

**EIN:** 01-0557037

**Name:** SHARE AND CARE COCKAYNE SYNDROME NETWORK

**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 G  
(Form 990 or 990-EZ)**

**Supplemental Information Regarding  
Fundraising or Gaming Activities**

OMB No 1545-0047

**2018**

**Open to Public  
Inspection**

Complete if the organization answered "Yes" on Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a  
 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  
SHARE AND CARE COCKAYNE SYNDROME NETWORK

Employer identification number  
01-0557037

**Part I Fundraising Activities.** Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.

- 1** Indicate whether the organization raised funds through any of the following activities. Check all that apply.
- a  Mail solicitations
  - b  Internet and email solicitations
  - c  Phone solicitations
  - d  In-person solicitations
  - e  Solicitation of non-government grants
  - f  Solicitation of government grants
  - g  Special fundraising events
- 2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?  Yes  No
- b** If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
<b>Total</b>						

**3** List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing

**Part II Fundraising Events.** Complete if the organization answered "Yes" on Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

Revenue		(a) Event #1	(b) Event #2	(c) Other events	(d)
		<b>JAMI'S BUTTERFLY BASH</b> (event type)	(event type)	(total number)	Total events (add col (a) through col (c))
Revenue	<b>1</b> Gross receipts . . . . .				
	<b>2</b> Less Contributions . . . . .				
	<b>3</b> Gross income (line 1 minus line 2) . . . . .				
Direct Expenses	<b>4</b> Cash prizes . . . . .				
	<b>5</b> Noncash prizes . . . . .				
	<b>6</b> Rent/facility costs . . . . .				
	<b>7</b> Food and beverages . . . . .				
	<b>8</b> Entertainment . . . . .				
	<b>9</b> Other direct expenses . . . . .				
	<b>10</b> Direct expense summary Add lines 4 through 9 in column (d) . . . . . ▶				
	<b>11</b> Net income summary Subtract line 10 from line 3, column (d) . . . . . ▶				

**Part III Gaming.** Complete if the organization answered "Yes" on Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

Revenue		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col (a) through col (c))
		<b>1</b> Gross revenue . . . . .			
Direct Expenses	<b>2</b> Cash prizes . . . . .				
	<b>3</b> Noncash prizes . . . . .				
	<b>4</b> Rent/facility costs . . . . .				
	<b>5</b> Other direct expenses . . . . .				
	<b>6</b> Volunteer labor . . . . .	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	
<b>7</b> Direct expense summary Add lines 2 through 5 in column (d) . . . . . ▶					
<b>8</b> Net gaming income summary Subtract line 7 from line 1, column (d) . . . . . ▶					

**9** Enter the state(s) in which the organization conducts gaming activities \_\_\_\_\_

**a** Is the organization licensed to conduct gaming activities in each of these states?  Yes  No

**b** If "No," explain \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**10a** Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year?  Yes  No

**b** If "Yes," explain \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

- 11** Does the organization conduct gaming activities with nonmembers?  Yes  No
- 12** Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming?  Yes  No
- 13** Indicate the percentage of gaming activity conducted in
- |          |                             |   |
|----------|-----------------------------|---|
| <b>a</b> | The organization's facility | % |
| <b>b</b> | An outside facility         | % |

**14** Enter the name and address of the person who prepares the organization's gaming/special events books and records

Name ▶ .....

Address ▶ .....

**15a** Does the organization have a contract with a third party from whom the organization receives gaming revenue?  Yes  No

**b** If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ \_\_\_\_\_ and the amount of gaming revenue retained by the third party ▶ \$ \_\_\_\_\_

**c** If "Yes," enter name and address of the third party

Name ▶ .....

Address ▶ .....

**16** Gaming manager information

Name ▶ .....

Gaming manager compensation ▶ \$ .....

Description of services provided ▶ .....

Director/officer                       Employee                       Independent contractor

**17** Mandatory distributions

- a** Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license?  Yes  No
- b** Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ \_\_\_\_\_

**Part IV Supplemental Information.** Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information. See instructions.

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

Complete to provide information for responses to specific questions on Form 990 or 990-EZ or to provide any additional information.

▶ Attach to Form 990 or 990-EZ.

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

OMB No 1545-0047

**2018****Open to Public Inspection**

Department of the Treasury

Name of the organization

SHARE AND CARE COCKAYNE SYNDROME NETWORK

Employer identification number

01-0557037

**990 Schedule O, Supplemental Information**

Return Reference	Explanation
FORM 990-EZ, PART I, LINE 8 - OTHER REVENUE	DESCRIPTION REFUNDS/REIMBURSEMENTS AMOUNT 307

**990 Schedule O, Supplemental Information**

<b>Return Reference</b>	<b>Explanation</b>
FORM 990-EZ, PART I, LINE 16 - OTHER EXPENSES	DESCRIPTION SUPPLIES AMOUNT 9,135 DESCRIPTION TELEPHONE AMOUNT 9,206 DESCRIPTION BANK FEES AMOUNT 344 DESCRIPTION AUTOMOBILE EXPENSES AMOUNT 1,482 DESCRIPTION TRAVEL AMOUNT 4,813 DESCRIPTION FAMILY SUPPORT AMOUNT 7,562 DESCRIPTION WEBSITE AMOUNT 907 DESCRIPTION FAMILY CONFERENCE EXPENSES AMOUNT 111,770 DESCRIPTION RESEARCH SUPPORT/NIH AMOUNT 654 DESCRIPTION DUES & SUBSCRIPTIONS AMOUNT 973 DESCRIPTION OPERATIONS AMOUNT 658 DESCRIPTION ADVERTISING/FUNDRAISING AMOUNT 2,956 DESCRIPTION STAFF DEVELOPMENT/VOLUNTEERS AMOUNT 496 TOTAL TO FORM 990-EZ, LINE 16 150,956

**990 Schedule O, Supplemental Information**

<b>Return Reference</b>	<b>Explanation</b>
FORM 990-EZ, PART I, LINE 20 - OTHER CHANGES IN NET ASSETS	DESCRIPTION PRIOR PERIOD ADJUSTMENT AMOUNT -619