

990

Return of Organization Exempt From Income Tax

OMB No. 1545-0047

2019

Form (Rev. January 2020)

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

Open to Public Inspection

Do not enter social security numbers on this form as it may be made public.  
Go to www.irs.gov/Form990 for instructions and the latest information.

**A** For the 2019 calendar year, or tax year beginning and ending

<b>B</b> Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Final return/terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	<b>C</b> Name of organization <b>RETT SYNDROME RESEARCH TRUST, INC</b>		<b>D</b> Employer identification number <b>** - ***7439</b>
	Doing business as		<b>E</b> Telephone number <b>203-445-0041</b>
	Number and street (or P.O. box if mail is not delivered to street address)	Room/suite	
	<b>67 UNDER CLIFF ROAD</b>		<b>G</b> Gross receipts \$ <b>8,843,348.</b>
	City or town, state or province, country, and ZIP or foreign postal code <b>TRUMBULL, CT 06611</b>		
<b>F</b> Name and address of principal officer: <b>MONICA COENRAADS</b> <b>67 UNDERCLIFF ROAD, TRUMBULL, CT 06611</b>		<b>H(a)</b> Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No <b>H(b)</b> Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. (see instructions) <b>H(c)</b> Group exemption number ▶	

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

**J** Website: ▶ **WWW.RSRT.ORG**

**K** Form of organization:  Corporation  Trust  Association  Other ▶ **L** Year of formation: **2007** **M** State of legal domicile: **CT**

**Part I Summary**

<b>Activities &amp; Governance</b>	1 Briefly describe the organization's mission or most significant activities: <b>THE ORGANIZATION'S MISSION IS FOCUSED ON THE DEVELOPMENT OF TREATMENTS AND CURES FOR RETT SYNDROME</b>	
	2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.	
	3	Number of voting members of the governing body (Part VI, line 1a) ..... <b>3</b> <b>14</b>
	4	Number of independent voting members of the governing body (Part VI, line 1b) ..... <b>4</b> <b>14</b>
	5	Total number of individuals employed in calendar year 2019 (Part V, line 2a) ..... <b>5</b> <b>9</b>
	6	Total number of volunteers (estimate if necessary) ..... <b>6</b> <b>75</b>
	7a	Total unrelated business revenue from Part VIII, column (C), line 12 ..... <b>7a</b> <b>0.</b>
	7b	Net unrelated business taxable income from Form 990-T, line 39 ..... <b>7b</b> <b>0.</b>
<b>Revenue</b>	8 Contributions and grants (Part VIII, line 1h) ..... <b>9,639,117.</b> <b>8,348,103.</b>	
	9 Program service revenue (Part VIII, line 2g) ..... <b>0.</b> <b>128,333.</b>	
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d) ..... <b>25,063.</b> <b>38,677.</b>	
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) ..... <b>0.</b> <b>0.</b>	
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12) ..... <b>9,664,180.</b> <b>8,515,113.</b>	
<b>Expenses</b>	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3) ..... <b>9,619,077.</b> <b>8,530,142.</b>	
	14 Benefits paid to or for members (Part IX, column (A), line 4) ..... <b>0.</b> <b>0.</b>	
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) ..... <b>1,208,155.</b> <b>1,493,133.</b>	
	16a Professional fundraising fees (Part IX, column (A), line 11e) ..... <b>0.</b> <b>0.</b>	
	b Total fundraising expenses (Part IX, column (D), line 25) ▶ <b>591,337.</b>	
	17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) ..... <b>549,960.</b> <b>641,832.</b>	
	18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) ..... <b>11,377,192.</b> <b>10,665,107.</b>	
19 Revenue less expenses. Subtract line 18 from line 12 ..... <b>-1,713,012.</b> <b>-2,149,994.</b>		
<b>Net Assets or Fund Balances</b>	20 Total assets (Part X, line 16) ..... <b>11,319,755.</b> <b>9,801,315.</b>	
	21 Total liabilities (Part X, line 26) ..... <b>15,692,025.</b> <b>16,250,240.</b>	
	22 Net assets or fund balances. Subtract line 21 from line 20 ..... <b>-4,372,270.</b> <b>-6,448,925.</b>	

**Part II Signature Block**

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

<b>Sign Here</b>	Signature of officer	Date			
	<b>MONICA COENRAADS, EXECUTIVE DIRECTOR</b> Type or print name and title				
<b>Paid Preparer Use Only</b>	Print/Type preparer's name <b>JOHN M. ROLLERI, CPA</b>	Preparer's signature	Date	Check if self-employed <input checked="" type="checkbox"/>	PTIN <b>P00182555</b>
	Firm's name ▶ <b>KNIGHT ROLLERI SHEPPARD CPAS LLP</b>	Firm's address ▶ <b>1499 POST ROAD, SUITE 1040 FAIRFIELD, CT 06824</b>	Firm's EIN ▶ <b>** - ***6122</b>	Phone no. (203) <b>259-2727</b>	

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

# Application for Automatic Extension of Time To File an Exempt Organization Return

OMB No. 1545-0047

Department of the Treasury  
Internal Revenue Service

▶ **File a separate application for each return.**  
▶ **Go to [www.irs.gov/Form8868](http://www.irs.gov/Form8868) for the latest information.**

**Electronic filing (e-file).** You can electronically file Form 8868 to request a 6-month automatic extension of time to file any of the forms listed below with the exception of Form 8870, Information Return for Transfers Associated With Certain Personal Benefit Contracts, for which an extension request must be sent to the IRS in paper format (see instructions). For more details on the electronic filing of this form, visit [www.irs.gov/e-file-providers/e-file-for-charities-and-non-profits](http://www.irs.gov/e-file-providers/e-file-for-charities-and-non-profits).

## Automatic 6-Month Extension of Time. Only submit original (no copies needed).

All corporations required to file an income tax return other than Form 990-T (including 1120-C filers), partnerships, REMICs, and trusts must use Form 7004 to request an extension of time to file income tax returns.

<b>Type or print</b>	Name of exempt organization or other filer, see instructions.  <b>RETT SYNDROME RESEARCH TRUST, INC</b>	Taxpayer identification number (TIN)  <b>** - ***7439</b>
File by the due date for filing your return. See instructions.	Number, street, and room or suite no. If a P.O. box, see instructions. <b>67 UNDER CLIFF ROAD</b>	
	City, town or post office, state, and ZIP code. For a foreign address, see instructions. <b>TRUMBULL, CT 06611</b>	

Enter the Return Code for the return that this application is for (file a separate application for each return) 0 1

Application Is For	Return Code	Application Is For	Return Code
Form 990 or Form 990-EZ	01	Form 990-T (corporation)	07
Form 990-BL	02	Form 1041-A	08
Form 4720 (individual)	03	Form 4720 (other than individual)	09
Form 990-PF	04	Form 5227	10
Form 990-T (sec. 401(a) or 408(a) trust)	05	Form 6069	11
Form 990-T (trust other than above)	06	Form 8870	12

**MONICA COENRAADS**

- The books are in the care of ▶ **67 UNDER CLIFF ROAD - TRUMBULL, CT 06611**  
Telephone No. ▶ **203-445-0041** Fax No. ▶ \_\_\_\_\_
- If the organization does not have an office or place of business in the United States, check this box
- If this is for a Group Return, enter the organization's four digit Group Exemption Number (GEN) \_\_\_\_\_. If this is for the whole group, check this box . If it is for part of the group, check this box  and attach a list with the names and TINs of all members the extension is for.

1 I request an automatic 6-month extension of time until **NOVEMBER 16, 2020**, to file the exempt organization return for the organization named above. The extension is for the organization's return for:  
▶  calendar year **2019** or  
▶  tax year beginning \_\_\_\_\_, and ending \_\_\_\_\_

2 If the tax year entered in line 1 is for less than 12 months, check reason:  Initial return  Final return  
 Change in accounting period

3a If this application is for Forms 990-BL, 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less any nonrefundable credits. See instructions.	<b>3a</b>	\$	0.
b If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit.	<b>3b</b>	\$	0.
c <b>Balance due.</b> Subtract line 3b from line 3a. Include your payment with this form, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions.	<b>3c</b>	\$	0.

**Caution:** If you are going to make an electronic funds withdrawal (direct debit) with this Form 8868, see Form 8453-EO and Form 8879-EO for payment instructions.

# IRS e-file Signature Authorization for an Exempt Organization

# 2019

For calendar year 2019, or fiscal year beginning \_\_\_\_\_, 2019, and ending \_\_\_\_\_, 20\_\_\_\_

Department of the Treasury  
Internal Revenue Service

▶ **Do not send to the IRS. Keep for your records.**

▶ **Go to [www.irs.gov/Form8879EO](http://www.irs.gov/Form8879EO) for the latest information.**

Name of exempt organization

Employer identification number

**RETT SYNDROME RESEARCH TRUST, INC**

**\*\* - \*\*\*7439**

Name and title of officer

**MONICA COENRAADS  
EXECUTIVE DIRECTOR**

### Part I Type of Return and Return Information (Whole Dollars Only)

Check the box for the return for which you are using this Form 8879-EO and enter the applicable amount, if any, from the return. If you check the box on line 1a, 2a, 3a, 4a, or 5a, below, and the amount on that line for the return being filed with this form was blank, then leave line 1b, 2b, 3b, 4b, or 5b, whichever is applicable, blank (do not enter -0-). But, if you entered -0- on the return, then enter -0- on the applicable line below. Do not complete more than one line in Part I.

1a	Form 990 check here	▶ <input checked="" type="checkbox"/>	b	Total revenue, if any (Form 990, Part VIII, column (A), line 12)	1b	<u>8,515,113.</u>
2a	Form 990-EZ check here	▶ <input type="checkbox"/>	b	Total revenue, if any (Form 990-EZ, line 9)	2b	_____
3a	Form 1120-POL check here	▶ <input type="checkbox"/>	b	Total tax (Form 1120-POL, line 22)	3b	_____
4a	Form 990-PF check here	▶ <input type="checkbox"/>	b	Tax based on investment income (Form 990-PF, Part VI, line 5)	4b	_____
5a	Form 8868 check here	▶ <input type="checkbox"/>	b	Balance Due (Form 8868, line 3c)	5b	_____

### Part II Declaration and Signature Authorization of Officer

Under penalties of perjury, I declare that I am an officer of the above organization and that I have examined a copy of the organization's 2019 electronic return and accompanying schedules and statements and to the best of my knowledge and belief, they are true, correct, and complete. I further declare that the amount in Part I above is the amount shown on the copy of the organization's electronic return. I consent to allow my intermediate service provider, transmitter, or electronic return originator (ERO) to send the organization's return to the IRS and to receive from the IRS (a) an acknowledgement of receipt or reason for rejection of the transmission, (b) the reason for any delay in processing the return or refund, and (c) the date of any refund. If applicable, I authorize the U.S. Treasury and its designated Financial Agent to initiate an electronic funds withdrawal (direct debit) entry to the financial institution account indicated in the tax preparation software for payment of the organization's federal taxes owed on this return, and the financial institution to debit the entry to this account. To revoke a payment, I must contact the U.S. Treasury Financial Agent at 1-888-353-4537 no later than 2 business days prior to the payment (settlement) date. I also authorize the financial institutions involved in the processing of the electronic payment of taxes to receive confidential information necessary to answer inquiries and resolve issues related to the payment. I have selected a personal identification number (PIN) as my signature for the organization's electronic return and, if applicable, the organization's consent to electronic funds withdrawal.

Officer's PIN: check one box only

I authorize **KNIGHT ROLLERI SHEPPARD CPAS LLP** to enter my PIN **16161**  
ERO firm name Enter five numbers, but do not enter all zeros

as my signature on the organization's tax year 2019 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I also authorize the aforementioned ERO to enter my PIN on the return's disclosure consent screen.

As an officer of the organization, I will enter my PIN as my signature on the organization's tax year 2019 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I will enter my PIN on the return's disclosure consent screen.

Officer's signature ▶ \_\_\_\_\_ Date ▶ \_\_\_\_\_

### Part III Certification and Authentication

ERO's EFIN/PIN. Enter your six-digit electronic filing identification number (EFIN) followed by your five-digit self-selected PIN.

**06175129929**

Do not enter all zeros

I certify that the above numeric entry is my PIN, which is my signature on the 2019 electronically filed return for the organization indicated above. I confirm that I am submitting this return in accordance with the requirements of Pub. 4163, Modernized e-File (MeF) Information for Authorized IRS e-file Providers for Business Returns.

ERO's signature ▶ \_\_\_\_\_ Date ▶ \_\_\_\_\_

**ERO Must Retain This Form - See Instructions  
Do Not Submit This Form to the IRS Unless Requested To Do So**

Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response or note to any line in this Part III [X]

1 Briefly describe the organization's mission: THE ORGANIZATION'S MISSION IS FOCUSED ON THE DEVELOPMENT OF TREATMENTS AND CURES FOR RETT SYNDROME AND RELATED MECP2 DISORDERS.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? [ ] Yes [X] No

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? [ ] Yes [X] No

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses.

4a (Code: ) (Expenses \$ 9,730,984. including grants of \$ 8,530,142. ) (Revenue \$ 164,776. ) THE ORGANIZATION PROVIDES FUNDING TO LEADING RESEARCH INSTITUTIONS WORKING ON RETT SYNDROME AND RELATED MECP2 DISORDERS. RESEARCH IS AIMED AT 1) RESTORING LEVELS OF MECP2 PROTEIN, 2) IDENTIFYING OBJECTIVE TOOLS TO MEASURE RETT SYMPTOMS 3) ESTABLISH A CLINICAL TRIAL NETWORK 4) IDENTIFY FUNCTION OF MECP2 PROTEIN.

4b (Code: ) (Expenses \$ 134,543. including grants of \$ ) (Revenue \$ ) THE ORGANIZATION SPONSORS SCIENTIFIC WORKSHOPS THAT BRING THE LEADING RETT RESEARCHERS TOGETHER WITH ELITE SCIENTISTS IN SYNERGISTIC FIELDS TO EXCHANGE DATA AND SET RESEARCH DIRECTION.

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

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

4e Total program service expenses 9,865,527.

**Part IV Checklist of Required Schedules**

		Yes	No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A</i>	X	
2	Is the organization required to complete Schedule B, Schedule of Contributors?	X	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i>		X
4	<b>Section 501(c)(3) organizations.</b> Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II</i>		X
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? <i>If "Yes," complete Schedule C, Part III</i>		X
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I</i>		X
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i>		X
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i>		X
9	Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV</i>		X
10	Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi endowments? <i>If "Yes," complete Schedule D, Part V</i>		X
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI</i>	X	
b	Did the organization report an amount for investments - other securities in Part X, line 12, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII</i>		X
c	Did the organization report an amount for investments - program related in Part X, line 13, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII</i>		X
d	Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX</i>		X
e	Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i>		X
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i>	X	
12a	Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i>	X	
b	Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i>		X
13	Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?		X
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV</i>	X	
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV</i>	X	
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV</i>		X
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I</i>		X
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II</i>		X
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i>		X
20a	Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>		X
b	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		
21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	X	

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question number, Question text, and Yes/No columns. Rows include questions 22 through 38 regarding grants, compensation, tax-exempt bonds, excess benefit transactions, and other IRS requirements.

Note: All Form 990 filers are required to complete Schedule O

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

Table with 3 columns: Question number, Question text, and Yes/No columns. Rows include questions 1a, 1b, and 1c regarding Form 1096, W-2G forms, and backup withholding rules.

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

Table with columns for question number, question text, and Yes/No checkboxes. Includes questions 2a through 16 regarding employee counts, tax returns, unrelated business income, foreign accounts, prohibited transactions, and charitable contributions.



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

Check if Schedule O contains a response or note to any line in this Part VI [X]

Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include 1a (14), 1b (14), 2, 3, 4, 5, 6, 7a, 7b, 8a, 8b, 9.

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

Table with 3 columns: Question, Yes, No. Rows include 10a, 10b, 11a, 11b, 12a, 12b, 12c, 13, 14, 15a, 15b, 16a, 16b.

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed CA, CT, IL, MA, MD, NJ, NY, PA
18 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (Section 501(c)(3)s only) available for public inspection.
19 Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
20 State the name, address, and telephone number of the person who possesses the organization's books and records



**Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors**

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

**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees**

1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations. See instructions for the order in which to list the persons above.

Check this box if neither the organization nor any related organization compensated any current officer, director, or trustee.

(A) Name and title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) INGRID HARDING CO-FOUNDER AND TRUSTEE	2.00	X						0.	0.	0.
(2) LAWRENCE MATTIS SECRETARY	2.00	X		X				0.	0.	0.
(3) ADRIAN BIRD TRUSTEE	2.00	X						0.	0.	0.
(4) HEIDI EPSTEIN VICE CHAIRMAN	2.00	X		X				0.	0.	0.
(5) ANTHONY SCHOENER CHAIRMAN	5.00	X		X				0.	0.	0.
(6) MARCI VALNER TREASURER	2.00	X		X				0.	0.	0.
(7) RACHEL STEVENSON TRUSTEE	2.00	X						0.	0.	0.
(8) STEPHANIE BOHN TRUSTEE	2.00	X						0.	0.	0.
(9) ALBA TULL TRUSTEE	2.00	X						0.	0.	0.
(10) BRAD ZELINGER TRUSTEE	2.00	X						0.	0.	0.
(11) MARC TESLER TRUSTEE	2.00	X						0.	0.	0.
(12) MONICA COENRAADS EXECUTIVE DIRECTOR AND CO-	50.00	X	X					187,917.	0.	33,988.
(13) TIM FREEMAN CHIEF DEVELOPMENT OFFICER	50.00				X			208,333.	0.	0.
(14) RANDALL CARPENTER CHIEF MEDICAL OFFICER	50.00				X			165,000.	0.	0.
(15) EDRIAN COLINA CREATIVE DIRECTOR	40.00					X		126,667.	0.	16,553.
(16) TIMOTHY RILEY CHIEF SCIENTIFIC OFFICER	50.00					X		350,000.	0.	0.
(17) JANA VON HEHN DIRECTOR OF RESEARCH	50.00					X		169,583.	0.	0.



**Part VIII Statement of Revenue**

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

		(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512 - 514	
Contributions, Gifts, Grants and Other Similar Amounts	1 a Federated campaigns	1a				
	b Membership dues	1b				
	c Fundraising events	1c				
	d Related organizations	1d				
	e Government grants (contributions)	1e				
	f All other contributions, gifts, grants, and similar amounts not included above	1f 8,348,103.				
	g Noncash contributions included in lines 1a-1f	1g \$ 8,000.				
	<b>h Total. Add lines 1a-1f</b>		<b>8,348,103.</b>			
	Program Service Revenue	2 a LICENSING	Business Code 900099	128,333.	128,333.	
b						
c						
d						
e						
f All other program service revenue						
<b>g Total. Add lines 2a-2f</b>			<b>128,333.</b>			
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		36,443.	36,443.		
	4 Income from investment of tax-exempt bond proceeds					
	5 Royalties					
	6 a Gross rents	6a	(i) Real (ii) Personal			
		b Less: rental expenses	6b			
		c Rental income or (loss)	6c			
	d Net rental income or (loss)					
	7 a Gross amount from sales of assets other than inventory	7a	(i) Securities (ii) Other	330,469.		
		b Less: cost or other basis and sales expenses	7b	328,235.		
		c Gain or (loss)	7c	2,234.		
	d Net gain or (loss)			2,234.	2,234.	
	8 a Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c). See Part IV, line 18	8a				
	b Less: direct expenses	8b				
c Net income or (loss) from fundraising events						
9 a Gross income from gaming activities. See Part IV, line 19	9a					
b Less: direct expenses	9b					
c Net income or (loss) from gaming activities						
10 a Gross sales of inventory, less returns and allowances	10a					
b Less: cost of goods sold	10b					
c Net income or (loss) from sales of inventory						
Miscellaneous Revenue	11 a	Business Code				
	b					
	c					
	d All other revenue					
	<b>e Total. Add lines 11a-11d</b>					
<b>12 Total revenue. See instructions</b>		<b>8,515,113.</b>	<b>164,776.</b>	<b>0.</b>	<b>2,234.</b>	

**Part IX Statement of Functional Expenses**

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

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

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
<b>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</b>				
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	8,530,142.	8,530,142.		
2 Grants and other assistance to domestic individuals. See Part IV, line 22				
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16				
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	561,250.	421,973.	59,830.	79,447.
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7 Other salaries and wages	790,652.	594,447.	84,285.	111,920.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits	51,325.	38,589.	5,471.	7,265.
10 Payroll taxes	89,906.	67,595.	9,584.	12,727.
11 Fees for services (nonemployees):				
a Management				
b Legal				
c Accounting	784.		784.	
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees				
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Sch O.)	51,751.	16,818.	34,933.	
12 Advertising and promotion				
13 Office expenses	8,817.	1,052.	7,567.	198.
14 Information technology				
15 Royalties				
16 Occupancy	5,070.	3,812.	540.	718.
17 Travel				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings				
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	1,061.	1,013.	5.	43.
23 Insurance	5,915.	1,973.	1,971.	1,971.
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a <b>FUNDRAISING</b>	371,936.			371,936.
b <b>SCIENTIFIC MEETINGS AND</b>	134,543.	134,543.		
c <b>MISCELLANEOUS</b>	39,307.	34,627.	1,822.	2,858.
d <b>PRINTING AND PUBLICATIO</b>	6,294.	6,007.	30.	257.
e All other expenses	16,354.	12,936.	1,421.	1,997.
25 <b>Total functional expenses.</b> Add lines 1 through 24e	10,665,107.	9,865,527.	208,243.	591,337.
26 <b>Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.				

Check here  if following SOP 88-2 (ASC 958-720)

**Part X Balance Sheet**

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

		(A) Beginning of year		(B) End of year	
Assets	1	Cash - non-interest-bearing	8,694,126.	1	8,232,008.
	2	Savings and temporary cash investments		2	1,100.
	3	Pledges and grants receivable, net	2,623,507.	3	1,567,147.
	4	Accounts receivable, net		4	
	5	Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		5	
	6	Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7	Notes and loans receivable, net		7	
	8	Inventories for sale or use		8	
	9	Prepaid expenses and deferred charges		9	
	10a	Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 6,440.		
	b	Less: accumulated depreciation	10b 5,380.	2,122.	10c 1,060.
	11	Investments - publicly traded securities		11	
	12	Investments - other securities. See Part IV, line 11		12	
	13	Investments - program-related. See Part IV, line 11		13	
	14	Intangible assets		14	
	15	Other assets. See Part IV, line 11		15	
16	<b>Total assets.</b> Add lines 1 through 15 (must equal line 33)		11,319,755.	16	9,801,315.
Liabilities	17	Accounts payable and accrued expenses	19,879.	17	31,908.
	18	Grants payable	15,672,146.	18	16,218,332.
	19	Deferred revenue		19	
	20	Tax-exempt bond liabilities		20	
	21	Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22	Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		22	
	23	Secured mortgages and notes payable to unrelated third parties		23	
	24	Unsecured notes and loans payable to unrelated third parties		24	
	25	Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D		25	
	26	<b>Total liabilities.</b> Add lines 17 through 25		15,692,025.	26
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.				
	27	Net assets without donor restrictions	-4,372,270.	27	-6,448,925.
	28	Net assets with donor restrictions		28	
	Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.				
	29	Capital stock or trust principal, or current funds		29	
	30	Paid-in or capital surplus, or land, building, or equipment fund		30	
	31	Retained earnings, endowment, accumulated income, or other funds		31	
32	<b>Total net assets or fund balances</b>		-4,372,270.	32	-6,448,925.
33	<b>Total liabilities and net assets/fund balances</b>		11,319,755.	33	9,801,315.

Form 990 (2019)

**Part XI Reconciliation of Net Assets**

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	8,515,113.
2	Total expenses (must equal Part IX, column (A), line 25)	2	10,665,107.
3	Revenue less expenses. Subtract line 2 from line 1	3	-2,149,994.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	-4,372,270.
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	73,339.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	-6,448,925.

**Part XII Financial Statements and Reporting**

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

		Yes	No
1	Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other		
If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.			
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?		X
If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both:			
<input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis			
2b	Were the organization's financial statements audited by an independent accountant?	X	
If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both:			
<input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis			
2c	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant?	X	
If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.			
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		X
3b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits		

Form 990 (2019)





**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 fails 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 grants.") .....	5990613.	7849652.	12518139.	9631117.	8340103.	44329624.
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 <b>Total.</b> Add lines 1 through 3 .....	5990613.	7849652.	12518139.	9631117.	8340103.	44329624.
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f) .....						
6 <b>Public support.</b> Subtract line 5 from line 4.						44329624.

**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 .....	5990613.	7849652.	12518139.	9631117.	8340103.	44329624.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources .....	13,509.	10,864.	11,583.	23,178.	36,443.	95,577.
9 Net income from unrelated business activities, whether or not the business is regularly carried on .....						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) .....						
11 <b>Total support.</b> Add lines 7 through 10						44425201.
12 Gross receipts from related activities, etc. (see instructions) .....					12	
13 <b>First five years.</b> If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here .....	<input type="checkbox"/>					

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

14 Public support percentage for 2019 (line 6, column (f) divided by line 11, column (f)) .....	14	99.78	%
15 Public support percentage from 2018 Schedule A, Part II, line 14 .....	15	99.82	%
16a <b>33 1/3% support test - 2019.</b> 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 .....	<input checked="" type="checkbox"/>		
b <b>33 1/3% support test - 2018.</b> 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 .....	<input type="checkbox"/>		
17a <b>10% -facts-and-circumstances test - 2019.</b> 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 .....	<input type="checkbox"/>		
b <b>10% -facts-and-circumstances test - 2018.</b> 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 .....	<input type="checkbox"/>		
18 <b>Private foundation.</b> If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions .....	<input type="checkbox"/>		

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

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
<b>9</b> Amounts from line 6 .....						
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources .....						
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 .....						
<b>c</b> Add lines 10a and 10b .....						
<b>11</b> Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on .....						
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) .....						
<b>13 Total support.</b> (Add lines 9, 10c, 11, and 12.)						
<b>14 First five years.</b> If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and <b>stop here</b> .....						

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

<b>15</b> Public support percentage for 2019 (line 8, column (f), divided by line 13, column (f)) .....	<b>15</b>	%
<b>16</b> Public support percentage from 2018 Schedule A, Part III, line 15 .....	<b>16</b>	%

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

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

- 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 in line 12 on 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>		
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>		
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>		
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>		
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>		
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>		
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>		
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>		
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>		
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?		
c <b>Substitutions only.</b> Was the substitution the result of an event beyond the organization's control?		
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>		
7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as 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>		
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>		
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>		
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>		
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>		
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 10b below.</i>		
b Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i>		

**Part IV Supporting Organizations** (continued)

	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? If "Yes" to a, b, or c, provide detail in Part VI.		

**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? 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.		
<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? 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.		

**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)? 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).		

**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? If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).		
<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? If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.		

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

**1** Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).

**a**  The organization satisfied the Activities Test. Complete line 2 below.

**b**  The organization is the parent of each of its supported organizations. Complete line 3 below.

**c**  The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).

**2** Activities Test. Answer (a) and (b) below.

	Yes	No
<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? If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.		
<b>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? 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.		
<b>3</b> Parent of Supported Organizations. Answer (a) and (b) below.		
<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? Provide details in Part VI.		
<b>b</b> Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.		

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

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

Section A - Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
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	<b>Adjusted Net Income</b> (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):		
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	<b>Total</b> (add lines 1a, 1b, and 1c)	1d	
e	<b>Discount</b> 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	<b>Minimum Asset Amount</b> (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	<b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6	

7  Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).

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

Section D - Distributions	Current Year
1 Amounts paid to supported organizations to accomplish exempt purposes	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	
4 Amounts paid to acquire exempt-use assets	
5 Qualified set-aside amounts (prior IRS approval required)	
6 Other distributions (describe in Part VI). See instructions.	
7 <b>Total annual distributions.</b> 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 <b>Total</b> 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. For result greater than zero, explain in Part VI. See instructions.			
6 Remaining underdistributions for 2019. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.			
7 <b>Excess distributions carryover to 2020.</b> 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			





SCHEDULE D (Form 990)

Supplemental Financial Statements

OMB No. 1545-0047

2019

Open to Public Inspection

Complete if the organization answered "Yes" on Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.

Attach to Form 990.

Go to www.irs.gov/Form990 for instructions and the latest information.

Department of the Treasury Internal Revenue Service

Name of the organization

RETT SYNDROME RESEARCH TRUST, INC

Employer identification number

\*\* - \*\*\*7439

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts. Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

Table with 3 columns: Line number, (a) Donor advised funds, (b) Funds and other accounts. Rows 1-4 for values, 5-6 for Yes/No questions.

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

Table with 3 columns: Line number, Description, Held at the End of the Tax Year. Rows 1-7 for descriptions and values, 8-9 for Yes/No questions.

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

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

Table with 3 columns: Line number, Description, Amount. Rows 1a-1b for art collection descriptions, 2 for financial gain amounts.

**Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets** (continued)

3 Using the organization's acquisition, accession, and other records, check any of the following that make significant use of its collection items (check all that apply):

- a  Public exhibition
- b  Scholarly research
- c  Preservation for future generations
- d  Loan or exchange program
- e  Other \_\_\_\_\_

4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.

5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?  Yes  No

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

1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?  Yes  No

b If "Yes," explain the arrangement in Part XIII and complete the following table:

	Amount
c Beginning balance	1c
d Additions during the year	1d
e Distributions during the year	1e
f Ending balance	1f

2a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability?  Yes  No

b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided on Part XIII

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

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

2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:

- a Board designated or quasi-endowment  %
- b Permanent endowment  %
- c Term endowment  %

The percentages on lines 2a, 2b, and 2c should equal 100%.

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

	Yes	No
(i) Unrelated organizations	3a(i)	
(ii) Related organizations	3a(ii)	
b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R?	3b	

4 Describe in Part XIII the intended uses of the organization's endowment funds.

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

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment		6,440.	5,380.	1,060.
e Other				
<b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.)				1,060.

Part VII Investments - Other Securities.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

Table with 3 columns: (a) Description of security or category, (b) Book value, (c) Method of valuation. Rows include (1) Financial derivatives, (2) Closely held equity interests, (3) Other, and sub-rows (A) through (H).

Part VIII Investments - Program Related.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

Table with 3 columns: (a) Description of investment, (b) Book value, (c) Method of valuation. Rows numbered (1) through (9).

Part IX Other Assets.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

Table with 2 columns: (a) Description, (b) Book value. Rows numbered (1) through (9).

Part X Other Liabilities.

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

Table with 2 columns: (a) Description of liability, (b) Book value. Row 1 includes sub-rows (1) Federal income taxes, (2) through (9).

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII... [X]

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

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

1	Total revenue, gains, and other support per audited financial statements		1	8,515,113.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a		
b	Donated services and use of facilities	2b		
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	0.
3	Subtract line 2e from line 1		3	8,515,113.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b		4c	0.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)		5	8,515,113.

**Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return.**

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

1	Total expenses and losses per audited financial statements		1	10,665,107.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a		
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d		2e	0.
3	Subtract line 2e from line 1		3	10,665,107.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b		4c	0.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)		5	10,665,107.

**Part XIII Supplemental Information.**

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

**PART X, LINE 2:**

THE ORGANIZATION HAS BEEN GRANTED TAX-EXEMPT STATUS BY THE INTERNAL REVENUE SERVICE UNDER INTERNAL REVENUE CODE SECTION 501(C)(3).

ACCORDINGLY, NO PROVISION FOR FEDERAL OR STATE INCOME TAXES HAS BEEN RECORDED IN THE ACCOMPANYING FINANCIAL STATEMENTS. MANAGEMENT OF THE

ORGANIZATION DOES NOT BELIEVE IT HAS ANY UNCERTAIN TAX POSITIONS. THE ORGANIZATION'S TAX RETURNS REMAIN OPEN TO EXAMINATION BY REGULATORY

AUTHORITIES FROM DECEMBER 31, 2017.

**SCHEDULE F  
(Form 990)**

**Statement of Activities Outside the United States**

OMB No. 1545-0047

**2019**

Department of the Treasury  
Internal Revenue Service

▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.

▶ Attach to Form 990.

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

Open to Public  
Inspection

Name of the organization

Employer identification number

**RETT SYNDROME RESEARCH TRUST, INC**

**\*\* - \*\*\*7439**

**Part I General Information on Activities Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 14b.

**1 For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? .....  Yes  No

**2 For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

**3 Activities per Region.** (The following Part I, line 3 table can be duplicated if additional space is needed.)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA, AUSTRIA, BELGIUM	0	0	GRANTS TO RECIPIENTS LOCATED IN THE REGION		1,247,251.
<b>3 a Subtotal</b> .....	0	0			1,247,251.
<b>b Total from continuation sheets to Part I</b> .....	0	0			0.
<b>c Totals</b> (add lines 3a and 3b) .....	0	0			1,247,251.

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule F (Form 990) 2019

**Part II** Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

1 (a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		UNITED KINGDOM	TO DETERMINE MECP2 PROTEIN FUNCTION (MECP2 CONSORTIUM)	375,017.	WIRE TRANSFER	0.		
		UNITED KINGDOM	GENE THERAPY CONSORTIUM	429,971.	WIRE TRANSFER	0.		
		UNITED KINGDOM	MECP2 REACTIVATION	58,504.	WIRE TRANSFER	0.		
		UNITED KINGDOM	RNA TRANSPPLICING	316,260.	WIRE TRANSFER	0.		
		UNITED KINGDOM	RETT SYNDROME STUDIES	20,000.	WIRE TRANSFER	0.		
		CANADA	GENE DUPLICATION STUDIES	47,500.	WIRE TRANSFER	0.		

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter

3 Enter total number of other organizations or entities





**Part IV Foreign Forms**

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* .....  Yes  No
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A; don't file with Form 990)* .....  Yes  No
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Corporations (see Instructions for Form 5471)* .....  Yes  No
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621)* .....  Yes  No
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865)* .....  Yes  No
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; don't file with Form 990)* .....  Yes  No

Schedule F (Form 990) 2019

**Part V Supplemental Information**

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.

**PART I, LINE 2:**

**RSRT WORKS CLOSELY WITH THE UNIVERSITY OF EDINBURGH AND GLASGOW UNIVERSITY AND MONITORS FUNDING AND PROGRESS OF THE RESEARCH IT PERFORMS.**

**SCHEDULE I  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Grants and Other Assistance to Organizations,  
Governments, and Individuals in the United States**

Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.  
▶ Attach to Form 990.  
▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2019**

Open to Public  
Inspection

Name of the organization

**RETT SYNDROME RESEARCH TRUST, INC**

Employer identification number  
\*\*-\*\*\*7439

**Part I General Information on Grants and Assistance**

- 1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?  Yes  No
- 2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

**Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments.** Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
BAYLOR COLLEGE OF MEDICINE 1 BAYLOR PLAZA HOUSTON, TX 77030	**_***3878	501(C)(3)	223,391.	0.			PRECLINICAL, DRUG DEVELOPMENT
HARVARD UNIVERSITY 25 SHATTUCK STREET BOSTON, MA 02115	**_***3580	501(C)(3)	514,195.	0.			REACTIVATING SILENT MECP2 DRUG SCREENING MECP2 FUNCTION
FRED HUTCHINSON CANCER RESEARCH CENTER - 1100 FAIRVIEW AVE N - SEATTLE, WA 98109	**_***6071	501(C)(3)	58,000.	0.			REACTIVATING SILENT MECP2 ENT CONFIRMATION
RETT SYNDROME CENTER AT MONTEFIORE MEDICAL CENTER - 3415 BAINBRIDGE AVE - BRONX, NY 10467	**_***0114	501(C)(3)	75,000.	0.			COPAXONE SUPPLEMENT
OREGON HEALTH AND SCIENCES UNIVERSITY FOUNDATION - 3181 S.W. SAM JACKSON PARK - PORTLAND, OR 97239	**_***3114	501(C)(3)	495,423.	0.			MECP2 CONSORTIUM
NATIONWIDE CHILDREN'S HOSPITAL 700 CHILDRENS DRIVE COLUMBUS, OH 43205	**_***6372	501(C)(3)	50,830.	0.			GENE THERAPY CONSORTIUM

- 2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table ..... 12.
- 3 Enter total number of other organizations listed in the line 1 table ..... 6.

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990. **SEE PART IV FOR COLUMN (H) DESCRIPTIONS**

**Part II** Continuation of Grants and Other Assistance to Governments and Organizations in the United States (Schedule I (Form 990), Part II).

(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
CASE WESTERN RESERVE UNIVERSITY 10900 EUCLID AVENUE CLEVELAND, OH 44106	**-***8992	501(C)(3)	279,978.	0.			PRE-CLINICAL TESTING OF KETAMINE COMPOUNDS
UNIVERSITY OF CALIFORNIA AT SAN DIEGO - 9500 GILMAN DRIVE - LA JOLLA, CA 92093	**-***6144	501(C)(3)	215,471.	0.			IDENTIFICATION OF MODIFIER GENES THAT SUPPRESS THE EFFECTS OF MECP2 MUTATIONS
WHITEHEAD INSTITUTE OF BIOMEDICAL RESEARCH - 9 CAMBRIDGE CENTER - CAMBRIDGE, MA 02142	**-***3412	501(C)(3)	214,950.	0.			DRUG TESTING
YALE UNIVERSITY YALE UNIVERSITY NEW HAVEN, CT 06520	**-***6973	501(C)(3)	157,972.	0.			PROTEIN REPLACEMENT AS A THERAPEUTIC IMPROVING DELIVERY PLATFORMS
UNIVERSITY OF MASSASHUSSETTS UNIVERSITY OF MASSACHUSETTS AMHERST, MA 01003	**-***4125	115	891,120.	0.			RNA EDITING AND DNA EDITING AS THERAPEUTIC STRATEGY TO TREAT RETT ENHANCING READTHROUGH
MASSACHUSETTS INSTITUTE OF TECHNOLOGY - 77 MASSACHUSETTS AVE - CAMBRIDGE, MA 02139	**-***3594	501(C)(3)	777,332.	0.			RNA EDITING AS THERAPEUTIC STRATEGY TO TREAT RETT.
MECP2 CONSORTIUM			187,994.	0.			MECP2 CONSORTIUM
GENE THERAPY CONSORTIUM			1,480,816.	0.			GENE THERAPY CONSORTIUM
CLINICAL TRIAL CONSORTIUM			306,634.	0.			CLINICAL TRIAL CONSORTIUM

**Part II** Continuation of Grants and Other Assistance to Governments and Organizations in the United States (Schedule I (Form 990), Part II.)

(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
OMBD CONSORTIUM			619,186.	0.			OMBD CONSORTIUM
OTHER			112,653.	0.			BURDEN OF ILLNESS STUDY PROTEIN REPLACEMENT AS A THERAPEUTIC PROCEDURE
IMPROVING DELIVERY PLATFORM			59,000.	0.			IMPROVING DELIVERY PLATFORM

**Part III.** Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22. Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance

**Part IV** Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

**PART II, LINE 1, COLUMN (H):**  
**NAME OF ORGANIZATION OR GOVERNMENT: UNIVERSITY OF MASSASHUSSETTS**  
**(H) PURPOSE OF GRANT OR ASSISTANCE: RNA EDITING AND DNA EDITING AS THERAPEUTIC STRATEGY TO TREAT RETT ENHANCING READTHROUGH CAPABILITY FOR NONSENSE MUTATIONS. DEVELOPMENT OF SIRNA COMPOUNDS TO TREAT DUPLICATION SYNDROME.**

**SCHEDULE J  
(Form 990)**

**Compensation Information**

OMB No. 1545-0047

**2019**

Open to Public Inspection

For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

- ▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 23.
- ▶ Attach to Form 990.
- ▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

Department of the Treasury  
Internal Revenue Service

Name of the organization

**RETT SYNDROME RESEARCH TRUST, INC**

Employer identification number

**\*\*-\*\*\*7439**

**Part I Questions Regarding Compensation**

	Yes	No
<b>1a</b> Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items. <input type="checkbox"/> First-class or charter travel <input type="checkbox"/> Travel for companions <input type="checkbox"/> Tax indemnification and gross-up payments <input type="checkbox"/> Discretionary spending account <input type="checkbox"/> Housing allowance or residence for personal use <input type="checkbox"/> Payments for business use of personal residence <input type="checkbox"/> Health or social club dues or initiation fees <input type="checkbox"/> Personal services (such as maid, chauffeur, chef)		
<b>b</b> If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain .....	<b>1b</b>	
<b>2</b> Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a? .....	<b>2</b>	
<b>3</b> Indicate which, if any, of the following the organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III. <input type="checkbox"/> Compensation committee <input type="checkbox"/> Independent compensation consultant <input checked="" type="checkbox"/> Form 990 of other organizations <input type="checkbox"/> Written employment contract <input type="checkbox"/> Compensation survey or study <input checked="" type="checkbox"/> Approval by the board or compensation committee		
<b>4</b> During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:		
<b>a</b> Receive a severance payment or change-of-control payment? .....	<b>4a</b>	<b>X</b>
<b>b</b> Participate in, or receive payment from, a supplemental nonqualified retirement plan? .....	<b>4b</b>	<b>X</b>
<b>c</b> Participate in, or receive payment from, an equity-based compensation arrangement? .....	<b>4c</b>	<b>X</b>
If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.		
<b>Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.</b>		
<b>5</b> For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of:		
<b>a</b> The organization? .....	<b>5a</b>	<b>X</b>
<b>b</b> Any related organization? .....	<b>5b</b>	<b>X</b>
If "Yes" on line 5a or 5b, describe in Part III.		
<b>6</b> For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of:		
<b>a</b> The organization? .....	<b>6a</b>	<b>X</b>
<b>b</b> Any related organization? .....	<b>6b</b>	<b>X</b>
If "Yes" on line 6a or 6b, describe in Part III.		
<b>7</b> For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described on lines 5 and 6? If "Yes," describe in Part III .....	<b>7</b>	<b>X</b>
<b>8</b> Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III .....	<b>8</b>	<b>X</b>
<b>9</b> If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)? .....	<b>9</b>	

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule J (Form 990) 2019

**Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees.** Use duplicate copies if additional space is needed.  
 For each individual whose compensation must be reported on Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii).  
 Do not list any individuals that aren't listed on Form 990, Part VII.

**Note:** The sum of columns (B)(i)-(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

(A) Name and Title	(B) Breakdown of W-2 and/or 1099-MISC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation in column (B) reported as deferred on prior Form 990
	(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
(1) MONICA COENRAADS EXECUTIVE DIRECTOR AND CO-	(i) 187,917.	0.	0.	0.	33,988.	221,905.	0.
(ii)	0.	0.	0.	0.	0.	0.	0.
(2) TIM FREEMAN CHIEF DEVELOPMENT OFFICER	(i) 208,333.	0.	0.	0.	0.	208,333.	0.
(ii)	0.	0.	0.	0.	0.	0.	0.
(3) RANDALL CARPENTER CHIEF MEDICAL OFFICER	(i) 165,000.	0.	0.	0.	0.	165,000.	0.
(ii)	0.	0.	0.	0.	0.	0.	0.
(4) TIMOTHY RILEY CHIEF SCIENTIFIC OFFICER	(i) 350,000.	0.	0.	0.	0.	350,000.	0.
(ii)	0.	0.	0.	0.	0.	0.	0.
(5) JANA VON HEHN DIRECTOR OF RESEARCH	(i) 169,583.	0.	0.	0.	0.	169,583.	0.
(ii)	0.	0.	0.	0.	0.	0.	0.
(i)							
(ii)							
(i)							
(ii)							
(i)							
(ii)							
(i)							
(ii)							
(i)							
(ii)							
(i)							
(ii)							
(i)							
(ii)							
(i)							
(ii)							
(i)							
(ii)							
(i)							
(ii)							





SCHEDULE O  
(Form 990 or 990-EZ)

Department of the Treasury  
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

▶ Attach to Form 990 or 990-EZ.

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

OMB No. 1545-0047

2019

Open to Public  
Inspection

Name of the organization

RETT SYNDROME RESEARCH TRUST, INC

Employer identification number

\*\* - \*\*\*7439

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

AND RELATED MECP2 DISORDERS.

FORM 990, PART III, LINE 4D, OTHER PROGRAM SERVICES:

THE ORGANIZATION PROVIDES FUNDING TO LEADING RESEARCH INSTITUTIONS  
WORKING ON RETT SYNDROME AND RELATED MECP2 DISORDERS. RESEARCH IS AIMED  
AT 1) RESTORING LEVELS OF MECP2 PROTEIN, 2) IDENTIFYING OBJECTIVE TOOLS  
TO MEASURE RETT SYMPTOMS 3) ESTABLISH A CLINICAL TRIAL NETWORK 4)  
IDENTIFY FUNCTION OF MECP2 PROTEIN.

THE ORGANIZATION SPONSORS SCIENTIFIC WORKSHOPS THAT BRING THE LEADING  
RETT RESEARCHERS TOGETHER WITH ELITE SCIENTISTS IN SYNERGISTIC FIELDS  
TO EXCHANGE DATA AND SET RESEARCH DIRECTION.

FORM 990, PART VI, SECTION B, LINE 11B:

LINE 11A EXPLANATION - A COPY OF FORM 990 IS GIVEN TO THE BOARD OF  
DIRECTORS FOR REVIEW PRIOR TO ITS FILING.

FORM 990, PART VI, SECTION B, LINE 12C:

THE ORGANIZATION MAINTAINS A CONFLICT OF INTEREST POLICY THAT MUST BE  
SIGNED BY THE TRUSTEES ON AN ANNUAL BASIS.

FORM 990, PART VI, SECTION B, LINE 15:

THE COMPENSATION OF THE EXECUTIVE DIRECTOR IS REVIEWED BY THE BOARD AND  
COMPARED TO THE COMPENSATION OF EXECUTIVE DIRECTORS/PRESIDENTS OF  
ORGANIZATIONS OF SIMILAR SIZE.

Name of the organization

RETT SYNDROME RESEARCH TRUST, INC

Employer identification number

\*\* - \*\*\* 7439

FORM 990, PART VI, SECTION C, LINE 18:

THE ORGANIZATION'S GOVERNING DOCUMENTS, POLICIES AND FINANCIAL STATEMENTS ARE AVAILABLE UPON REQUEST AND VIA THEIR WEBSITE

FORM 990, PART VI, SECTION C, LINE 19:

THE ORGANIZATION'S GOVERNING DOCUMENTS, POLICIES AND FINANCIAL STATEMENTS ARE AVAILABLE UPON REQUEST AND VIA THEIR WEBSITE

FORM 990, PART XI, LINE 9, CHANGES IN NET ASSETS:

PRIOR PERIOD ADJUSMTENT 73,339.

FORM 990, PART XII, LINE 2C

NO CHANGE FROM PRIOR YEAR