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Part III

Statement of Program Service Accomplishments

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

☐ Yes ☒ No

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 \$ 7,302,969 including grants of \$ 7,152,602) (Revenue \$)

THE ORGANIZATION PROVIDES FUNDING TO LEADING RESEARCH INSTITUTIONS WORKING ON RETT SYNDROME AND RELATED MECP2 DISORDERS RESEARCH IS AIMED AT 1) REVERSING THE UNDERLYING MECP2 GENETIC DEFECT, 2) IDENTIFYING COMPENSATORY MECHANISMS THAT MIGHT BYPASS THE GENETIC DEFECT AND 3) IDENTIFYING EXISTING DRUGS,COMPOUNDS AND PROCEDURES TO AMELIORATE RETT SYMPTOMS GRANTS ARE BOTH PAID AND COMMITTED FUNDS 4) IDENTIFY FUNCTION OF MECP2 PROTEIN

4b

(Code) (Expenses \$ 80,532 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 \$)

THE ORGANIZATION PROVIDES FUNDING TO LEADING RESEARCH INSTITUTIONS WORKING ON RETT SYNDROME AND RELATED MECP2 DISORDERS RESEARCH IS AIMED AT 1)REVERSING THE UNDERLYING MECP2 GENETIC DEFECT, 2)IDENTIFYING COMPENSATORY MECHANISMS THAT MIGHT BYPASS THE GENETIC DEFECT, 3) IDENTIFYING EXISTING DRUGS,COMPOUNDS AND PROCEDURES TO AMELIORATE RETT SYMPTOMS GRANTS ARE BOTH PAID AND COMMITTED FUNDS 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

7,383,501

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)? If "Yes," complete Schedule A 	1 Yes	
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)? 	2 Yes	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I	3	No
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II	4	No
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? If "Yes," complete Schedule C, Part III	5	No
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? If "Yes," complete Schedule D, Part I 	6	No
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II 	7	No
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III 	8	No
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? If "Yes," complete Schedule D, Part IV 	9	No
10 Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? If "Yes," complete Schedule D, Part V 	10	No
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? If "Yes," complete Schedule D, Part VI 	11a	No
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? If "Yes," complete Schedule D, Part VII 	11b	No
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? If "Yes," complete Schedule D, Part VIII 	11c	No
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? If "Yes," complete Schedule D, Part IX 	11d Yes	
e Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X 	11e	No
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)? If "Yes," complete Schedule D, Part X 	11f Yes	
12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII 	12a Yes	
b Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional 	12b	No
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13	No
14a Did the organization maintain an office, employees, or agents outside of the United States?	14a	No
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? If "Yes," complete Schedule F, Parts I and IV 	14b	No
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? If "Yes," complete Schedule F, Parts II and IV 	15 Yes	
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? If "Yes," complete Schedule F, Parts III and IV 	16	No
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? If "Yes," complete Schedule G, Part I (see instructions)	17	No
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II	18	No
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III	19	No
20a Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a	No
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b	

Part IV

Checklist of Required Schedules (continued)

21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21	Yes	
22	Did the organization report more than \$5,000 of grants or other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22		No
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	23		No
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>	24a		No
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
c	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
25a	Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a		No
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>	25b		No
26	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? <i>If so, complete Schedule L, Part II</i>	26		No
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>	27		No
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)			
a	A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28a		No
b	A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28b		No
c	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? <i>If "Yes," complete Schedule L, Part IV</i>	28c		No
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i> . . .	29		No
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>	30		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31		No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>	32		No
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>	33		No
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>	34		No
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		No
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35b		
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	36		No
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>	37		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Note. All Form 990 filers are required to complete Schedule O	38	Yes	

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

☐

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable.		
1b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable.		
1c			
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return.		
2b		Yes	
3a			No
3b			
4a			No
b			
5a			No
5b			No
5c			
6a			No
6b			
7 Organizations that may receive deductible contributions under section 170(c).			
7a			No
7b			
7c			No
7d			
7e			
7f			
7g			
7h			
8			
9 Sponsoring organizations maintaining donor advised funds.			
9a			
9b			
10 Section 501(c)(7) organizations. Enter			
10a			
10b			
11 Section 501(c)(12) organizations. Enter			
11a			
11b			
12a			
12b			
13 Section 501(c)(29) qualified nonprofit health insurance issuers.			
13a			
13b			
13c			
14a			No
14b			

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

		Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year	8	
If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O			
1b	Enter the number of voting members included in line 1a, above, who are independent	8	
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?	2	No
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?	3	No
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4	No
5	Did the organization become aware during the year of a significant diversion of the organization's assets?	5	No
6	Did the organization have members or stockholders?	6	No
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?	7a	No
7b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?	7b	No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following		
8a	The governing body?	8a	Yes
8b	Each committee with authority to act on behalf of the governing body?	8b	Yes
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	9	No

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

		Yes	No
10a	Did the organization have local chapters, branches, or affiliates?	10a	No
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?	10b	
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	11a	Yes
11b	Describe in 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	12a	Yes
12b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	Yes
12c	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	12c	Yes
13	Did the organization have a written whistleblower policy?	13	Yes
14	Did the organization have a written document retention and destruction policy?	14	Yes
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	15a	Yes
15b	Other officers or key employees of the organization	15b	Yes
If "Yes" to line 15a or 15b, describe the process in 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?	16a	No
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?	16b	

Section C. Disclosure

17	List the States with which a copy of this Form 990 is required to be filed▶CT
18	Section 6104 requires an organization to make its Form 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply. 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, physical address, and telephone number of the person who possesses the books and records of the organization ▶MONICA COENRAADS 67 UNDER CLIFF ROAD TRUMBULL,CT 06611 (203)445-0041

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

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

Form **990** (2013)

Part VII

1b	Sub-Total			
c	Total from continuation sheets to Part VII, Section A			
d	Total (add lines 1b and 1c)	205,133	0	0

2 Total number of individuals (including but not limited to those l
\$100,000 of reportable compensation from the organization▶1

		Yes	No
3	Did the organization list any former officer, director or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>	3	No
4	For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? <i>If "Yes," complete Schedule J for such individual</i>	4	No
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>	5	No

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

(A) Name and business address	(B) Description of services	(C) Compensation

2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization ►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	1a	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	5,645,435			
	g	Noncash contributions included in lines 1a-1f \$					
	h	Total. Add lines 1a-1f		5,645,435			
Program Service Revenue	2a		Business Code				
	b						
	c						
	d						
	e						
	f	All other program service revenue					
	g	Total. Add lines 2a-2f					
	Other Revenue	3	Investment income (including dividends, interest, and other similar amounts)		15,004		
4		Income from investment of tax-exempt bond proceeds					
5		Royalties					
6a		Gross rents	(i) Real	(ii) Personal			
b		Less rental expenses					
c		Rental income or (loss)					
d		Net rental income or (loss)					
7a		Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other			
b		Less cost or other basis and sales expenses					
c		Gain or (loss)					
d		Net gain or (loss)			411		411
8a		Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c) See Part IV, line 18	a				
b		Less direct expenses	b				
c		Net income or (loss) from fundraising events					
9a		Gross income from gaming activities See Part IV, line 19	a				
b		Less direct expenses	b				
c		Net income or (loss) from gaming activities					
10a		Gross sales of inventory, less returns and allowances	a				
b		Less cost of goods sold	b				
c		Net income or (loss) from sales of inventory					
	Miscellaneous Revenue	Business Code					
11a							
b							
c							
d	All other revenue						
e	Total. Add lines 11a-11d						
12	Total revenue. See Instructions		5,660,850	0	0	15,415	

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
1	Grants and other assistance to governments and organizations in the United States. See Part IV, line 21.	7,152,602	7,152,602		
2	Grants and other assistance to individuals in the United States. See Part IV, line 22.				
3	Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16.				
4	Benefits paid to or for members.				
5	Compensation of current officers, directors, trustees, and key employees.	229,563	90,790	45,929	92,844
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.				
8	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions).				
9	Other employee benefits.	18,438	7,292	3,689	7,457
10	Payroll taxes.	19,847	7,849	3,971	8,027
11	Fees for services (non-employees):				
a	Management.				
b	Legal.				
c	Accounting.	5,098	1,700	1,699	1,699
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 Schedule O).				
12	Advertising and promotion.				
13	Office expenses.	6,541	1,854	2,791	1,896
14	Information technology.				
15	Royalties.				
16	Occupancy.				
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.	3,669	3,669		
23	Insurance.	3,624	1,208	1,208	1,208
24	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).				
a	FUNDRAISING	133,126			133,126
b	SCIENTIFIC MEETINGS AND	80,532	80,532		
c	RESEARCH	15,630	15,630		
d	BANK AND CREDIT CARD FE	7,988	3,159	1,598	3,231
e	All other expenses	25,926	17,216	2,259	6,451
25	Total functional expenses. Add lines 1 through 24e.	7,702,584	7,383,501	63,144	255,939
26	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 ☐ 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 X

					(A)		(B)
					Beginning of year		End of year
Assets	1	Cash—non-interest-bearing			4,386,650	1	4,694,376
	2	Savings and temporary cash investments				2	
	3	Pledges and grants receivable, net			191,400	3	1,079,668
	4	Accounts receivable, net				4	
	5	Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L				5	
	6	Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions) Complete Part II of Schedule L				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				
	b	Less accumulated depreciation	10b			10c	
	11	Investments—publicly traded securities			16	11	20
	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			3,669	15	0
16	Total assets. Add lines 1 through 15 (must equal line 34)			4,581,735	16	5,774,064	
Liabilities	17	Accounts payable and accrued expenses			6,882	17	22,238
	18	Grants payable			4,947,497	18	8,166,204
	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 current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons Complete Part II of Schedule L				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	Total liabilities. Add lines 17 through 25			4,954,379	26	8,188,442
Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here ☒ and complete lines 27 through 29, and lines 33 and 34.						
	27	Unrestricted net assets			-372,644	27	-2,414,378
	28	Temporarily restricted net assets				28	
	29	Permanently restricted net assets				29	
	Organizations that do not follow SFAS 117 (ASC 958), check here ☐ and complete lines 30 through 34.						
	30	Capital stock or trust principal, or current funds				30	
	31	Paid-in or capital surplus, or land, building or equipment fund				31	
	32	Retained earnings, endowment, accumulated income, or other funds				32	
	33	Total net assets or fund balances			-372,644	33	-2,414,378
	34	Total liabilities and net assets/fund balances			4,581,735	34	5,774,064

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	5,660,850
2	Total expenses (must equal Part IX, column (A), line 25)	2	7,702,584
3	Revenue less expenses Subtract line 2 from line 1	3	-2,041,734
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	-372,644
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 in Schedule O)	9	0
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	-2,414,378

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 ☐ Cash ☒ Accrual ☐ 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? 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 ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis		No
2b	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 ☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis	Yes	
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? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O	Yes	
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?		No
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 in Schedule O and describe any steps taken to undergo such audits		

SCHEDULE A
(Form 990 or 990EZ)

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. ▶ See separate instructions.
▶ Information about Schedule A (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2013

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 11, 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)

3

☐

A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii)**.

4

☐

A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii)**. Enter the hospital's name, city, and state _____

5

☐

An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv)**. (Complete Part II)

6

☐

A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v)**.

7

☒

An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)**. (Complete Part II)

8

☐

A community trust described in **section 170(b)(1)(A)(vi)** (Complete Part II)

9

☐

An 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)

10

☐

An organization organized and operated exclusively to test for public safety See **section 509(a)(4)**.

11

☐

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 that describes the type of supporting organization and complete lines 11e through 11h

a

☐

Type I

b

☐

Type II

c

☐

Type III - Functionally integrated

d

☐

Type III - Non-functionally integrated

e

☐

By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2)

f

☐

If the organization received a written determination from the IRS that it is a Type I, Type II, or Type III supporting organization, check this box

g

☐

Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?

(i)

A person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the supported organization?

(ii)

A family member of a person described in (i) above?

(iii)

A 35% controlled entity of a person described in (i) or (ii) above?

h

☐

Provide the following information about the supported organization(s)

	Yes	No
11g(i)		
11g(ii)		
11g(iii)		

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 9 above or IRC section (see instructions))	(iv) Is the organization in col (i) listed in your governing document?		(v) Did you notify the organization in col (i) of your support?		(vi) Is the organization in col (i) organized in the U S ?		(vii) Amount of monetary support
			Yes	No	Yes	No	Yes	No	
Total									

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

Cat No 11285F

Schedule A (Form 990 or 990-EZ) 2013

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) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants ")	1,294,570	2,168,051	4,013,762	3,810,786	5,645,435	16,932,604
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	1,294,570	2,168,051	4,013,762	3,810,786	5,645,435	16,932,604
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						
6 Public support. Subtract line 5 from line 4						16,932,604

Section B. Total Support							
Calendar year (or fiscal year beginning in) ▶		(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
7	Amounts from line 4	1,294,570	2,168,051	4,013,762	3,810,786	5,645,435	16,932,604
8	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	13,381	9,145	13,082	20,348	15,004	70,960
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 IV)	-230					-230
11	Total support (Add lines 7 through 10)						17,003,334
12	Gross receipts from related activities, etc (see instructions)					12	
13	First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here ☐						

Section C. Computation of Public Support Percentage			
14	Public support percentage for 2013 (line 6, column (f) divided by line 11, column (f))	14	99 580 %
15	Public support percentage for 2012 Schedule A, Part II, line 14	15	99 470 %
16a	33 1/3% support test—2013. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ☒		
b	33 1/3% support test—2012. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization ☐		
17a	10%-facts-and-circumstances test—2013. 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 IV how the organization meets the "facts-and-circumstances" test The organization qualifies as a publicly supported organization ☐		
b	10%-facts-and-circumstances test—2012. 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 IV how the organization meets the "facts-and-circumstances" test The organization qualifies as a publicly supported organization ☐		
18	Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions ☐		

Part IIISupport Schedule for Organizations Described in Section 509(a)(2)
(Complete only if you checked the box on line 9 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) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support (Subtract line 7c from line 6.)						

Section B. Total Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						
14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here ▶						

Section C. Computation of Public Support Percentage		
15 Public support percentage for 2013 (line 8, column (f) divided by line 13, column (f))	15	
16 Public support percentage from 2012 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage		
17 Investment income percentage for 2013 (line 10c, column (f) divided by line 13, column (f))	17	
18 Investment income percentage from 2012 Schedule A, Part III, line 17	18	
19a 33 1/3% support tests—2013. 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—2012. 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 **Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; and Part III, line 12. Also complete this part for any additional information. (See instructions).

Facts And Circumstances Test

Return Reference	Explanation	
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SCHEDULE D
(Form 990)

Supplemental Financial Statements

OMB No 1545-0047

2013

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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

▶ Attach to Form 990. ▶ See separate instructions. ▶ Information about Schedule D (Form 990) and its instructions is at www.irs.gov/form990.

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" to Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1	Total number at end of year	
2	Aggregate contributions to (during year)	
3	Aggregate grants from (during year)	
4	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" to 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
a	Total number of conservation easements
b	Total acreage restricted by conservation easements
c	Number of conservation easements on a certified historic structure included in (a)
d	Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register

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, and enforcing conservation easements during the year ▶

7

Amount of expenses incurred in monitoring, inspecting, 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" to Form 990, Part IV, line 8.

1a

If the organization elected, as permitted under SFAS 116 (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 SFAS 116 (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) Revenues included in 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 SFAS 116 (ASC 958) relating to these items

a

Revenues included in Form 990, Part VIII, line 1

▶ \$

b

Assets included in Form 990, Part X

▶ \$

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

Cat No 52283D

Schedule D (Form 990) 2013

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" to 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
- c Beginning balance

d Additions during the year

e Distributions during the year

f Ending balance

	Amount
1c	
1d	
1e	
1f	
- 2a Did the organization include an amount on Form 990, Part X, line 21?

☐ 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" to Form 990, Part IV, line 10.

- | | (a)Current year | (b)Prior year | b (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 Temporarily restricted endowment ▶
- The percentages in 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
3a(i)		
3a(ii)		
3b		
- b If "Yes" to 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' to 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				
e Other				
Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c).) ▶				0

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return Complete if the organization answered 'Yes' to Form 990, Part IV, line 12a.						
1	Total revenue, gains, and other support per audited financial statements	1	5,671,350			
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12					
a	Net unrealized gains on investments				2a	
b	Donated services and use of facilities				2b	10,500
c	Recoveries of prior year grants				2c	
d	Other (Describe in Part XIII)				2d	
e	Add lines 2a through 2d	2e	10,500			
3	Subtract line 2e from line 1	3	5,660,850			
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	5,660,850			

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return. Complete if the organization answered 'Yes' to Form 990, Part IV, line 12a.						
1	Total expenses and losses per audited financial statements	1	7,713,085			
2	Amounts included on line 1 but not on Form 990, Part IX, line 25					
a	Donated services and use of facilities				2a	10,500
b	Prior year adjustments				2b	
c	Other losses				2c	
d	Other (Describe in Part XIII)				2d	
e	Add lines 2a through 2d	2e	10,500			
3	Subtract line 2e from line 1	3	7,702,585			
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	7,702,585			

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.

[illegible]

SCHEDULE F
(Form 990)

Department of the Treasury
Internal Revenue Service

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. ► See separate instructions.
► Information about Schedule F (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2013

Open to Public
Inspection

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" to 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 region	(d) Activities conducted in region (by type) (e g , 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 region	(f) Total expenditures for and investments in region
3a Sub-total	0	0			0
b Total from continuation sheets to Part I	0	0			0
c Totals (add lines 3a and 3b)	0	0			0

Part II **Grants and Other Assistance to Organizations or Entities Outside the United States.** Complete if the organization answered "Yes" to 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 non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			UNITED KINGDOM	TO DETERMINE MECP2 PROTEIN FUNCTION	218,088				
			ISRAEL	CLINICAL TRIAL	98,980				

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" to Form 990, Part IV, line 16.
Part III can be duplicated if additional space is needed.

[illegible]

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 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)*

☐

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 file Form 5713, International Boycott Report (see Instructions for Form 5713).*

☐

Yes

☒

No

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).

[illegible]

Schedule I
(Form 990)

Department of the Treasury
Internal Revenue Service

Name of the organization
RETT SYNDROME RESEARCH TRUST INC

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

Complete if the organization answered "Yes," to Form 990, Part IV, line 21 or 22.
▶ Attach to Form 990

▶ Information about Schedule I (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2013

Open to Public
Inspection

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 Governments and Organizations in the United States. Complete if the organization answered "Yes" to 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 Code 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
See Additional Data Table							

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 Individuals in the United States. Complete if the organization answered "Yes" to 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 non-cash assistance

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
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Form 990,Schedule I, Part II, Grants and Other Assistance to Governments and Organizations in the United States

(a) Name and address of organization or government	(b) EIN	(c) IRC Code 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
WEILL 1305 YORK AVE 13TH FLOOR NEWYORK,NY 10021	15-0532082		100,854				GENE THERAPY
ALBERT EINSTEIN 1300 MORRIE PARK AVENUE BRONX,NY 10461	11-3162422		402,165				CLINICAL TRIAL
MGH 55 FRUIT ST BOSTON,MA 02114	04-1564655		125,000				REACTIVATING SILENT MECP2
CASE WESTERN 10900 EUCLID AVENUE CLEVELAND,OH 44106	34-1018992		100,000				PRE-CLINICAL TESTING OF COMPOUNDS
OREGON HSU 3181 SW SAM JACKSON PARK RD PORTLAND,OR 97239	93-1176109		164,911				GENE THERAPY
UNIVERSITY OF MASSACHUSETTS 333 SOUTH STREET SUITE 400 SHREWSBURY,MA 01545	04-3167352		250,000				EXPERIMENTS TO EXPLORE REACTIVATION OF SILENT X-CHROMOSOME
CENTER FOR COMPARATIVE MEDICINE DEPARTMENT OF NEUROSCIENCE CHARLOTTESVILLE,VA 22908	54-6001796		10,123				EXPLORING IMMUNE FUNCTION

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 to provide any additional information.****▶ Attach to Form 990 or 990-EZ.****▶ Information about Schedule O (Form 990 or 990-EZ) and its instructions is at
www.irs.gov/form990.**

OMB No 1545-0047

2013**Open to Public
Inspection**Name of the organization
RETT SYNDROME RESEARCH TRUST INC**Employer identification number**

26-0687439

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 11	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
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