

990

Return of Organization Exempt From Income Tax

OMB No. 1545-

0047 2021

Open to Public Inspection

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

Form 990 Department of the Treasury Internal Revenue Service

For the 2021 calendar year, or tax year beginning 01-01-2021, and ending 12-31-2021

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

C Name of organization: RETT SYNDROME RESEARCH TRUST INC. Doing business as: Number and street (or P.O. box if mail is not delivered to street address): 67 UNDER CLIFF ROAD. Room/suite: City or town, state or province, country, and ZIP or foreign postal code: TRUMBULL, CT 06611

D Employer identification number: 26-0687439. E Telephone number: (203) 445-0041. G Gross receipts \$ 8,369,464

F Name and address of principal officer: MONICA COENRAADS, 67 UNDERCLIFF ROAD, TRUMBULL, CT 06611

H(a) Is this a group return for subordinates? Yes No. H(b) Are all subordinates included? Yes No. H(c) 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

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

Table with 2 columns: Description, Amount. Rows 2-7b: 2 Check this box if the organization discontinued its operations... 3 Number of voting members... 4 Number of independent voting members... 5 Total number of individuals employed... 6 Total number of volunteers... 7a Total unrelated business revenue... 7b Net unrelated business taxable income...

Table with 3 columns: Description, Prior Year, Current Year. Rows 8-12: 8 Contributions and grants... 9 Program service revenue... 10 Investment income... 11 Other revenue... 12 Total revenue—add lines 8 through 11...

Table with 3 columns: Description, Prior Year, Current Year. Rows 13-19: 13 Grants and similar amounts paid... 14 Benefits paid to or for members... 15 Salaries, other compensation... 16a Professional fundraising fees... 16b Total fundraising expenses... 17 Other expenses... 18 Total expenses... 19 Revenue less expenses...

Table with 3 columns: Description, Beginning of Current Year, End of Year. Rows 20-22: 20 Total assets... 21 Total liabilities... 22 Net assets or fund balances...

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.

Sign Here: Signature of officer: MONICA COENRAADS CHIEF EXECUTIVE OFFICER. Date: 2022-05-13

Paid Preparer Use Only: Print/Type preparer's name, Preparer's signature, Date, Check if self-employed, PTIN P00182555, Firm's name KNIGHT ROLLERI SHEPPARD CPAS LLP, Firm's EIN 06-1156122, Firm's address 2150 POST ROAD 5TH FL FAIRFIELD, CT 06824, Phone no. (203) 259-2727

**Part III Statement of Program Service Accomplishments**

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

**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  No

If "Yes," describe these new services on Schedule O.

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

If "Yes," describe these changes on Schedule O.

**4** Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

**4a** (Code: ) (Expenses \$ **4,164,248** including grants of \$ **3,172,189** ) (Revenue \$ **78,903** )  
THE ORGANIZATION PROVIDES FUNDING TO LEADING RESEARCH INSTITUTIONS AND COMPANIES WORKING ON RETT SYNDROME AND RELATED MECP2 DISORDERS.

**4b** (Code: ) (Expenses \$ 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 \$ )

(Code: ) (Expenses \$ including grants of \$ ) (Revenue \$ )  
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.

(Code: ) (Expenses \$ 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.

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

**4e** Total program service expenses **4,164,248**

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Question Text, and Yes/No columns. Rows include questions 1 through 21, with sub-questions 11a-e and 12a-b. Questions cover topics like organizational type, lobbying, donor funds, and fundraising activities.

Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question ID, Question Text, and Yes/No columns. Rows include questions 22 through 38 regarding tax-exempt bond issues, excess benefit transactions, and related party transactions.

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 ID, Question Text, and Yes/No columns. Rows include questions 1a, 1b, and 1c regarding Form 1096, Forms W-2G, and gaming winnings.

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

Table with 17 main rows (2a-17) and sub-rows (a-e) for each. Columns include question text, a numeric column (2a-17), and a 'No' column. Row 2a contains the value '8'. Row 17 contains the value '20'.

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

Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members of the governing body at the end of the tax year... 1b Enter the number of voting members included in line 1a... 2 Did any officer, director, trustee, or key employee have a family relationship... 3 Did the organization delegate control over management duties... 4 Did the organization make any significant changes to its governing documents... 5 Did the organization become aware during the year of a significant diversion of the organization's assets... 6 Did the organization have members or stockholders... 7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body... 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body... 8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: 8a The governing body? 8b Each committee with authority to act on behalf of the governing body? 9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O.

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 Did the organization have local chapters, branches, or affiliates? 10b If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? 11b Describe on Schedule O the process, if any, used by the organization to review this Form 990. 12a Did the organization have a written conflict of interest policy? If "No," go to line 13 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe on Schedule O how this was done 13 Did the organization have a written whistleblower policy? 14 Did the organization have a written document retention and destruction policy? 15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? 15a The organization's CEO, Executive Director, or top management official 15b Other officers or key employees of the organization If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions. 16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? 16b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?

Section C. Disclosure

Table with 2 columns: Question, Answer. Rows include: 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 Form 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply. [X] Own website [ ] Another's website [ ] Upon request [ ] Other (explain in Schedule O) 19 Describe in 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: MONICA COENRAADS 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 (203) 445-0041

**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 the 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, Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.

- List all of the organization's **former** officers, key employees, or 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 the 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 dotted 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/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(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) ADRIAN BIRD ..... TRUSTEE	2.00 .....	X						0	0	0
(2) ALBA TULL ..... TRUSTEE	2.00 .....	X						0	0	0
(3) BRAD ZELINGER ..... TRUSTEE	2.00 .....	X						0	0	0
(4) BRIAN WHITMER ..... TRUSTEE	2.00 .....	X						0	0	0
(5) HEIDI EPSTEIN ..... VICE CHAIRMAN	2.00 .....	X		X				0	0	0
(6) INGRID HARDING ..... CO-FOUNDER AND TRUSTEE	2.00 .....	X						0	0	0
(7) LAWRENCE MATTIS ..... SECRETARY	2.00 .....	X		X				0	0	0
(8) MARC TESLER ..... TRUSTEE	2.00 .....	X						0	0	0
(9) MARCI VALNER ..... TREASURER	2.00 .....	X		X				0	0	0
(10) MONICA COENRAADS ..... CHIEF EXECUTIVE OFFICER	50.00 .....	X		X				220,000	0	0
(11) RACHAEL STEVENSON ..... TRUSTEE	2.00 .....	X						0	0	0
(12) RACHEL ROTHSCHILD ..... TRUSTEE	2.00 .....	X						0	0	0
(13) STEPHANIE BOHN ..... TRUSTEE	2.00 .....	X						0	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 Amt Similar Amounts				
<b>1a</b> Federated campaigns . . . . .		<b>1a</b>		
<b>b</b> Membership dues . . . . .		<b>1b</b>		
<b>c</b> Fundraising events . . . . .		<b>1c</b>		
<b>d</b> Related organizations . . . . .		<b>1d</b>		
<b>e</b> Government grants (contributions) . . . . .		<b>1e</b>	155,395	
<b>f</b> All other contributions, gifts, grants, and similar amounts not included above . . . . .		<b>1f</b>	7,826,025	
<b>g</b> Noncash contributions included in lines 1a - 1f:\$ . . . . .		<b>1g</b>		
<b>h Total.</b> Add lines 1a-1f . . . . .				7,981,420

Program Service Revenue		Business Code				
			(A)	(B)	(C)	(D)
<b>2a</b> LICENSING		900099	78,903	78,903		
<b>b</b> BIOREPOSITORY		900099	36,170	36,170		
<b>c</b>						
<b>d</b>						
<b>e</b>						
<b>f</b> All other program service revenue.						
<b>g Total.</b> Add lines 2a-2f. . . . .			115,073			

Other Revenue	<b>3</b> Investment income (including dividends, interest, and other similar amounts)		29,868	29,868			
	<b>4</b> Income from investment of tax-exempt bond proceeds						
	<b>5</b> Royalties . . . . .						
	<b>6a</b> Gross rents	(i) Real					
		(ii) Personal					
		<b>6b</b> Less: rental expenses					
		<b>6c</b> Rental income or (loss)					
	<b>d</b> Net rental income or (loss) . . . . .						
	<b>7a</b> Gross amount from sales of assets other than inventory	(i) Securities	243,103				
		(ii) Other					
		<b>7b</b> Less: cost or other basis and sales expenses	244,653				
		<b>7c</b> Gain or (loss)	-1,550				
	<b>d</b> Net gain or (loss) . . . . .		-1,550	-1,550			
	<b>8a</b> Gross income from fundraising events (not including \$ of contributions reported on line 1c). See Part IV, line 18 . . . . .						
		<b>8b</b> Less: direct expenses					
	<b>c</b> Net income or (loss) from fundraising events . . . . .						
	<b>9a</b> Gross income from gaming activities. See Part IV, line 19 . . . . .						
		<b>9b</b> Less: direct expenses					
	<b>c</b> Net income or (loss) from gaming activities . . . . .						
	<b>10a</b> Gross sales of inventory, less returns and allowances . . . . .						
<b>10b</b> Less: cost of goods sold							
<b>c</b> Net income or (loss) from sales of inventory . . . . .							
Miscellaneous Revenue	Business Code						
<b>11a</b>							
<b>b</b>							
<b>c</b>							
<b>d</b> All other revenue . . . . .							
<b>e Total.</b> Add lines 11a-11d . . . . .							
<b>12 Total revenue.</b> See instructions . . . . .			8,124,811	143,391	0	0	

**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

**Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.**

	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
<b>1</b> Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	3,172,189	3,172,189		
<b>2</b> Grants and other assistance to domestic individuals. See Part IV, line 22				
<b>3</b> Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.				
<b>4</b> Benefits paid to or for members				
<b>5</b> Compensation of current officers, directors, trustees, and key employees				
<b>6</b> Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
<b>7</b> Other salaries and wages	991,287	702,222	76,009	213,056
<b>8</b> Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
<b>9</b> Other employee benefits	44,996	31,875	3,450	9,671
<b>10</b> Payroll taxes	64,594	45,758	4,953	13,883
<b>11</b> Fees for services (non-employees):				
<b>a</b> Management				
<b>b</b> Legal				
<b>c</b> Accounting				
<b>d</b> Lobbying				
<b>e</b> Professional fundraising services. See Part IV, line 17				
<b>f</b> Investment management fees				
<b>g</b> Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)	189,294	132,818	24,707	31,769
<b>12</b> Advertising and promotion				
<b>13</b> Office expenses	12,592	2,567	9,246	779
<b>14</b> Information technology				
<b>15</b> Royalties				
<b>16</b> Occupancy				
<b>17</b> Travel				
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials				
<b>19</b> Conferences, conventions, and meetings				
<b>20</b> Interest				
<b>21</b> Payments to affiliates				
<b>22</b> Depreciation, depletion, and amortization				
<b>23</b> Insurance	5,914	1,972	1,971	1,971
<b>24</b> Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
<b>a</b> FUNDRAISING	163,636			163,636
<b>b</b> MISCELLANEOUS	74,440	58,968	4,125	11,347
<b>c</b> SCIENTIFIC MEETINGS AND	4,494	4,494		
<b>d</b> POSTAGE AND SHIPPING	3,805	2,695	292	818
<b>e</b> All other expenses	11,880	8,690	1,556	1,634
<b>25</b> Total functional expenses. Add lines 1 through 24e	4,739,121	4,164,248	126,309	448,564
<b>26</b> Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720).				

**Part X Balance Sheet**

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

		(A) Beginning of year		(B) End of year
<b>Assets</b>	<b>1</b> Cash-non-interest-bearing . . . . .	9,864,917	<b>1</b>	11,909,266
	<b>2</b> Savings and temporary cash investments		<b>2</b>	
	<b>3</b> Pledges and grants receivable, net . . . . .	2,112,358	<b>3</b>	1,671,693
	<b>4</b> Accounts receivable, net . . . . .		<b>4</b>	
	<b>5</b> 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		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		<b>6</b>	
	<b>7</b> Notes and loans receivable, net . . . . .		<b>7</b>	
	<b>8</b> Inventories for sale or use . . . . .		<b>8</b>	
	<b>9</b> Prepaid expenses and deferred charges . . . . .		<b>9</b>	
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	<b>10a</b> 6,440		
	<b>b</b> Less: accumulated depreciation	<b>10b</b> 6,440	<b>10c</b> 0	0
	<b>11</b> Investments—publicly traded securities . . . . .		<b>11</b>	1,058
	<b>12</b> Investments—other securities. See Part IV, line 11 . . . . .		<b>12</b>	
	<b>13</b> Investments—program-related. See Part IV, line 11 . . . . .		<b>13</b>	
	<b>14</b> Intangible assets . . . . .		<b>14</b>	
	<b>15</b> Other assets. See Part IV, line 11		<b>15</b>	
<b>16 Total assets:</b> Add lines 1 through 15 (must equal line 33) . . . . .	11,977,275	<b>16</b>	13,582,017	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses . . . . .	13,007	<b>17</b>	11,499
	<b>18</b> Grants payable . . . . .	7,455,485	<b>18</b>	5,676,046
	<b>19</b> Deferred revenue . . . . .		<b>19</b>	
	<b>20</b> Tax-exempt bond liabilities . . . . .		<b>20</b>	
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D		<b>21</b>	
	<b>22</b> 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		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties . . . . .		<b>23</b>	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties . . . . .		<b>24</b>	
	<b>25</b> 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		<b>25</b>	
	<b>26 Total liabilities.</b> Add lines 17 through 25 . . . . .	7,468,492	<b>26</b>	5,687,545
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.</b>			
	<b>27</b> Net assets without donor restrictions . . . . .	4,508,783	<b>27</b>	7,894,472
	<b>28</b> Net assets with donor restrictions		<b>28</b>	
	<b>Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.</b>			
	<b>29</b> Capital stock or trust principal, or current funds . . . . .		<b>29</b>	
	<b>30</b> Paid-in or capital surplus, or land, building or equipment fund . . . . .		<b>30</b>	
	<b>31</b> Retained earnings, endowment, accumulated income, or other funds		<b>31</b>	
	<b>32</b> Total net assets or fund balances	4,508,783	<b>32</b>	7,894,472
<b>33</b> Total liabilities and net assets/fund balances	11,977,275	<b>33</b>	13,582,017	

**Part XI Reconciliation of Net Assets**

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

<b>1</b>	Total revenue (must equal Part VIII, column (A), line 12)	<b>1</b>	8,124,811
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25)	<b>2</b>	4,739,121
<b>3</b>	Revenue less expenses. Subtract line 2 from line 1	<b>3</b>	3,385,690
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	<b>4</b>	4,508,783
<b>5</b>	Net unrealized gains (losses) on investments	<b>5</b>	
<b>6</b>	Donated services and use of facilities	<b>6</b>	
<b>7</b>	Investment expenses	<b>7</b>	
<b>8</b>	Prior period adjustments	<b>8</b>	
<b>9</b>	Other changes in net assets or fund balances (explain in Schedule O)	<b>9</b>	0
<b>10</b>	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (A))	<b>10</b>	7,894,472

**Part XII Financial Statements and Reporting**

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

	Yes	No
<b>1</b> 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 on Schedule O.		
<b>2a</b> Were the organization's financial statements compiled or reviewed by an independent accountant? 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		No
<b>b</b> Were the organization's financial statements audited by an independent accountant? 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	Yes	
<b>c</b> 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? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.		No
<b>3a</b> 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?		No
<b>b</b> If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits.		

**Additional Data**

**Return to Form**

**Software ID:**

**Software Version:**

**Form 990, Special Condition Description:**

**Special Condition Description**

**SCHEDULE A**  
**(Form 990)**

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

OMB No. 1545-0047

**2021**

**Open to Public Inspection**

**Name of the organization**  
RETT SYNDROME RESEARCH TRUST INC

**Employer identification number**  
26-0687439

**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).)
- 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:

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- 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 on lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
  - a  **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
  - b  **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
  - c  **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
  - d  **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
  - e  Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
  - f Enter the number of supported organizations . . . . . \_\_\_\_\_
  - g Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
<b>Total</b>						

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

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grant.") . . .	12,518,139	9,631,117	8,340,103	7,664,611	7,837,691	45,991,661
<b>2</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . . .						
<b>3</b> The value of services or facilities furnished by a governmental unit to the organization without charge..						
<b>4 Total.</b> Add lines 1 through 3	12,518,139	9,631,117	8,340,103	7,664,611	7,837,691	45,991,661
<b>5</b> The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f) . . .						
<b>6 Public support.</b> Subtract line 5 from line 4.						45,991,661

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
<b>7</b> Amounts from line 4. . . . .	12,518,139	9,631,117	8,340,103	7,664,611	7,837,691	45,991,661
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources . . . . .	11,583	23,178	36,443	62,327	29,868	163,399
<b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on. . . . .						
<b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . . . .						
<b>11 Total support.</b> Add lines 7 through 10						46,155,060
<b>12</b> Gross receipts from related activities, etc. (see instructions) . . . . .					<b>12</b>	
<b>13 First 5 years.</b> If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and <b>stop here</b> . . . . .						<input type="checkbox"/>

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

<b>14</b> Public support percentage for 2021 (line 6, column (f) divided by line 11, column (f)) . . . . .	<b>14</b>	99.650 %
<b>15</b> Public support percentage for 2020 Schedule A, Part II, line 14 . . . . .	<b>15</b>	99.690 %
<b>16a 33 1/3% support test—2021.</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 <b>stop here.</b> The organization qualifies as a publicly supported organization . . . . .		<input checked="" type="checkbox"/>
<b>b 33 1/3% support test—2020.</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 <b>stop here.</b> The organization qualifies as a publicly supported organization . . . . .		<input type="checkbox"/>
<b>17a 10%-facts-and-circumstances test—2021.</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 <b>stop here.</b> 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—2020.</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 <b>stop here.</b> 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>18 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) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(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) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(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 on line 10b, whether or not the business is regularly carried on.						
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . . . .						
<b>13 Total support.</b> (Add lines 9, 10c, 11, and 12.) . . . . .						
<b>14 First 5 years.</b> If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and <b>stop here.</b> . . . . . <input type="checkbox"/>						

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

<b>15</b> Public support percentage for 2021 (line 8, column (f) divided by line 13, column (f)) . . . . .	<b>15</b>	
<b>16</b> Public support percentage from 2020 Schedule A, Part III, line 15 . . . . .	<b>16</b>	

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

<b>17</b> Investment income percentage for <b>2021</b> (line 10c, column (f) divided by line 13, column (f)) . . . . .	<b>17</b>	
<b>18</b> Investment income percentage from <b>2020</b> Schedule A, Part III, line 17 . . . . .	<b>18</b>	

**19a 33 1/3% support tests—2021.** 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—2020.** If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and **stop here.** The organization qualifies as a publicly supported organization . . . . .

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

**Part IV Supporting Organizations**

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

**Section A. All Supporting Organizations**

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

**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 on lines 11b and 11c below, the governing body of a supported organization?		
<b>b</b> A family member of a person described on 11a above?		
<b>c</b> A 35% controlled entity of a person described on line 11a or 11b above? <i>If "Yes" to 11a, 11b, or 11c, provide detail in Part VI</i>		

**Section B. Type I Supporting Organizations**

	Yes	No
<b>1</b> Did the officers, directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>		
<b>2</b> Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? <i>If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised or controlled the supporting organization.</i>		

**Section C. Type II Supporting Organizations**

	Yes	No
<b>1</b> Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <i>If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).</i>		

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

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

**2** Activities Test. **Answer lines 2a and 2b below.**

	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? <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>		
<b>b</b> Did the activities described on line 2a, above 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 lines 3a and 3b below.**

	Yes	No
<b>a</b> Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>If "Yes" or "No", provide details in Part VI.</i>		
<b>b</b> Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? <i>If "Yes," describe in Part VI. the role played by the organization in this regard.</i>		

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

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

**Section A - Adjusted Net Income**

(A) Prior Year

(B) Current Year  
(optional)

- |   |          |  |  |
|---|----------|--|--|
| <b>1</b> Net short-term capital gain  | <b>1</b> |  |  |
| <b>2</b> Recoveries of prior-year distributions   | <b>2</b> |  |  |
| <b>3</b> Other gross income (see instructions)  | <b>3</b> |  |  |
| <b>4</b> Add lines 1 through 3  | <b>4</b> |  |  |
| <b>5</b> Depreciation and depletion   | <b>5</b> |  |  |
| <b>6</b> Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions) | <b>6</b> |  |  |
| <b>7</b> Other expenses (see instructions)  | <b>7</b> |  |  |
| <b>8 Adjusted Net Income</b> (subtract lines 5, 6 and 7 from line 4)  | <b>8</b> |  |  |

**Section B - Minimum Asset Amount**

(A) Prior Year

(B) Current Year  
(optional)

- |  |           |  |  |
|--|-----------|--|--|
| <b>1</b> Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year): | <b>1</b>  |  |  |
| <b>a</b> Average monthly value of securities   | <b>1a</b> |  |  |
| <b>b</b> Average monthly cash balances   | <b>1b</b> |  |  |
| <b>c</b> Fair market value of other non-exempt-use assets  | <b>1c</b> |  |  |
| <b>d Total</b> (add lines 1a, 1b, and 1c)  | <b>1d</b> |  |  |
| <b>e Discount</b> claimed for blockage or other factors ( <i>explain in detail in Part VI</i> ):   |           |  |  |
| <b>2</b> Acquisition indebtedness applicable to non-exempt use assets  | <b>2</b>  |  |  |
| <b>3</b> Subtract line 2 from line 1d  | <b>3</b>  |  |  |
| <b>4</b> Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).                                  | <b>4</b>  |  |  |
| <b>5</b> Net value of non-exempt-use assets (subtract line 4 from line 3)  | <b>5</b>  |  |  |
| <b>6</b> Multiply line 5 by 0.035  | <b>6</b>  |  |  |
| <b>7</b> Recoveries of prior-year distributions  | <b>7</b>  |  |  |
| <b>8 Minimum Asset Amount</b> (add line 7 to line 6)   | <b>8</b>  |  |  |

**Section C - Distributable Amount**

Current Year

- |  |          |  |
|--|----------|--|
| <b>1</b> Adjusted net income for prior year (from Section A, line 8, Column A)   | <b>1</b> |  |
| <b>2</b> Enter 85% of line 1   | <b>2</b> |  |
| <b>3</b> Minimum asset amount for prior year (from Section B, line 8, Column A)  | <b>3</b> |  |
| <b>4</b> Enter greater of line 2 or line 3   | <b>4</b> |  |
| <b>5</b> Income tax imposed in prior year  | <b>5</b> |  |
| <b>6 Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions) | <b>6</b> |  |

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

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

(continued)

Section D - Distributions		Current Year
<b>1</b> Amounts paid to supported organizations to accomplish exempt purposes	<b>1</b>	
<b>2</b> Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	<b>2</b>	
<b>3</b> Administrative expenses paid to accomplish exempt purposes of supported organizations	<b>3</b>	
<b>4</b> Amounts paid to acquire exempt-use assets	<b>4</b>	
<b>5</b> Qualified set-aside amounts (prior IRS approval required - provide details in <b>Part VI</b> )	<b>5</b>	
<b>6</b> Other distributions (describe in <b>Part VI</b> ). See instructions	<b>6</b>	
<b>7 Total annual distributions.</b> Add lines 1 through 6.	<b>7</b>	
<b>8</b> Distributions to attentive supported organizations to which the organization is responsive (provide details in <b>Part VI</b> ). See instructions	<b>8</b>	
<b>9</b> Distributable amount for 2021 from Section C, line 6	<b>9</b>	
<b>10</b> Line 8 amount divided by Line 9 amount	<b>10</b>	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2021	(iii) Distributable Amount for 2021
<b>1</b> Distributable amount for 2021 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2021 (reasonable cause required-- explain in <b>Part VI</b> ). See instructions.			
<b>3</b> Excess distributions carryover, if any, to 2021:			
<b>a</b> From 2016. . . . .			
<b>b</b> From 2017. . . . .			
<b>c</b> From 2018. . . . .			
<b>d</b> From 2019. . . . .			
<b>e</b> From 2020. . . . .			
<b>f Total</b> of lines 3a through e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2021 distributable amount			
<b>i</b> Carryover from 2016 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
<b>4</b> Distributions for 2021 from Section D, line 7: \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2021 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from line 4.			
<b>5</b> Remaining underdistributions for years prior to 2021, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>6</b> Remaining underdistributions for 2021. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>7 Excess distributions carryover to 2022.</b> Add lines 3j and 4c.			
<b>8</b> Breakdown of line 7:			
<b>a</b> Excess from 2017. . . . .			
<b>b</b> Excess from 2018. . . . .			
<b>c</b> Excess from 2019. . . . .			
<b>d</b> Excess from 2020. . . . .			
<b>e</b> Excess from 2021. . . . .			

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

### Facts And Circumstances Test

Return Reference	Explanation

## **Additional Data**

**Return to Form**

**Software ID:**

**Software Version:**

**SCHEDULE D**  
**(Form 990)**

**Supplemental Financial Statements**

OMB No. 1545-0047

**2021**

**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](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**

26-0687439

**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.

	(a) Donor advised funds	(b) Funds and other accounts
<b>1</b> Total number at end of year . . . . .		
<b>2</b> Aggregate value of contributions to (during year)		
<b>3</b> Aggregate value of grants from (during year)		
<b>4</b> Aggregate value at end of year . . . . .		

**5** Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? . . . . .  **Yes**  **No**

**6** Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? . . . . .  **Yes**  **No**

**Part II Conservation Easements.**

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

**1** Purpose(s) of conservation easements held by the organization (check all that apply).

Preservation of land for public use (e.g., recreation or education)  Preservation of an historically important land area

Protection of natural habitat  Preservation of a certified historic structure

Preservation of open space

**2** Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.

	Held at the End of the Year
<b>a</b> Total number of conservation easements . . . . .	<b>2a</b>
<b>b</b> Total acreage restricted by conservation easements . . . . .	<b>2b</b>
<b>c</b> Number of conservation easements on a certified historic structure included in (a) . . . . .	<b>2c</b>
<b>d</b> Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register . . . . .	<b>2d</b>

**3** Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year ▶ \_\_\_\_\_

**4** Number of states where property subject to conservation easement is located ▶ \_\_\_\_\_

**5** Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? . . . . .  **Yes**  **No**

**6** Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year  
▶ \_\_\_\_\_

**7** Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year  
▶ \$ \_\_\_\_\_

**8** Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? . . . . .  **Yes**  **No**

**9** In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.

**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.

**1a** If the organization elected, as permitted under FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items.

**b** If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items:

(i) Revenue included on Form 990, Part VIII, line 1 . . . . . ▶ \$ \_\_\_\_\_

(ii) Assets included in Form 990, Part X . . . . . ▶ \$ \_\_\_\_\_

**2** If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items:

**a** Revenue included on Form 990, Part VIII, line 1 . . . . . ▶ \$ \_\_\_\_\_

**b** Assets included in Form 990, Part X . . . . . ▶ \$ \_\_\_\_\_

**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 are a 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 programs
  - 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    |
|--|-----------|
| <b>c</b> Beginning balance . . . . .             | <b>1c</b> |
| <b>d</b> Additions during the year . . . . .     | <b>1d</b> |
| <b>e</b> Distributions during the year . . . . . | <b>1e</b> |
| <b>f</b> Ending balance . . . . .                | <b>1f</b> |
- 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 in 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
<b>1a</b> Beginning of year balance . . . . .					
<b>b</b> Contributions . . . . .					
<b>c</b> Net investment earnings, gains, and losses					
<b>d</b> Grants or scholarships . . . . .					
<b>e</b> Other expenditures for facilities and programs . . . . .					
<b>f</b> Administrative expenses . . . . .					
<b>g</b> 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:

- (i)** Unrelated organizations . . . . .
- (ii)** Related organizations . . . . .

	Yes	No
<b>3a(i)</b>		
<b>3a(ii)</b>		
<b>3b</b>		

- b** If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R? . . . . .
- 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
<b>1a</b> Land . . . . .				
<b>b</b> Buildings . . . . .				
<b>c</b> Leasehold improvements				
<b>d</b> Equipment . . . . .	6,440		6,440	0
<b>e</b> Other . . . . .				
<b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).) . . . ▶				0

**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.

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives . . . . .		
(2) Closely-held equity interests . . . . .		
(3) Other _____		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 12.)		

**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.

(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
<b>Total.</b> (Column (b) must equal Form 990, Part X, col.(B) line 13.)		

**Part IX Other Assets.**

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

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col.(B) line 15.)	

**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.

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col.(B) line 25.)	

**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 FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII

**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.

<b>1</b>	Total revenue, gains, and other support per audited financial statements . . . . .		<b>1</b>	8,132,811
<b>2</b>	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
<b>a</b>	Net unrealized gains (losses) on investments . . . . .	<b>2a</b>		
<b>b</b>	Donated services and use of facilities . . . . .	<b>2b</b>	8,000	
<b>c</b>	Recoveries of prior year grants . . . . .	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>		
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .	<b>2e</b>	8,000	
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .	<b>3</b>	8,124,811	
<b>4</b>	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .	<b>4c</b>	0	
<b>5</b>	Total revenue. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 12.) . . . . .	<b>5</b>	8,124,811	

**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.

<b>1</b>	Total expenses and losses per audited financial statements . . . . .		<b>1</b>	4,747,122
<b>2</b>	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
<b>a</b>	Donated services and use of facilities . . . . .	<b>2a</b>	8,000	
<b>b</b>	Prior year adjustments . . . . .	<b>2b</b>		
<b>c</b>	Other losses . . . . .	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>		
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .	<b>2e</b>	8,000	
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .	<b>3</b>	4,739,122	
<b>4</b>	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .	<b>4c</b>	0	
<b>5</b>	Total expenses. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 18.) . . . . .	<b>5</b>	4,739,122	

**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.

Return Reference	Explanation
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, 2019 .

**Additional Data**

[Return to Form](#)

**Software ID:**  
**Software Version:**

**2021**

**Open to Public Inspection**

# Statement of Activities Outside the United States

▶ Complete if the organization answered "Yes" to 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.

**SCHEDULE F  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

Name of the organization  
RETT SYNDROME RESEARCH TRUST INC

**Employer identification number**

26-0687439

**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 or 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 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
(1) EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA, AUSTRIA, BELGIUM			GRANTS TO RECIPIENTS LOCATED IN THE REGION		364,789
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					
(8)					
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
<b>3a</b> Sub-total . . . . .	0	0			364,789
<b>b</b> Total from continuation sheets to Part I . . . . .	0	0			0
<b>c Totals</b> (add lines 3a and 3b)	0	0			364,789

**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.

<b>1</b>	<b>(a)</b> Name of organization	<b>(b)</b> IRS code section and EIN (if applicable)	<b>(c)</b> Region	<b>(d)</b> Purpose of grant	<b>(e)</b> Amount of cash grant	<b>(f)</b> Manner of cash disbursement	<b>(g)</b> Amount of noncash assistance	<b>(h)</b> Description of noncash assistance	<b>(i)</b> Method of valuation (book, FMV, appraisal, other)
(1)			UNITED KINGDOM	MECP2 REACTIVATION	85,000	WIRE TRANSFER	0		
(2)			UNITED KINGDOM	GENE THERAPY CONSORTIUM	145,075	WIRE TRANSFER	0		
(3)			UNITED KINGDOM		134,714	WIRE TRANSFER	0		
(4)									
(5)									
(6)									
(7)									
(8)									
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									

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 III Grants and Other Assistance to Individuals Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 16.

Part III can be duplicated if additional space is needed.

<b>(a)</b> Type of grant or assistance	<b>(b)</b> Region	<b>(c)</b> Number of recipients	<b>(d)</b> Amount of cash grant	<b>(e)</b> Manner of cash disbursement	<b>(f)</b> Amount of noncash assistance	<b>(g)</b> Description of noncash assistance	<b>(h)</b> Method of valuation (book, FMV, appraisal, other)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

**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

**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.

ReturnReference	Explanation
PART I, LINE 2:	RSRT WORKS CLOSELY WITH THE UNIVERSITY OF EDINBURGH AND MONITORS FUNDING AND PROGRESS OF THE RESEARCH IT PERFORMS.
PART III ACCOUNTING METHOD:	

## Additional Data

**Software ID:**

**Software Version:**

**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

**2021**

**Open to Public  
Inspection**

Name of the organization  
RETT SYNDROME RESEARCH TRUST INC

**Employer identification number**  
26-0687439

**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.

(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 noncash assistance	(h) Purpose of grant or assistance
(1) BAYLOR COLLEGE OF MEDICINE C/O RETT SYNDROME TRUMBULL,CT 06611			189,576	0			MECP2 CONSORTIUM
(2) BEAM THERAPEUTICS 26 LANDSDOWNE CAMBRIDGE,MA 02139	81-5238376		639,300	0			DNA EDITING
(3) CALIFORNIA INSTITUTE OF TECHNOLOGIES 1200 E CALIFORNIA BLVD PASADENA,CA 91125	95-1643307		53,898	0			MEPC2 REGULATION
(4) CIITIZEN CORPORATION 3000 EL CAMINO REAL PALO ALTO,CA 94306			178,000	0			DIGITAL NATIONAL REGISTRY
(5) CLINICAL TRIAL CONSORTIUM C/O RETT SYNDROME TRUMBULL,CT 06611			106,202	0			CLINICAL TRIAL CONSORTIUM
(6) CORIELL INSTITUTE FOR MEDICAL RESEARCH 403 HADDON AVENUE CAMDEN,NJ 08103			150,836	0			BIO REPOSITORY
(7) DSG C/O RETT SYNDROME TRUMBULL,CT 06611			180,263	0			RETT RESEARCH
(8) DUKE UNIVERSITY SCHOOL OF MEDICINE C/O RETT SYNDROME TRUMBULL,CT 06611			87,519	0			RETT RESEARCH
(9) EMERALD INNOVATIONS 1 BROADWAY 14TH FLOOR CAMBRIDGE,MA 02142			21,444	0			OUTCOME MEASURES
(10) EMORY UNIVERSITY C/O RETT SYNDROME TRUMBULL,CT 06611			68,935	0			RETT RESEARCH
(11) FRED HUTCHINSON CANCER RESEARCH C/O RETT SYNDROME TRUMBULL,CT 06611			134,895	0			RETT RESEARCH
(12) HARVARD STEM CELL INSTITUTE C/O RETT SYNDROME TRUMBULL,CT 06611			36,343	0			RETT RESEARCH
(13) HOSPITAL FOR SICK CHILDREN C/O RETT SYNDROME TRUMBULL,CT 06611			190,000	0			GENOME EDITING FOR MECP2 DUPLICATION SYNDROME
(14) JACKSON LABORATORIES 600 MAIN STREET BAR HARBOR,ME 04609			106,959	0			RETT RESEARCH
(15) JACKSON LABORATORIES 600 MAIN STREET BAR HARBOR,ME 04609			88,296	0			MOUSE MODELS ALLELIC SERIES
(16) KETAMINE TRIAL			53,780	0			RETT RESEARCH

C/O RETT SYNDROME TRUMBULL,CT 06611							
(17) MASSACHUSETTS INSTITUTE OF TECHNOLOGY 77 MASSACHUSETTS AVE CAMBRIDGE,MA 02139	04-2103594	501(C)(3)	612,334	0			RNA EDITING
(18) OREGON HEALTH AND SCIENCES UNIVERSITY FOUNDATION 3181 SW SAM JACKSON PARK PORTLAND,OR 97239	23-7083114	501(C)(3)	115,000	0			RNA EDITING
(19) RETT SYNDROME CENTER AT MONTEFIORE MEDICAL CENTER 3415 BAINBRIDGE AVE BRONX,NY 10467	13-1740114	501(C)(3)	25,000	0			RETT CLINIC
(20) UC DAVIS C/O RETT SYNDROME TRUMBULL,CT 06611			131,293	0			RETT RESEARCH
(21) UNIVERSITY OF CALIFORNIA DAVIS/PETER BEAL 1 SHIELDS AVENUE DAVIS,CA 95616	95-6006144	501(C)(3)	174,200	0			RNA EDITING
(22) UNIVERSITY OF MASSASHUSSETS MEDICAL SCHOOL 55 N LAKE AVE WORCESTER,MA 01655	54-2084125		218,311	0			RETT RESEARCH
(23) UNIVERSITY OF MASSASHUSSETS MEDICAL SCHOOL 55 N LAKE AVE WORCESTER,MA 01655	54-2084125	501(C)(3)	641,740	0			RNA/DNA EDITING;READTHROUGH THERAPY; MECP2 DUPLICATION SYNDROME
(24) UNIVERSITY OF PENNSYLVANIA C/O RETT SYNDROME TRUMBULL,CT 06611			380,686	0			RETT RESEARCH

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

**3** Enter total number of other organizations listed in the line 1 table . . . . .

**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 noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					

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

Return Reference

Explanation

**Additional Data**

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**Schedule J**  
**(Form 990)**

**Compensation Information**

OMB No. 1545-0047

**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.**

**2021**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

Name of the organization  
RETT SYNDROME RESEARCH TRUST INC

Employer identification number

26-0687439

**Part I Questions Regarding Compensation**

**1a** 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"/> Housing allowance or residence for personal use |
| <input type="checkbox"/> Travel for companions                    | <input type="checkbox"/> Payments for business use of personal residence |
| <input type="checkbox"/> Tax idemnification and gross-up payments | <input type="checkbox"/> Health or social club dues or initiation fees   |
| <input type="checkbox"/> Discretionary spending account           | <input type="checkbox"/> Personal services (e.g., maid, chauffeur, chef) |

**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

**2** Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, officers, including the CEO/Executive Director, regarding the items checked on Line 1a?

**3** Indicate which, if any, of the following the filing 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"/> Written employment contract                                |
| <input type="checkbox"/> Independent compensation consultant        | <input type="checkbox"/> Compensation survey or study                               |
| <input checked="" type="checkbox"/> Form 990 of other organizations | <input checked="" type="checkbox"/> Approval by the board or compensation committee |

**4** 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:

- a** Receive a severance payment or change-of-control payment?
  - b** Participate in, or receive payment from, a supplemental nonqualified retirement plan?
  - c** Participate in, or receive payment from, an equity-based compensation arrangement?
- If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.

**Only 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.**

**5** 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:

- a** The organization?
  - b** Any related organization?
- If "Yes," on line 5a or 5b, describe in Part III.

**6** 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:

- a** The organization?
  - b** Any related organization?
- If "Yes," on line 6a or 6b, describe in Part III.

**7** For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described in lines 5 and 6? If "Yes," describe in Part III.

**8** 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.

**9** If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?

	Yes	No
<b>1b</b>		
<b>2</b>		
<b>4a</b>		No
<b>4b</b>		No
<b>4c</b>		No
<b>5a</b>		No
<b>5b</b>		No
<b>6a</b>		No
<b>6b</b>		No
<b>7</b>		No
<b>8</b>		No
<b>9</b>		



**Part III Supplemental Information**

Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II. Also complete this part for any additional information.

Return Reference	Explanation
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## **Additional Data**

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**Software Version:**

**SCHEDULE O**  
**(Form 990)**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

**2021****Open to Public  
Inspection**Name of the organization  
RETT SYNDROME RESEARCH TRUST INC

Employer identification number

26-0687439

Return Reference	Explanation
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 CHIEF EXECUTIVE OFFICER AND CHIEF DEVELOPMENT OFFICE IS REVIEWED BY THE BOARD AND COMPARED TO THE COMPENSATION OF EXECUTIVE DIRECTORS/PRESIDENTS OF ORGANIZATIONS OF SIMILAR SIZE.
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

## **Additional Data**

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