

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)

OMB No. 1545-1150
2019
Open to Public Inspection

Do not enter social security numbers on this form as it may be made public.
Go to www.irs.gov/Form990EZ for instructions and the latest information.

A For the 2019 calendar year, or tax year beginning 01-01-2019, and ending 12-31-2019

- 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
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. **\$ 88,939**

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	1	83,325
	2	Program service revenue including government fees and contracts	2	
	3	Membership dues and assessments	3	
	4	Investment income	4	
	5a	Gross amount from sale of assets other than inventory	5a	
	b	Less: cost or other basis and sales expenses	5b	
	c	Gain or (loss) from sale of assets other than inventory (Subtract line 5b from line 5a)	5c	
	6	Gaming and fundraising events		
	a	Gross income from gaming (attach Schedule G if greater than \$15,000)	6a	
	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	
c	Less: direct expenses from gaming and fundraising events	6c		
d	Net income or (loss) from gaming and fundraising events (add lines 6a and 6b and subtract line 6c)	6d		
7a	Gross sales of inventory, less returns and allowances	7a		
b	Less: cost of goods sold	7b		
c	Gross profit or (loss) from sales of inventory (Subtract line 7b from line 7a)	7c		
8	Other revenue (describe in Schedule O)	8	5,614	
9	Total revenue. Add lines 1, 2, 3, 4, 5c, 6d, 7c, and 8	9	88,939	

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	0
	14	Occupancy, rent, utilities, and maintenance	14	3,477
	15	Printing, publications, postage, and shipping	15	833
	16	Other expenses (describe in Schedule O)	16	104,523
17	Total expenses. Add lines 10 through 16	17	108,833	
Net Assets	18	Excess or (deficit) for the year (Subtract line 17 from line 9)	18	-19,894
	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	43,507
	20	Other changes in net assets or fund balances (explain in Schedule O)	20	0
	21	Net assets or fund balances at end of year. Combine lines 18 through 20	21	23,613

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	25,989	22 6,095
23 Land and buildings	17,518	23 17,518
24 Other assets (describe in Schedule O)		24
25 Total assets	43,507	25 23,613
26 Total liabilities (describe in Schedule O).	0	26 0
27 Net assets or fund balances (line 27 of column (B) must agree with line 21)	43,507	27 23,613

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?
SUPPORTING CHILDREN AND FAMILIES WITH COCKAYNE SYNDROME.

Expenses
(Required for section 501(c)(3) and 501(c)(4) organizations; optional for others.)

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

28 See Additional Data Table		
(Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>	28a	
29 See Additional Data Table		
(Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>	29a	
30 See Additional Data Table		
(Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>	30a	
31 Other program services (describe in Schedule O)		
(Grants \$) If this amount includes foreign grants, check here <input type="checkbox"/>	31a	
32 Total program service expenses (add lines 28a through 31a)	32	82,653

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/PRESIDE	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. [X]

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, and 41.

41 List the states with which a copy of this return is filed.
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, and 45b.

	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	No
b If "Yes," was the related organization a section 527 organization?	49b	

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.

***** Signature of officer	2021-01-11 Date
JACQUELINE ARIAS CLARK EXECUTIVE DIRECTOR/PRESIDENT Type or print name and title	

Paid Preparer Use Only	Print/Type preparer's name CRAIG KLEIN	Preparer's signature	Date 2020-12-22	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>28 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) If this amount includes foreign grants, check here . . . ► <input type="checkbox"/></p>	28a	70,788

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

<p>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.</p>	<p>Expenses (Required for section 501(c)(3) and 501(c)(4) organizations; optional for others.)</p>	
<p>29 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) If this amount includes foreign grants, check here . . . <input type="checkbox"/></p>	<p>29a</p>	<p>11,465</p>

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

<p>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.</p>	<p>Expenses (Required for section 501(c)(3) and 501(c)(4) organizations; optional for others.)</p>	
<p>30 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) If this amount includes foreign grants, check here . . . <input type="checkbox"/></p>	<p>30a</p>	<p style="text-align: right;">400</p>

**TY 2019 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)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

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

OMB No. 1545-0047

2019

Open to Public Inspection

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		
Total						

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization failed to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grant.") . . .	199,854	176,891	248,561	106,096	83,325	814,727
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	199,854	176,891	248,561	106,096	83,325	814,727
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). . .						163,449
6 Public support. Subtract line 5 from line 4.						651,278

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
7 Amounts from line 4. . .	199,854	176,891	248,561	106,096	83,325	814,727
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources. . . .						
9 Net income from unrelated business activities, 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.). . .	6,711		166	307	5,614	12,798
11 Total support. Add lines 7 through 10						827,525

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 2019 (line 6, column (f) divided by line 11, column (f))	14	78.700 %
15 Public support percentage for 2018 Schedule A, Part II, line 14	15	81.450 %

16a 33 1/3% support test—2019. 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—2018. 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—2019. 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—2018. 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) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
1	Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2	Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3	Gross receipts from activities that are not an unrelated trade or business under section 513						
4	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf.						
5	The value of services or facilities furnished by a governmental unit to the organization without charge						
6	Total. Add lines 1 through 5						
7a	Amounts included on lines 1, 2, and 3 received from disqualified persons						
b	Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year.						
c	Add lines 7a and 7b.						
8	Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶		(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
9	Amounts from line 6.						
10a	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources.						
b	Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975.						
c	Add lines 10a and 10b.						
11	Net income from unrelated business activities not included 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.)						

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 2019 (line 8, column (f) divided by line 13, column (f))	15	
16	Public support percentage from 2018 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17	Investment income percentage for 2019 (line 10c, column (f) divided by line 13, column (f))	17	
18	Investment income percentage from 2018 Schedule A, Part III, line 17	18	

19a 33 1/3% support tests—2019. 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—2018. 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>		

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>		
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>		

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>		

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?		
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>		
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>		

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	<input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.		
b	<input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.		
c	<input type="checkbox"/> 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>	Yes	No
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>		
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>		
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

- 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	<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)

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 2019 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-2019	(iii) Distributable Amount for 2019
1 Distributable amount for 2019 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2019 (reasonable cause required-- explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2019:			
a From 2014.			
b From 2015.			
c From 2016.			
d From 2017.			
e From 2018.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2019 distributable amount			
i Carryover from 2014 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
4 Distributions for 2019 from Section D, line 7:			
\$			
a Applied to underdistributions of prior years			
b Applied to 2019 distributable amount			
c Remainder. Subtract lines 4a and 4b from 4.			
5 Remaining underdistributions for years prior to 2019, 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 2019. 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 2020. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2015.			
b Excess from 2016.			
c Excess from 2017.			
d Excess from 2018.			
e Excess from 2019.			

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 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 for the latest information.

2019
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: 5,614.

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990-EZ, PART I, LINE 16 - OTHER EXPENSES	DESCRIPTION: SUPPLIES. AMOUNT: 5,437. DESCRIPTION: TELEPHONE. AMOUNT: 9,148. DESCRIPTION: BANK FEES. AMOUNT: 601. DESCRIPTION: AUTOMOBILE EXPENSES. AMOUNT: 2,197. DESCRIPTION: TRAVEL. AMOUNT: 2,195. DESCRIPTION: FAMILY SUPPORT. AMOUNT: 11,465. DESCRIPTION: WEBSITE. AMOUNT: 651. DESCRIPTION: FAMILY CONFERENCE EXPENSES. AMOUNT: 70,788. DESCRIPTION: RESEARCH SUPPORT/NIH. AMOUNT: 400. DESCRIPTION: DUES & SUBSCRIPTIONS. AMOUNT: 1,593. DESCRIPTION: OPERATIONS. AMOUNT: 48. TOTAL TO FORM 990-EZ, LINE 16: 104,523.