Department of the Treasury

Internal Revenue Service

EXTENDED TO NOVEMBER 15, 2024 Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations) Do not enter social security numbers on this form as it may be made public. Go to www.irs.gov/Form990 for instructions and the latest information.



| Α | For th | e 2023 calendar year, or tax year beginning and e | ending | | | | |
|-------------------------|--------------------------|---|---|------------------------------|-----------------------------|--|--|
| В | Check if applicat | e: C Name of organization | | D Employer identific | cation number | | |
| | Addr | | | | | | |
| | Name | Doing business as | 26-06874 | 39 | | | |
| | Initial returr | | E Telephone number | | | | |
| | Final returr termi | | 203-445- | | | | |
| _ | ated | City or town, state or province, country, and ZIP or foreign postal code | | G Gross receipts \$ | 8,872,437. | | |
| | | ded TRUMBULL, CT 06611 | | H(a) Is this a group re | | | |
| | Appli tion pend | | | for subordinates | | | |
| | | 67 UNDERCLIFF ROAD, TRUMBULL, CT 06611 | | H(b) Are all subordinates in | | | |
| - | | empt status: $X 501(c)(3) 501(c) ()$ (insert no.) 4947(a)(1) o | or 527 | | list. See instructions | | |
| | Webs | | | H(c) Group exemption | n number | | |
| | | f organization: X Corporation Trust Association Other | L Year | of formation: 2007 | State of legal domicile: CT | | |
| P | art I | Summary | | ZAUTONIC MT | COTON TO | | |
| e | 1 | Briefly describe the organization's mission or most significant activities: THE C FOCUSED ON THE DEVELOPMENT OF TREATMENTS | AND C | LAIION 5 MI | TH GANNEUME | | |
| Activities & Governance | | | | | | | |
| veri | 2 | 5 | | I | 14 sets. | | |
| ĝ | 3 | | | | 14 | | |
| 8 0 | 4 | Number of independent voting members of the governing body (Part VI, line 1b) . | | ····· | 8 | | |
| itie | 5 | | employed in calendar year 2023 (Part V, line 2a) (estimate if necessary) | | | | |
| ži | | Total unrelated business revenue from Part VIII, column (C), line 12 | | | 0.0 | | |
| Ă | | Net unrelated business taxable income from Form 990-T, Part I, line 11 | | | 0. | | |
| | | | | Prior Year | Current Year | | |
| đ | 8 | Contributions and grants (Part VIII, line 1h) | | 7,028,813. | 8,080,684. | | |
| ň | 9 | Program service revenue (Part VIII, line 2g) | | 39,122. | 106,950. | | |
| Revenue | 10 | Investment income (Part VIII, column (A), lines 3, 4, and 7d) | | 30,058. | 336,181. | | |
| £ | 11 | Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) | | 0. | 0. | | |
| | 12 | Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12) | | 7,097,993. | 8,523,815. | | |
| | 13 | Grants and similar amounts paid (Part IX, column (A), lines 1-3) | | 2,073,337. | 9,938,988. | | |
| | 14 | Benefits paid to or for members (Part IX, column (A), line 4) | | 0. | 0. | | |
| ŝ | 15 | Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) | | 1,237,769. | 1,287,803. | | |
| Expenses | 16a | Professional fundraising fees (Part IX, column (A), line 11e) | | 0. | 0. | | |
| be | | Total fundraising expenses (Part IX, column (D), line 25) 749, 61 | 15. | | | | |
| Ш | 17 | Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) | | 731,059. | 1,111,513. | | |
| | 18 | Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) | | 4,042,165. | 12,338,304. | | |
| | 19 | Revenue less expenses. Subtract line 18 from line 12 | | 3,055,828. | -3,814,489. | | |
| s or | | | | ginning of Current Year | End of Year | | |
| set | 20 | Total assets (Part X, line 16) | | 14,883,080. | 18,457,084. | | |
| Net Assets | 21 | Total liabilities (Part X, line 26) | | 3,932,779. | 11,321,272. | | |
| N ^E | 22 | Net assets or fund balances. Subtract line 21 from line 20 | | 10,950,301. | 7,135,812. | | |
| I P | art 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 | Signature of officer | | | Date | |
|--|---|------------------------------------|------|----------------------------|--|
| Here MONICA COENRAADS, CHIEF EXECUTIVE OFFICER | | | | | |
| | Type or print name and title | | | | |
| | Print/Type preparer's name | Preparer's signature | Date | Check X PTIN | |
| Paid | JOHN M. ROLLERI, CPA | | | if self-employed P00182555 | |
| Preparer | | RD CPAS, LLP | | Firm's EIN 06-1156122 | |
| Use Only | Firm's address 2150 POST ROAD, | 5TH FL | | | |
| | FAIRFIELD, CT 063 | 824 | | Phone no. (203) 259-2727 | |
| May the II | RS discuss this return with the preparer shown ab | oove? See instructions | | X Yes No | |
| LHA For | Paperwork Reduction Act Notice, see the sepa | arate instructions. 332001 12-21-2 | 23 | Form 990 (2023) | |

SEE SCHEDULE O FOR ORGANIZATION MISSION STATEMENT CONTINUATION

| | 990 (2023) RETT SYNDROME RESEARCH TRUST, INC 26-0687439 t III Statement of Program Service Accomplishments 26-0687439 | Pa |
|-------|---|--------------|
| Fai | 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 TREATMEN | \mathbf{T} |
| | 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? | x |
| | prior Form 990 or 990-EZ? | |
| 3 | Did the organization cease conducting, or make significant changes in how it conducts, any program services? | Х |
| | 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, ar | nd |
| | revenue, if any, for each program service reported. (Code:) (Expenses \$ 11,144,171. including grants of \$ 9,938,988.) (Revenue \$ 106,9 | 5 |
| 4a | (Code:) (Expenses \$1,144,171. including grants of \$9,938,988.) (Revenue \$106,9 THE ORGANIZATION PROVIDES FUNDING TO LEADING RESEARCH INSTITUTIONS A | |
| | COMPANIES WORKING ON RETT SYNDROME AND RELATED MECP2 DISORDERS. | |
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| | | |
| | | |
| 4b | (Code:) (Expenses \$ 252,369. including grants of \$) (Revenue \$ | |
| -10 | THE ORGANIZATION SPONSORS SCIENTIFIC WORKSHOPS THAT BRING THE LEADIN | G |
| | RETT RESEARCHERS TOGETHER WITH ELITE SCIENTISTS IN SYNERGISTIC FIELD | |
| | TO EXCHANGE DATA AND SET RESEARCH DIRECTION. | |
| | | |
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| | | |
| | | |
| 4c | (Code:) (Expenses \$ including grants of \$) (Revenue \$) | |
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| | | |
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| | | |
| 4d | Other program services (Describe on Schedule O.) | |
| 40 | (Expenses \$ including grants of \$) (Revenue \$) Total program service expenses 11,396,540. | |
| 4e | Total program service expenses 11,396,540. | 0 (|
| 32002 | 2 12-21-23 | - (|
| | 3 | |
| 20 | 624 759649 397-0001 2023.04000 RETT SYNDROME RESEARCH TRUS 397-0 | 0 |

| | 000 | (0000) |
|------|-----|--------|
| ⊢orm | 990 | (2023) |

Part IV Checklist of Required Schedules

RETT SYNDROME RESEARCH TRUST, INC

| | | | 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 | X | |
| 2 | Is the organization required to complete Schedule B, Schedule of Contributors? See instructions | 2 | Х | <u> </u> |
| 3 | Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for | | | x |
| | public office? If "Yes," complete Schedule C, Part I | 3 | | |
| 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 | | x |
| 5 | Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Rev. Proc. 98-19? <i>If</i> "Yes," <i>complete Schedule C, Part III</i> | 5 | | x |
| 6 | Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to | 6 | | x |
| 7 | provide advice on the distribution or investment of amounts in such funds or accounts? <i>If</i> "Yes," <i>complete Schedule D, Part I</i> Did the organization receive or hold a conservation easement, including easements to preserve open space, | 0 | | |
| ' | the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II | 7 | | x |
| 8 | Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete | , | | |
| Ū | Schedule D, Part III | 8 | | x |
| 9 | Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for | | | |
| | amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? If "Yes," complete Schedule D, Part IV | 9 | | x |
| 10 | Did the organization, directly or through a related organization, hold assets in donor-restricted endowments | | | |
| | or in quasi-endowments? If "Yes," complete Schedule D, Part V | 10 | | X |
| 11 | If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X, as applicable. | | | |
| а | Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI | 11a | | x |
| b | Did the organization report an amount for investments - other securities in Part X, line 12, that is 5% or more of its total | | | |
| | assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII | | | Х |
| с | 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 | | X |
| d | Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in | | | |
| | Part X, line 16? If "Yes," complete Schedule D, Part IX | 11d | | X |
| | Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X | 11e | | X |
| t | Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses | | | x |
| 10- | the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If</i> "Yes," <i>complete Schedule D, Part X</i> Did the organization obtain separate, independent audited financial statements for the tax year? <i>If</i> "Yes," <i>complete</i> | 11f | | <u> </u> |
| | Schedule D, Parts XI and XII | 12a | х | |
| b | Was the organization included in consolidated, independent audited financial statements for the tax year? | | | v |
| 40 | If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional | 12b 13 | | X X |
| 13 14 a | Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i> Did the organization maintain an office, employees, or agents outside of the United States? | 14a | | X |
| | Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, | 170 | | |
| 2 | 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 | х | |
| 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 | Х | |
| 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 | | X |
| 17 | Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, | 47 | | x |
| 40 | column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I</i> . See instructions Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines | 17 | | |
| 18 | 1c and 8a? If "Yes," complete Schedule G, Part II | 18 | | x |
| 19 | Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If</i> "Yes," <i>complete Schedule G, Part III</i> | 19 | | x |
| 20a | Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H | 20a | | Х |
| b | If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? | 20b | | |
| 21 | Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or | | | |
| | domestic government on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II | 21 | X | |
| 33200 | 3 12-21-23 | Form | 990 | (2023) |

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| Form 990 (202 |
|---------------|
|---------------|

Part IV Checklist of Required Schedules (continued)

| | | | Yes | No |
|--------|--|-----|-----|----------|
| 22 | Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on | | | |
| | Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III | 22 | | X |
| 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? If "Yes," complete | | | |
| | Schedule J | 23 | Х | |
| 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? If "Yes," answer lines 24b through 24d and complete | | | |
| | Schedule K. If "No," go to line 25a | 24a | | X |
| b | Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? | 24b | | |
| С | 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), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit | | | |
| | transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I | 25a | | X |
| 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? If "Yes," complete | | | |
| | Schedule L, Part I | 25b | | X |
| 26 | Did the organization report any amount on Part X, line 5 or 22, for receivables from or 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? If "Yes," complete Schedule L, Part II | 26 | | X |
| 27 | Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, | | | |
| | creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled | | | |
| | entity (including an employee thereof) or family member of any of these persons? If "Yes," complete Schedule L, Part III | 27 | | X |
| 28 | Was the organization a party to a business transaction with one of the following parties? (See the Schedule L, Part IV, | | | |
| | instructions for applicable filing thresholds, conditions, and exceptions): | | | |
| а | A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If | | | |
| | "Yes," complete Schedule L, Part IV | 28a | | X |
| | A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV | 28b | | X |
| С | A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b?If | | | |
| | "Yes," complete Schedule L, Part IV | 28c | v | x |
| 29 | Did the organization receive more than \$25,000 in noncash contributions? <i>If</i> "Yes," <i>complete Schedule M</i> | 29 | Х | |
| 30 | Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation | | | v |
| | contributions? If "Yes," complete Schedule M | 30 | | X X |
| 31 | Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I | 31 | | |
| 32 | Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete | | | x |
| ~~ | Schedule N, Part II | 32 | | |
| 33 | Did the organization own 100% of an entity disregarded as separate from the organization under Regulations | | | v |
| | sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I | 33 | | X |
| 34 | Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and | ~ | | v |
| 05 - | Part V, line 1 | 34 | | X |
| | Did the organization have a controlled entity within the meaning of section 512(b)(13)? | 35a | | |
| D | If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity | 25h | | |
| 26 | within the meaning of section 512(b)(13)? <i>If</i> "Yes," <i>complete Schedule R, Part V, line 2</i> Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? | 35b | | |
| 36 | | 36 | | x |
| 27 | If "Yes," complete Schedule R, Part V, line 2 Did the organization conduct more than 5% of its activities through an entity that is not a related organization | 30 | | |
| 37 | | 37 | | x |
| 38 | and that is treated as a partnership for federal income tax purposes? <i>If</i> "Yes," <i>complete Schedule R, Part VI</i> | 31 | | <u> </u> |
| 00 | Note: All Form 990 filers are required to complete Schedule O | 38 | х | |
| Par | | 00 | | I |
| | 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 1a 16 | | | |
| | Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable 1b | | | |
| | Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming | | | |
| Ũ | (gambling) winnings to prize winners? | 1c | | |
| 332004 | 4 12-21-23 | | 990 | (2023) |
| | 5 | | | / |

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| 023) | \mathbf{RETT} | SYNDROME | RESEARCH | TRUST, | INC |
|--------------|-----------------|---------------|----------------|----------|-----------------------|
| Statements R | egardin | g Other IRS F | ilings and Tax | Complian | ce (continued) |

| | | | Yes | No |
|---------|--|------------|-----|----------|
| 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 2a 8 | | | |
| b | If at least one is reported on line 2a, did the organization file all required federal employment tax returns? | 2b | | X |
| 3a | Did the organization have unrelated business gross income of \$1,000 or more during the year? | 3a | | X |
| | If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O | 3b | | |
| 4a | At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a | | | v |
| | financial account in a foreign country (such as a bank account, securities account, or other financial account)? | 4a | | X |
| b | If "Yes," enter the name of the foreign country | | | |
| | See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR). | F - | | х |
| 5a ⊾ | | 5a 5b | | X |
| b | Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction? | 50 50 | | |
| с 6а | | 30 | | |
| ou | any contributions that were not tax deductible as charitable contributions? | 6a | | x |
| b | If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts | | | |
| | were not tax deductible? | 6b | | |
| 7 | Organizations that may receive deductible contributions under section 170(c). | | | |
| а | Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor? | 7a | Х | |
| b | If "Yes," did the organization notify the donor of the value of the goods or services provided? | 7b | Х | |
| с | Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required | | | |
| | to file Form 8282? | 7c | | X |
| d | If "Yes," indicate the number of Forms 8282 filed during the year 7d | | | |
| е | Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract? | 7e | | |
| f | Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? | 7f | | |
| g | If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required? | 7g | | |
| h | If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C? | 7h | | |
| 8 | Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the | - | | |
| • | sponsoring organization have excess business holdings at any time during the year? | 8 | | |
| 9 | Sponsoring organizations maintaining donor advised funds. | 0- | | |
| a h | Did the sponsoring organization make any taxable distributions under section 4966? | 9a 9b | | <u> </u> |
| ь 10 | Did the sponsoring organization make a distribution to a donor, donor advisor, or related person? | 90 | | |
| а | Initiation fees and capital contributions included on Part VIII, line 12 10a | | | |
| b | Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities 10b | | | |
| 11 | Section 501(c)(12) organizations. Enter: | | | |
| а | Gross income from members or shareholders | | | |
| b | Gross income from other sources. (Do not net amounts due or paid to other sources against | | | |
| | amounts due or received from them.) | | | |
| 12a | Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041? | 12a | | |
| b | If "Yes," enter the amount of tax-exempt interest received or accrued during the year 12b | | | |
| 13 | Section 501(c)(29) qualified nonprofit health insurance issuers. | | | |
| а | Is the organization licensed to issue qualified health plans in more than one state? | 13a | | |
| | Note: See the instructions for additional information the organization must report on Schedule O. | | | |
| b | Enter the amount of reserves the organization is required to maintain by the states in which the | | | |
| _ | organization is licensed to issue qualified health plans 13b | | | |
| | Enter the amount of reserves on hand | 14a | | x |
| | Did the organization receive any payments for indoor tanning services during the tax year? If "Yes," has it filed a Form 720 to report these payments? <i>If "No," provide an explanation on Schedule O</i> | 14a 14b | | <u> </u> |
| 15 | Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or | | | <u> </u> |
| | excess parachute payment(s) during the year? | 15 | | x |
| | If "Yes," see the instructions and file Form 4720, Schedule N. | | | |
| 16 | Is the organization an educational institution subject to the section 4968 excise tax on net investment income? | 16 | | Х |
| | If "Yes," complete Form 4720, Schedule O. | | | |
| 17 | Section 501(c)(21) organizations. Did the trust, or any disqualified or other person engage in any activities | | | |
| | that would result in the imposition of an excise tax under section 4951, 4952 or 4953? | 17 | | |
| | If "Yes," complete Form 6069. | | | |
| 332005 | 5 12-21-23 | Form | 990 | (2023) |

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332005 12-21-23

Form 990 (2023)

Part V

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| Form 990 (2 | 023) |
|-------------|------|
|-------------|------|

RETT SYNDROME RESEARCH TRUST, INC

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

Х

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

| | | | | _ | Yes | N |
|-------|---|----------|------------------------|----------|--------------|-------|
| 1a | Enter the number of voting members of the governing body at the end of the tax year | 1a | 14 | L | | |
| | 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 on Schedule O. | | | | | |
| b | Enter the number of voting members included on line 1a, above, who are independent | 1b | 14 | Ŀ | | |
| 2 | Did any officer, director, trustee, or key employee have a family relationship or a business relationsh | p with | any other | | | |
| | officer, director, trustee, or key employee? | | | 2 | | X |
| 3 | Did the organization delegate control over management duties customarily performed by or under the | e direc | t supervision | | | |
| | of officers, directors, trustees, or key employees to a management company or other person? | | | 3 | | X |
| 4 | Did the organization make any significant changes to its governing documents since the prior Form | 990 wa | s filed? | 4 | | X |
| 5 | Did the organization become aware during the year of a significant diversion of the organization's as | | | 5 | | X |
| 6 | Did the organization have members or stockholders? | | | 6 | | X |
| 7a | Did the organization have members, stockholders, or other persons who had the power to elect or a more members of the governing body? | | | 7a | | x |
| b | Are any governance decisions of the organization reserved to (or subject to approval by) members, | | | | | |
| | persons other than the governing body? | | | 7b | | x |
| 8 | Did the organization contemporaneously document the meetings held or written actions undertaken during the ye | | | | | |
| | The governing body? | - | - | 8a | x | |
| | Each committee with authority to act on behalf of the governing body? | | | 8b | X | |
| 9 | Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be rea | | | | | |
| | organization's mailing address? If "Yes," provide the names and addresses on Schedule O | | | 9 | | X |
| ec | tion B. Policies (This Section B requests information about policies not required by the Internal R | evenue | e Code.) | | | |
| | | | | | Yes | No |
| Da | Did the organization have local chapters, branches, or affiliates? | | | 10a | | X |
| b | If "Yes," did the organization have written policies and procedures governing the activities of such c | hapter | s, affiliates, | | | |
| | and branches to ensure their operations are consistent with the organization's exempt purposes? | | | 10b | | |
| 1a | Has the organization provided a complete copy of this Form 990 to all members of its governing boo | ly befo | re filing the form? | 11a | Х | |
| b | Describe on Schedule O the process, if any, used by the organization to review this Form 990. | | | | | |
| 2a | Did the organization have a written conflict of interest policy? If "No," go to line 13 | | | 12a | X | |
| b | Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise | to con | flicts? | 12b | X | |
| С | Did the organization regularly and consistently monitor and enforce compliance with the policy? If ") on Schedule O how this was done | | | 12c | x | |
| 3 | Did the organization have a written whistleblower policy? | | | 13 | X | |
| 4 | Did the organization have a written document retention and destruction policy? | | | 14 | X | |
| 5 | Did the process for determining compensation of the following persons include a review and approv | | | | | |
| | persons, comparability data, and contemporaneous substantiation of the deliberation and decision? | | • | | | |
| а | The organization's CEO, Executive Director, or top management official | | | 15a | X | |
| | Other officers or key employees of the organization | | | 15b | X | |
| | If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions. | | | | | |
| 6a | Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrange | ment v | vith a | | | |
| | taxable entity during the year? | | | 16a | | X |
| b | If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate | te its p | articipation | | | |
| | in joint venture arrangements under applicable federal tax law, and take steps to safeguard the orga | nizatio | n's | | | |
| | exempt status with respect to such arrangements? | | | 16b | | |
| ec | tion C. Disclosure | | | | | |
| 7 | List the states with which a copy of this Form 990 is required to be filed CA, CT, IL, MA, M | ID,N | J,NY,PA | | | |
| 8 | Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, a | | | s)s only | /) avail | able |
| | for public inspection. Indicate how you made these available. Check all that apply. X Own website Another's website Upon request Other (explain) | | hadula () | | | |
| 19 | Describe on Schedule O whether (and if so, how) the organization made its governing documents, c | | | nd fina | ncial | |
| 5 | statements available to the public during the tax year. | Jimot | or interest policy, al | iu iiid | nudi | |
| 20 | State the name, address, and telephone number of the person who possesses the organization's bo | nke ar | id records | | | |
| | MONICA COENRAADS - 203-445-0041 | ions al | | | | |
| | 67 UNDER CLIFF ROAD, TRUMBULL, CT 06611 | | | | | |
| 32004 | 5 12-21-23 | | | Forn | n 990 | (2023 |
| | 7 | | | | | , |
| 20 | 624 759649 397-0001 2023.04000 RETT SYNDROME | RESI | EARCH TRUS | 39' | 7-0(| 001 |
| 20 | | сцот | micin 1100 | 55 | , , | • |

| 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, box 6 of 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, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.

• List all of the organization's former directors or trustees that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

See 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) | (B) | Ľ | (C) | | | (D) | (E) | (F) | | | |
|-----------------------------------|------------------------|--------------------------------|-----------------------|----------|--------------|---------------------------------|--------|-----------------|-----------------|------------------------------|--|
| Name and title | Average | Positio | | | ition | | | Reportable | Reportable | Estimated | |
| | hours per | box | , unle | ss pe | rson | than is bot | h an | compensation | compensation | amount of | |
| | week | <u> </u> | cer an | nd a d | irecto | or/trus | tee) | from | from related | other | |
| | (list any | ector | | | | | | the | organizations | compensation | |
| | hours for | or dir | ę. | | | ated | | organization | (W-2/1099-MISC/ | from the | |
| | related | ustee | truste | | æ | bensi | | (W-2/1099-MISC/ | 1099-NEC) | organization | |
| | organizations below | ual tri | ional | | ploye | t com | | 1099-NEC) | | and related organizations | |
| | line) | Individual trustee or director | Institutional trustee | Officer | Key employee | Highest compensated employee | Former | | | organizations | |
| (1) MONICA COENRAADS | 50.00 | <u> </u> | = | ò | ž | 포뇽 | F | | | | |
| CHIEF EXECUTIVE OFFICER | | x | | x | | | | 220,000. | 0. | 0. | |
| (2) TIMOTHY FREEMAN | 50.00 | | | | | | | , | | | |
| CHIEF DEVELOPMENT OFFICER | | x | | x | | | | 220,000. | Ο. | 0. | |
| (3) JANA VON HEHN | 50.00 | | | | | | | | | | |
| CHIEF SCIENTIFIC OFFICER | | X | | X | | | | 203,333. | 0. | 0. | |
| (4) RANDALL CARPENTER | 25.00 | | | | | | | | | | |
| CHIEF MEDICAL OFFICER | | Х | | Х | | | | 165,000. | 0. | 0. | |
| (5) ADRIAN BIRD | 2.00 | | | | | | | | | | |
| TRUSTEE | | Х | | | | | | 0. | 0. | 0. | |
| (6) ALBA TULL | 2.00 | | | | | | | | | | |
| TRUSTEE | | Х | | | | | | 0. | 0. | 0. | |
| (7) BRAD ZELINGER | 2.00 | | | | | | | | | _ | |
| TRUSTEE | | Х | | | | | | 0. | 0. | 0. | |
| (8) BRIAN WHITMER | 2.00 | | | | | | | | | _ | |
| TRUSTEE | | X | | | | | | 0. | 0. | 0. | |
| (9) HEIDI EPSTEIN | 2.00 | | | | | | | | | | |
| VICE CHAIRMAN | | X | | Х | | | | 0. | 0. | 0. | |
| (10) INGRID HARDING | 2.00 | | | | | | | | | • | |
| CO-FOUNDER AND TRUSTEE | | X | | | | | | 0. | 0. | 0. | |
| (11) LAWRENCE MATTIS | 2.00 | | | | | | | | | • | |
| SECRETARY | | X | | X | | | | 0. | 0. | 0. | |
| (12) MARC TESLER | 2.00 | | | | | | | 0 | 0 | 0 | |
| TRUSTEE | 2 00 | X | | | | | | 0. | 0. | 0. | |
| (13) MARCI VALNER | 2.00 | x | | x | | | | 0. | 0. | 0. | |
| TREASURER | 2.00 | <u>^</u> | | <u>^</u> | | | | 0. | 0. | 0. | |
| (14) RACHAEL STEVENSON | 2.00 | x | | | | | | 0. | 0. | 0. | |
| TRUSTEE | 2.00 | ^ | | | | | | 0. | 0. | 0. | |
| (15) RACHEL ROTHSCHILD TRUSTEE | 2.00 | x | | | | | | 0. | 0. | 0. | |
| (16) STEPHANIE BOHN | 2.00 | | | | | | | 0. | • | <u>· · ·</u> | |
| TRUSTEE | 2.00 | x | | | | | | 0. | 0. | 0. | |
| (17) ANTHONY SCHOENER | 2.00 | 1 | | - | | | | 0. | 0. | <u>v •</u> | |
| CHAIRMAN | 2.00 | x | | | | | | 0. | 0. | 0. | |
| 332007 12-21-23 | | | I | I | I | L | 1 | 0. | 0. | Form 990 (2023) | |
| 332001 12-21-23 | | | | | | ~ | | | | (2023) | |

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| Form 990 (2023) RETT SYN | | | | | | | | | 26-06 | 687 | 439 | P | age 8 |
|--|--|--------------------------------|--|---------|--------------|---------------------------------|---|---|---|-------|---------------------------------|--|----------------|
| Part VII Section A. Officers, Directors, Trus | | ploy | ees | | | ghe | st C | | | | | | |
| (A) Name and title | (B) Average hours per week | box, offic | (C) Position check more than one ess person is both an ind a director/trustee) | | | | (D) Reportable compensation from | (E) Reportable compensatio from related | in I | an | (F) timate nount other | of | |
| | (list any hours for related organizations below line) | Individual trustee or director | Institutional trustee | Officer | Key employee | Highest compensated employee | Former | the organization (W-2/1099-MISC/ 1099-NEC) | organization: (W-2/1099-MIS 1099-NEC) | | fr org and | pensa om th anizat d relat anizati | e ion ed |
| | | | | 0 | X | τe | | | | | | | |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| 1b Subtotal | l | | | | | L | L | 808,333. | | 0. | | | 0. |
| c Total from continuation sheets to Part V d Total (add lines 1b and 1c) | I, Section A | | | | | | | 0. 808,333. | | 0. | | | 0. |
| 2 Total number of individuals (including but r compensation from the organization | | | | | | | | - |),000 of reportabl | - | | | 4 |
| 3 Did the organization list any former officer, | - | | | • | | | Ŭ | | - | | - | Yes | No X |
| line 1a? <i>If "Yes," complete Schedule J for s</i> For any individual listed on line 1a, is the su and related organizations greater than \$15 | um of reportab | le co | omp | ensa | ation | n and | d otl | | the organization | | 3 4 | x | Λ |
| 5 Did any person listed on line 1a receive or a rendered to the organization? <i>If</i> "Yes," <i>corr</i> | accrue comper | nsati | ion f | rom | any | unr | elat | ed organization or indiv | idual for services | | 5 | | х |
| Section B. Independent Contractors 1 Complete this table for your five highest co | mpensated ind | depe | ende | ent c | ontr | acto | ors t | that received more than | \$100.000 of com | npens | ation f | rom | |
| the organization. Report compensation for | | | | | | | | | | | | | |
| (A) Name and business | address | NC | ONE | 3 | | | | (B) Description of s | services | С | (C ompei | | n |
| | | | | | | | _ | | | | | | |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| | | | | | | | | | | | | | |
| 2 Total number of independent contractors (\$100,000 of compensation from the organi | | ot lir | nite | d to | thos (| se lis) | stec | above) who received n | nore than | | | 000 / | |

332008 12-21-23

Form **990** (2023)

9

| Form | n 990 (| | | | ME | RESEARC | H TRUST, I | NC | 26-0687 | 439 Page |
|--|---------|--|-----------|--------------------|------------|--------------------|----------------------|---|---|---|
| Pa | rt VII | Statement of Re | even | ue | | | | | | |
| | | Check if Schedule O | conta | ins a respor | ise | or note to any lii | ne in this Part VIII | | | L |
| | | | | | | | (A) Total revenue | (B) Related or exempt function revenue | (C) Unrelated business revenue | (D) Revenue exclud from tax undel sections 512 - 5 |
| ts S | 1 a | Federated campaigns | | 1a | | | | | | |
| Contributions, Gifts, Grants and Other Similar Amounts | | | | | | | | | | |
| Å,G | | Fundraising events | | | | | | | | |
| ar / | | | | | | | 1 | | | |
| s, G | | Government grants (conti | | | | 178,021. | 1 | | | |
| rSi | | All other contributions, gifts, | | | | | | | | |
| ibut | | similar amounts not included | d abov | e 1f ' | 7, | 902,663. | | | | |
| d of | g | Noncash contributions included in | n lines 1 | la-1f 1g \$ | | | | | | |
| au | h | Total. Add lines 1a-1f | | | | | 8,080,684. | | | |
| | | | | | | Business Code | | | | |
| e | 2 a | LICENSING | | | | 900099 | 84,450. | 84,450. | | |
| le rvi | b | BIOREPOSITORY | ζ | | _ | 900099 | 22,500. | 22,500. | | |
| n S ent | С | | | | _ | | | | | |
| Rev | d | | | | _ | | | | | |
| Program Service Revenue | е | | | | _ | | | | | |
| " | f | All other program service | | | | | | | | |
| | g | Total. Add lines 2a-2f | | | | | 106,950. | | | |
| | 3 | Investment income (inclue | | | | | 333,088. | 333,088. | | |
| | 4 | other similar amounts) | | | | | 555,000. | 555,000. | | |
| | 4 5 | | | • | • | | | | | |
| | 5 | Royalties | | (i) Real | | (ii) Personal | | | | |
| | 6 9 | Gross rents | 6a | (i) Hour | | | 1 | | | |
| | | Gross rents Less: rental expenses | 6b | | | | | | | |
| | | Rental income or (loss) | 6c | | | | | | | |
| | | Net rental income or (loss | | | | | | | | |
| | | Gross amount from sales of | | (i) Securitie | | (ii) Other | | | | |
| | | assets other than inventory | | 351,71 | 5. | | | | | |
| | b | Less: cost or other basis | | | | | 1 | | | |
| anu | | and sales expenses | 7b | 348,622 | | | | | | |
| evenue | с | Gain or (loss) | 7c | 3,093 | 3. | | | | | |
| μ. | d | Net gain or (loss) | | | | | 3,093. | 3,093. | | |
| Other | 8 a | Gross income from fundraisi | ing eve | ents (not | | | | | | |
| ð | | including \$ | | | | | | | | |
| | | contributions reported on | | | | | | | | |
| | | Part IV, line 18 | | | 8a | | - | | | |
| | | Less: direct expenses | | L | 8b | | | | | |
| | | Net income or (loss) from | | | s | | | | | |
| | 9 a | Gross income from gamin | | | 0- | | | | | |
| | h | Part IV, line 19 | | | 9a 9b | | - | | | |
| | | Less: direct expenses Net income or (loss) from | | L | | | | | | |
| | | Gross sales of inventory, | | Г | | | | | | |
| | 10 0 | and allowances | | | 10a | | | | | |
| | h | Less: cost of goods sold | | Г | 10a 10b | | | | | |
| | | Net income or (loss) from | | L | | | | | | |
| <i>"</i> | | | | | | Business Code | | | | |
| sions | 11 a | | | | | | | | | |
| ane | b | | | | _ | | | | | |
| evell | с | | | | _ | | | | | |
| Miscellaneous Revenue | d | All other revenue | | | | | | | | |
| | | Total. Add lines 11a-11d | | | | | | | | |
| | 12 | Total revenue. See instruction | ons | | | | 8,523,815. | 443,131. | 0. | (|
| 33200 | 9 12-21 | | | | | | | | | Form 990 (20 |

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RETT SYNDROME RESEARCH TRUST, INC Part IX Statement of Functional Expenses

26-0687439 Page 10

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 respon | nse or note to any line in | this Part IX | (2) | |
|----------|--|------------------------------|---|--|---------------------------------------|
| | not include amounts reported on lines 6b, 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 domestic organizations and domestic governments. See Part IV, line 21 | 9,938,988. | 9,938,988. | | |
| 2 | Grants and other assistance to domestic | - / / | | | |
| | individuals. See Part IV, line 22 | | | | |
| 3 | Grants and other assistance to foreign | | | | |
| | organizations, foreign governments, and foreign | | | | |
| | individuals. See Part IV, lines 15 and 16 | | | | |
| 4 | Benefits paid to or for members | | | | |
| 5 | Compensation of current officers, directors, | | | | |
| | trustees, and key employees | | | | |
| 6 | Compensation not included above to disqualified | | | | |
| | persons (as defined under section 4958(f)(1)) and | | | | |
| | persons described in section 4958(c)(3)(B) | 1 1 4 8 0 0 0 | | | |
| 7 | Other salaries and wages | 1,147,836. | 806,159. | 135,466. | 206,211 |
| 8 | Pension plan accruals and contributions (include | | | | |
| | section 401(k) and 403(b) employer contributions) | E0 10C | | <u> </u> | 10 000 |
| 9 | Other employee benefits | 59,126. | 41,526. | 6,978. 9,541. | 10,622 |
| 10 | Payroll taxes | 80,841. | 56,777. | 9,541. | 14,523 |
| 11 | Fees for services (nonemployees): | | | | |
| | Management | | | | |
| | Legal | | | | |
| | Accounting | | | | |
| | Lobbying | | | | |
| | Professional fundraising services. See Part IV, line 17 | | | | |
| f | Investment management fees | | | | |
| g | column (A), amount, list line 11g expenses on Sch 0.) | 174,064. | 142,727. | 21,780. | 9,557. |
| 12 | Advertising and promotion | 1,1,0010 | 112,7274 | 2277000 | 57557 |
| 13 | Office expenses | 7,449. | 845. | 6,388. | 216 |
| 13 14 | Information technology | ,,1100 | 0101 | | |
| 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 | | | | |
| 23 | Insurance | 6,804. | 2,268. | 2,268. | 2,268 |
| 24 | Other expenses. Itemize expenses not covered above. (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A), amount, list line 24e expenses on Schedule 0.) | | | | |
| а | FUNDRAISING | 491,819. | | | 491,819. |
| b | SCIENTIFIC MEETINGS, TR | 252,369. | 252,369. | | |
| с | RESEARCH COSTS | 80,625. | 80,625. | | |
| d | MISCELLANEOUS | 68,439. | 51,633. | 6,623. | 10,183 |
| е | All other expenses | 29,944. | 22,623. | 3,105. | 4,216 |
| 25 | Total functional expenses. Add lines 1 through 24e | 12,338,304. | 11,396,540. | 192,149. | 749,615 |
| 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) | | | | Form 990 (2023 |

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Form **990** (2023)

16520624 759649 397-0001

33 Total liabilities and net assets/fund balances

Form 990 (2023)

Part X Balance Sheet

| Assets | 6 | Loans and other receivables from other disquali | | | | |
|---------------|-----|---|-------------------------|-------------|-----|-------------|
| | | under section 4958(f)(1)), and persons described | | 6 | | |
| | 7 | Notes and loans receivable, net | | 7 | | |
| | 8 | Inventories for sale or use | | 8 | | |
| A | 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 | | 4,988. | 11 | 1,078. |
| | 12 | Investments - other securities. See Part IV, line 1 | 1 | | 12 | |
| | 13 | Investments - program-related. See Part IV, line | 11 | | 13 | |
| | 14 | Intangible assets | | | 14 | |
| | 15 | Other assets. See Part IV, line 11 | | | 15 | |
| | 16 | Total assets. Add lines 1 through 15 (must equa | al line 33) | 14,883,080. | 16 | 18,457,084. |
| | 17 | Accounts payable and accrued expenses | | 13,000. | 17 | 35,125. |
| | 18 | Grants payable | | 3,919,779. | 18 | 11,286,147. |
| | 19 | Deferred revenue | | | 19 | |
| | 20 | Tax-exempt bond liabilities | | | 20 | |
| | 21 | Escrow or custodial account liability. Complete F | Part IV of Schedule D | | 21 | |
| es | 22 | Loans and other payables to any current or form | ner officer, director, | | | |
| Liabilities | | trustee, key employee, creator or founder, subst | | | | |
| iab | | controlled entity or family member of any of thes | | 22 | | |
| - | 23 | Secured mortgages and notes payable to unrela | | 23 | | |
| | 24 | Unsecured notes and loans payable to unrelated | | 24 | | |
| | 25 | Other liabilities (including federal income tax, page | yables 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 | | 3,932,779. | 26 | 11,321,272. |
| s | | Organizations that follow FASB ASC 958, che | ck here X | | | |
| JCe | | and complete lines 27, 28, 32, and 33. | | 10 050 001 | | F 105 010 |
| alar | 27 | Net assets without donor restrictions | | 10,950,301. | 27 | 7,135,812. |
| dB | 28 | Net assets with donor restrictions | | | 28 | |
| Fund Balances | | Organizations that do not follow FASB ASC 9 | 58, check here | | | |
| | | and complete lines 29 through 33. | | | | |
| tso | 29 | Capital stock or trust principal, or current funds | | | 29 | |
| Assets or | 30 | Paid-in or capital surplus, or land, building, or eq | | | 30 | |
| μ | 31 | Retained earnings, endowment, accumulated in | | | 31 | |
| Ne | 32 | Total net assets or fund balances | | 10,950,301. | 32 | 7,135,812. |
| | 33 | Total liabilities and net assets/fund balances | | 14,883,080. | 33 | 18,457,084. |

RETT SYNDROME RESEARCH TRUST, INC

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

1 Cash - non-interest-bearing

2 Savings and temporary cash investments

3 Pledges and grants receivable, net

4 Accounts receivable, net

controlled entity or family member of any of these persons

5 Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% 26-0687439 Page 11

(B)

End of year

3,121,261.

14,145,135.

1,189,610.

Form 990 (2023)

(A)

Beginning of year

13,831,961.

1,046,131.

1

2

3

4

5

| | 990 (2023) RETT SYNDROME RESEARCH TRUST, INC | 26-00 | <u>587439</u> | Paç | ge 12 |
|----|--|------------|---------------|-----|--------------|
| Pa | rt XI Reconciliation of Net Assets | | | | |
| | Check if Schedule O contains a response or note to any line in this Part XI | | | | |
| | | | | | |
| 1 | Total revenue (must equal Part VIII, column (A), line 12) | 1 | 8,52 | | |
| 2 | Total expenses (must equal Part IX, column (A), line 25) | 2 | 12,33 | | |
| 3 | Revenue less expenses. Subtract line 2 from line 1 | 3 | -3,81 | | |
| 4 | Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A)) | 4 | 10,95 | 0,3 | 01. |
| 5 | Net unrealized gains (losses) on investments | 5 | | | |
| 6 | Donated services and use of facilities | 6 | | | |
| 7 | Investment expenses | 7 | | | |
| 8 | Prior period adjustments | 8 | | | |
| 9 | Other changes in net assets or fund balances (explain on Schedule O) | 9 | | | 0. |
| 10 | Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, | | | | |
| | column (B)) | 10 | 7,13 | 5,8 | 12. |
| Pa | rt XII Financial Statements and Reporting | | | | _ |
| | Check if Schedule O contains a response or note to any line in this Part XII | | <u></u> | | |
| | | | | Yes | No |
| 1 | Accounting method used to prepare the Form 990: Cash X Accrual Other | | _ | | |
| | If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule | e O. | | | |
| 2a | Were the organization's financial statements compiled or reviewed by an independent accountant? | | 2a | | X |
| | If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed | d on a | | | |
| | separate basis, consolidated basis, or both: | | | | |
| | Separate basis Consolidated basis Both consolidated and separate basis | | | | |
| b | Were the organization's financial statements audited by an independent accountant? | | 2b | Х | |
| | If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separat | e basis, | | | |
| | consolidated basis, or both: | | | | |
| | X Separate basis Consolidated basis Both consolidated and separate basis | | | | |
| с | If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the | e audit, | | | |
| | review, or compilation of its financial statements and selection of an independent accountant? | | 2c | | Х |
| | If the organization changed either its oversight process or selection process during the tax year, explain on Sch | nedule O. | | | |
| 3a | As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the | | | | |
| | Uniform Guidance, 2 C.F.R. Part 200, Subpart F? | | За | | X |
| b | If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the requ | ired audit | | | |
| | or audits, explain why on Schedule O and describe any steps taken to undergo such audits | | 3b | | |

Form **990** (2023)

332012 12-21-23

| SCHEDULE A | ١ |
|------------|---|
|------------|---|

Department of the Treasury

Internal Revenue Service

(Form 990)

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section

4947(a)(1) nonexempt charitable trust. Attach to Form 990 or Form 990-EZ.

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

| OMB No. 1545-0047 |
|------------------------------|
| 2023 |
| Open to Public Inspection |

Employer identification number

| Name of the organization | Employer identification num |
|---|-------------------------------------|
| RETT SYNDROME RESEARCH TRUST, INC | 26-0687439 |
| Part I Reason for Public Charity Status. (All organizations must complete this part.) See instructi | ons. |
| 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: | |
| 5 An organization operated for the benefit of a college or university owned or operated by a governmenta | l 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 fron | 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.) | |
| | |

art II.)

9 An agricultural research organization described in section 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.

| а | 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. |

Type II. A supporting organization supervised or controlled in connection with its supported organization(s), by having b 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.

| ; | 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. |

J Type III non-functionally integrated. A supporting organization operated in connection with its supported organization(s) d 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.

|) | 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

c

| g Provide the following information | n about the supporte | ed organization(s). | | | | |
|---------------------------------------|----------------------|---|-------------------------------------|----|---|----------------------------|
| (i) Name of supported organization | (ii) EIN | (iii) Type of organization (described on lines 1-10 | (iv) Is the orga in your governi | | (v) Amount of monetary support (see instructions) | (vi) Amount of other |
| organization | | above (see instructions)) | Yes | No | support (see instructions) | support (see instructions) |
| | | | | | | |
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| | | | | | | |
| Total | | | | | | |

Schedule A (Form 990) 2023

Part II

RETT SYNDROME RESEARCH TRUST, INC

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.)

| See | ction A. Public Support | | | | | | |
|-------------|--|-----------------------------|----------------------------------|---------------------------|---------------------------------|---------------------|-----------------|
| Cale | ndar year (or fiscal year beginning in) | (a) 2019 | (b) 2020 | (c) 2021 | (d) 2022 | (e) 2023 | (f) Total |
| 1 | Gifts, grants, contributions, and | | | | | | |
| | membership fees received. (Do not | | | | | | |
| | include any "unusual grants.") | 8340103. | 7664611. | 7837691. | 6657601. | 7603093. | 38103099. |
| 2 | Tax revenues levied for the organ- | | | | | | |
| | ization'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 \dots | | | | | | |
| 4 | Total. Add lines 1 through 3 | 8340103. | 7664611. | 7837691. | 6657601. | 7603093. | 38103099. |
| 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. | | | | | | 38103099. |
| See | ction B. Total Support | | | | - | | |
| Cale | ndar year (or fiscal year beginning in) | (a) 2019 | (b) 2020 | (c) 2021 | (d) 2022 | (e) 2023 | (f) Total |
| 7 | Amounts from line 4 | 8340103. | 7664611. | 7837691. | 6657601. | 7603093. | 38103099. |
| 8 | Gross income from interest, | | | | | | |
| | dividends, payments received on | | | | | | |
| | securities loans, rents, royalties, | | | | | | |
| | and income from similar sources \dots | 36,443. | 62,327. | 29,868. | 30,209. | 333,088. | 491,935. |
| 9 | Net income from unrelated business | | | | | | |
| | activities, whether or not the | | | | | | |
| | business is regularly carried on | | | | | | |
| 10 | Other income. Do not include gain | | | | | | |
| | or loss from the sale of capital | | | | | | |
| | assets (Explain in Part VI.) | | | | | | |
| 11 | Total support. Add lines 7 through 10 | | | | | | 38595034. |
| 12 | Gross receipts from related activities | , etc. (see instruction | ons) | | | 12 | |
| 13 | First 5 years. If the Form 990 is for the | ne organization's fi | rst, second, third, ^r | fourth, or fifth tax | year as a section 5 | 501(c)(3) | |
| | organization, check this box and stop | ohere | | | | | |
| See | ction C. Computation of Publ | lic Support Pe | rcentage | | | | |
| | Public support percentage for 2023 (| | | | | 14 | 98.73 % |
| | Public support percentage from 2022 | | | | | 15 | 99.55 % |
| 1 6a | 33 1/3% support test - 2023. If the o | organization did no | ot check the box or | n line 13, and line | 14 is 33 1/3% or n | nore, check this be | |
| | stop here. The organization qualifies | | | | | | |
| b | 33 1/3% support test - 2022. If the o | | | | | | |
| | and stop here. The organization qua | | | | | | |
| 17a | 10% -facts-and-circumstances tes | t - 2023. If the org | anization did not c | heck a box on line | e 13, 16a, or 16b, a | and line 14 is 10% | or more, |
| | and if the organization meets the fact | ts-and-circumstanc | es test, check this | box and stop he | re. Explain in Part | VI how the organiz | zation |
| | meets the facts-and-circumstances te | - | | • • • • | | | |
| b | 10% -facts-and-circumstances tes | t - 2022. If the org | anization did not c | heck a box on line | e 13, 16a, 16b, or ⁻ | 17a, and line 15 is | 10% or |
| | more, and if the organization meets the | he facts-and-circur | nstances test, che | ck this box and st | op here. Explain in | n Part VI how the | |
| | organization meets the facts-and-circ | umstances test. Th | ne organization qu | alifies as a publicly | y supported organ | ization | |
| 18 | Private foundation. If the organization | on did not check a | box on line 13, 16a | a, 16b, 17a, or 17t | o, check this box a | nd see instruction | ns |
| | | | | | | Schedule A | (Form 990) 2023 |

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| Schedule A | (Form 990) | 2023 | \mathbf{RETT} | SYNDROME | RESEARCH | TRUST, |
|------------|------------|------------|-----------------|---------------|------------------|--------------|
| Part III | Support | Schedule f | for Organi | izations Desc | ribed in Section | on 509(a)(2) |

RETT SYNDROME RESEARCH TRUST, INC

(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.)

| Se | ction A. Public Support | | | | | | |
|----------|--|-----------------------|---------------------|------------------------|--------------------|-----------------|----------------------|
| Cale | ndar year (or fiscal year beginning in) | (a) 2019 | (b) 2020 | (c) 2021 | (d) 2022 | (e) 2023 | (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 per- formed, 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 bus- | | | | | | |
| | iness under section 513 | | | | | | |
| 4 | Tax revenues levied for the organ- | | | | | | |
| • | ization's benefit and either paid to | | | | | | |
| | or expended on its behalf | | | | | | |
| 5 | The value of services or facilities | | | | | | |
| Ŭ | furnished by a governmental unit to | | | | | | |
| | the organization without charge | | | | | | |
| 6 | | | | | | | |
| | Total. Add lines 1 through 5 | | | | | | |
| 10 | 3 received from disqualified persons | | | | | | |
| t | 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 See | Public support. (Subtract line 7c from line 6.) | | | | | | |
| Cale | ndar year (or fiscal year beginning in) | (a) 2019 | (b) 2020 | (c) 2021 | (d) 2022 | (e) 2023 | (f) Total |
| 9 | Amounts from line 6 | | | | | | |
| | 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 | | | | | | |
| | Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on | | | | | | |
| 12 | Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) | | | | | | |
| 13 | Total support. (Add lines 9, 10c, 11, and 12.) | | | | | | |
| 14 | First 5 years. If the Form 990 is for the | ne organization's f | irst, second, third | , fourth, or fifth tax | vyear as a section | 501(c)(3) organ | ization, |
| | | | | | | ····· | |
| Se | ction C. Computation of Publ | lic Support Pe | ercentage | | | | |
| 15 | Public support percentage for 2023 (| line 8, column (f), (| divided by line 13, | column (f)) | | 15 | % |
| | Public support percentage from 2022 | | | | | 16 | % |
| | ction D. Computation of Inve | | | | | | |
| 17 | Investment income percentage for 20 | 023 (line 10c, colur | mn (f), divided by | line 13, column (f) |) | 17 | % |
| | Investment income percentage from | | | | | 18 | % |
| | 33 1/3% support tests - 2023. If the | | | | | 33 1/3%, and li | ne 17 is not |
| | more than 33 1/3%, check this box a | | | | | | |
| b | 33 1/3% support tests - 2022. If the | | | | | | |
| | line 18 is not more than 33 1/3%, che | | | | | | |
| 20 | Private foundation. If the organization | | | | | | |
| | 23 12-21-23 | | , | | | | le A (Form 990) 2023 |
| | | | | 16 | | | . , |

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1

2

3a

3b

3c

4a

4b

4c

5a

5b

5c

6

7

8

9a

9b

9c

10a

10b

Schedule A (Form 990) 2023

Yes No

Part IV Supporting Organizations

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

Section A. All Supporting Organizations

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

332024 12-21-23

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17

Schedule A (Form 990) 2023 RETT SYNDROME RESEARCH TRUST, INC

| га | Supporting Organizations (continued) | | | |
|-----|---|-----|---------|----|
| | | | Yes | No |
| 11 | Has the organization accepted a gift or contribution from any of the following persons? | | | |
| а | 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? | 11a | | |
| b | A family member of a person described on line 11a above? | 11b | | |
| с | A 35% controlled entity of a person described on line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide | | | |
| | detail in Part VI. | 11c | | |
| Sec | tion B. Type I Supporting Organizations | | | |
| | | | Yes | No |
| 1 | Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, directors, or trustees at all times during the tax year? If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove officers, directors, or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year. | 1 | | |
| 2 | Did the organization operate for the benefit of any supported organization other than the supported | | | |
| | organization(s) that operated, supervised, or controlled the supporting organization? 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. | 2 | | |
| Sec | tion C. Type II Supporting Organizations | | | |
| | | | Yes | No |
| 1 | Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <i>If</i> " <i>No</i> ," <i>describe in</i> Part VI <i>how control or management of the supporting organization was vested in the same persons that controlled or managed</i> | | | |
| | the supported organization(s). | 1 | | |
| Sec | tion D. All Type III Supporting Organizations | | | |
| | | | Yes | No |

| | | | res | NO |
|---|--|---|-----|----|
| 1 | Did the organization provide to each of its supported organizations, by the last day of the fifth month of the | | | |
| | organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax | | | |
| | year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the | | | |
| | organization's governing documents in effect on the date of notification, to the extent not previously provided? | 1 | | |
| 2 | Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported | | | |
| | organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how | | | |
| | the organization maintained a close and continuous working relationship with the supported organization(s). | 2 | | |
| 3 | By reason of the relationship described on 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? If "Yes," describe in Part VI the role the organization's | | | |
| | supported organizations played in this regard. | 3 | | |

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 yeafsee instruction |
|--|
|--|

- 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 | governmental entity (| (see instructions). |
|-----|----------------------------|-----------------------|---------------------------|-----------------|-----------------------|---------------------|
|-----|----------------------------|-----------------------|---------------------------|-----------------|-----------------------|---------------------|

- 2 Activities Test. Answer lines 2a and 2b below.
- a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? *If* "Yes," *then in* **Part VI identify those supported organizations and explain** *how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.*
- b 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? 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.
- **3** Parent of Supported Organizations. **Answer lines 3a and 3b below.**
- a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? *If* "Yes" or "*No*" provide details in **Part VI.**
- b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? *If* "Yes," *describe in* **Part VI** *the role played by the organization in this regard*.
 332025 12-21-23

Schedule A (Form 990) 2023

2a

2b

За

3b

No

Yes

18

16520624 759649 397-0001

| Schedule A (Fo | rm 990) 2023 |
|----------------|--------------|
|----------------|--------------|

| RETT | SYNDROME | RESEARCH | TRUST, | INC |
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|------|----------|----------|--------|-----|

| | rt V Type III Non-Functionally Integrated 509(a)(3) Supporti | | - | 20-068/439 Page |
|---------|---|----|----------------|--------------------------------|
| га 1 | Check here if the organization satisfied the Integral Part Test as a qualifyi | | | Part VI) See instruction |
| • | All other Type III non-functionally integrated supporting organizations mu | • | | |
| Sect | ion A - Adjusted Net Income | | (A) Prior Year | (B) Current Year (optional) |
| 1 | Net short-term capital gain | 1 | | |
| 2 | Recoveries of prior-year distributions | 2 | | |
| 3 | Other gross income (see instructions) | 3 | | |
| 4 | Add lines 1 through 3. | 4 | | |
| 5 | Depreciation and depletion | 5 | | |
| 6 | Portion of operating expenses paid or incurred for production or | | | |
| | collection of gross income or for management, conservation, or | | | |
| | maintenance of property held for production of income (see instructions) | 6 | | |
| 7 | Other expenses (see instructions) | 7 | | |
| 8 | Adjusted Net Income (subtract lines 5, 6, and 7 from line 4) | 8 | | |
| ect | ion B - Minimum Asset Amount | | (A) Prior Year | (B) Current Year (optional) |
| 1 | Aggregate fair market value of all non-exempt-use assets (see | | | |
| | instructions for short tax year or assets held for part of year): | | | |
| а | Average monthly value of securities | 1a | | |
| b | Average monthly cash balances | 1b | | |
| с | Fair market value of other non-exempt-use assets | 1c | | |
| d | Total (add lines 1a, 1b, and 1c) | 1d | | |
| е | Discount claimed for blockage or other factors | | | |
| | (explain in detail in Part VI): | | | |
| 2 | Acquisition indebtedness applicable to non-exempt-use assets | 2 | | |
| 3 | Subtract line 2 from line 1d. | 3 | | |
| 4 | Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, | | | |
| | see instructions). | 4 | | |
| 5 | Net value of non-exempt-use assets (subtract line 4 from line 3) | 5 | | |
| 6 | Multiply line 5 by 0.035. | 6 | | |
| 7 | Recoveries of prior-year distributions | 7 | | |
| 8 | Minimum Asset Amount (add line 7 to line 6) | 8 | | |
| ect | ion C - Distributable Amount | | | Current Year |
| 1 | Adjusted net income for prior year (from Section A, line 8, column A) | 1 | | |
| 2 | Enter 0.85 of line 1. | 2 | | |
| 3 | Minimum asset amount for prior year (from Section B, line 8, column A) | 3 | | |
| 4 | Enter greater of line 2 or line 3. | 4 | | |
| 5 | Income tax imposed in prior year | 5 | | |
| 6 | Distributable Amount. Subtract line 5 from line 4, unless subject to | | | |
| | emergency temporary reduction (see instructions). | 6 | | |

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

Schedule A (Form 990) 2023

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| Par | t V Type III Non-Functionally Integrated 509 | (a)(3) Supporting Org | anizations (continu | ied) | |
|-------|---|-------------------------------|---------------------------------------|------|---|
| Secti | on D - Distributions | | | | Current Year |
| _1 | Amounts paid to supported organizations to accomplish exe | empt purposes | | 1 | |
| 2 | Amounts paid to perform activity that directly furthers exemption | ot purposes of supported | | | |
| | organizations, in excess of income from activity | | | 2 | |
| 3 | Administrative expenses paid to accomplish exempt purpose | es of supported organizatior | าร | 3 | |
| 4 | Amounts paid to acquire exempt-use assets | | 4 | | |
| 5 | Qualified set-aside amounts (prior IRS approval required - pro | ovide details in Part VI) | | 5 | |
| 6 | Other distributions (describe in Part VI). See instructions. | | | 6 | |
| 7 | Total annual distributions. Add lines 1 through 6. | | | 7 | |
| 8 | Distributions to attentive supported organizations to which the | he organization is responsive | e | | |
| | (provide details in Part VI). See instructions. | | | 8 | |
| 9 | Distributable amount for 2023 from Section C, line 6 | | | 9 | |
| 10 | Line 8 amount divided by line 9 amount | | - | 10 | |
| Secti | on E - Distribution Allocations (see instructions) | (i) Excess Distributions | (ii) Underdistributior Pre-2023 | าร | (iii) Distributable Amount for 2023 |
| _1 | Distributable amount for 2023 from Section C, line 6 | | | | |
| 2 | Underdistributions, if any, for years prior to 2023 (reason- | | | | |
| | able cause required - explain in Part VI). See instructions. | | | | |
| 3 | Excess distributions carryover, if any, to 2023 | | | | |
| a | From 2018 | | | | |
| b | From 2019 | | | | |
| с | From 2020 | | | | |
| d | From 2021 | | | | |
| e | From 2022 | | | | |
| f | Total of lines 3a through 3e | | | | |
| g | Applied to underdistributions of prior years | | | | |
| h | Applied to 2023 distributable amount | | | | |
| i | Carryover from 2018 not applied (see instructions) | | | | |
| j | Remainder. Subtract lines 3g, 3h, and 3i from line 3f. | | | | |
| 4 | Distributions for 2023 from Section D, | | | | |
| | line 7: \$ | | | | |
| a | Applied to underdistributions of prior years | | | | |
| b | Applied to 2023 distributable amount | | | | |
| С | Remainder. Subtract lines 4a and 4b from line 4. | | | | |
| 5 | Remaining underdistributions for years prior to 2023, if | | | | |
| | any. Subtract lines 3g and 4a from line 2. For result greater | | | | |
| | than zero, explain in Part VI. See instructions. | | | | |
| 6 | Remaining underdistributions for 2023. Subtract lines 3h | | | | |
| | and 4b from line 1. For result greater than zero, explain in | | | | |
| | Part VI. See instructions. | | | | |
| 7 | Excess distributions carryover to 2024. Add lines 3j | | | | |
| | and 4c. | | | | |
| 8 | Breakdown of line 7: | | | | |
| а | Excess from 2019 | | | | |
| b | Excess from 2020 | | | | |
| с | Excess from 2021 | | | | |
| d | Excess from 2022 | | | | |
| е | Excess from 2023 | | | | |

Schedule A (Form 990) 2023

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| Part VI | Form 990) 2023 Supplemental Inf Part IV, Section A, lines | ormation. P | rovide the expla | RESEARCH nations required 9b, 9c, 11a, 11b, | by Part II, line 10 | ; Part II, line 17a | 26-0687439 p or 17b; Part III, line 12; s 1 and 2; Part IV, Section C t V, Section B, line 1e; Part |
|---------|--|--------------------------------------|--|---|---------------------------------------|---|--|
| | line 1; Part IV, Section Section D, lines 5, 6, at (See instructions.) | D, lines 2 and 3 nd 8; and Part V | 3; Part IV, Sectio V, Section E, line | n E, lines 1c, 2a, es 2, 5, and 6. Als | 2b, 3a, and 3b; F to complete this | Part V, line 1; Par part for any addit | t V, Section B, line 1e; Part tional information. |
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| | | | | | | | Schedule A (Form 990 |

| SCHEDULE D |) |
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Department of the Treasury

| (Form | 990) |
|-------|------|
|-------|------|

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

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



Internal Revenue Service Name of the organization

RETT SYNDROME RESEARCH TRUST, INC

Employer identification number 26-0687439

| Par | | | Similar Funds or A | Accounts. Complete if the |
|-----|--|-----------------------------|---------------------------|----------------------------------|
| | organization answered "Yes" on Form 990, Part IV, line | | | |
| | | (a) Donor advise | d funds | (b) Funds and other accounts |
| 1 | Total number at end of year | | | |
| 2 | Aggregate value of contributions to (during year) | | | |
| 3 | Aggregate value of grants from (during year) | | | |
| 4 | Aggregate value at end of year | | | |
| 5 | Did the organization inform all donors and donor advisors in v | writing that the assets he | eld in donor advised fur | nds |
| | 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 a | dvisors in writing that gra | ant funds can be used | only |
| | for charitable purposes and not for the benefit of the donor o | r donor advisor, or for ar | y other purpose confe | rring |
| | impermissible private benefit? | | | Yes No |
| Par | | | | |
| 1 | Purpose(s) of conservation easements held by the organization | on (check all that apply). | | |
| | Preservation of land for public use (for example, recrea | tion or education) | Preservation of a histo | orically important land area |
| | Protection of natural habitat | , L | Preservation of a cert | • • |
| | Preservation of open space | | | |
| 2 | Complete lines 2a through 2d if the organization held a qualif | ied conservation contrib | ution in the form of a co | onservation easement on the last |
| _ | day of the tax year. | | | Held at the End of the Tax Year |
| а | Total number of conservation easements | | | 2a |
| h | Total acreage restricted by conservation easements | | | 2b |
| Č | Number of conservation easements on a certified historic stru | | | 2c |
| | Number of conservation easements included on line 2c acqu | | | 20 |
| u | on a historic structure listed in the National Register | | | 2d |
| 2 | Number of conservation easements modified, transferred, rel | | | |
| 3 | | eased, extilliguistied, of | leminaled by the organ | lization during the tax |
| | year | | | |
| 4 | Number of states where property subject to conservation eas | | line la constitue en el f | |
| 5 | Does the organization have a written policy regarding the per | | | |
| • | violations, and enforcement of the conservation easements it | | | |
| 6 | Staff and volunteer hours devoted to monitoring, inspecting, | handling of violations, ar | nd enforcing conservati | ion easements during the year |
| _ | | | • • • • • | |
| 7 | Amount of expenses incurred in monitoring, inspecting, hand | lling of violations, and en | forcing conservation ea | asements during the year |
| ~ | | | | A //A |
| 8 | Does each conservation easement reported on line 2d above | | | |
| | and section 170(h)(4)(B)(ii)? | | | |
| 9 | In Part XIII, describe how the organization reports conservation | | - | |
| | balance sheet, and include, if applicable, the text of the footn | note to the organization's | s financial statements th | hat describes the |
| Dor | organization's accounting for conservation easements. t III Organizations Maintaining Collections of | Art Historical Tra | agurag or Other | Similar Acceto |
| Par | | | asures, or Other | Similar Assets. |
| | Complete if the organization answered "Yes" on Form | | | |
| 1a | If the organization elected, as permitted under FASB ASC 95 | • | | |
| | of art, historical treasures, or other similar assets held for pub | | | ance of public |
| | service, provide in Part XIII the text of the footnote to its finar | | | |
| b | If the organization elected, as permitted under FASB ASC 95 | | | |
| | art, historical treasures, or other similar assets held for public | exhibition, education, o | r research in furtheranc | e of public service, |
| | provide the following amounts relating to these items. | | | |
| | (i) Revenue included on Form 990, Part VIII, line 1 | | | |
| | | | | |
| 2 | If the organization received or held works of art, historical trea | asures, or other similar a | ssets for financial gain, | provide |
| | the following amounts required to be reported under FASB A | SC 958 relating to these | items: | |
| а | Revenue included on Form 990, Part VIII, line 1 | | | \$ |
| | Assets included in Form 990, Part X | | | \$ |
| LHA | For Paperwork Reduction Act Notice, see the Instructions | s for Form 990. | | Schedule D (Form 990) 2023 |
| | 09-28-23 | | | |
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| | | NDROME RE | | | | | | 26-06 | | | age 2 |
|--------|---|----------------------|---------------|---------------|-------------------|--------------|-------------|------------|-----------------|----------------|--------------|
| | t III Organizations Maintaining C | | | | | | | | LS(contil | nuea) | |
| 3 | Using the organization's acquisition, accessi | on, and other reco | ords, chec | k any of the | e following th | at make sig | gnificant | use of its | | | |
| _ | collection items (check all that apply). | | | | - 1 | | | | | | |
| a | Public exhibition | | | | change progi | | | | | | |
| b | Scholarly research | | e 📖 | Other | | | | | | | |
| C A | Preservation for future generations | alloctions and ave | lain haw t | hav furthar | the executed | lion's avom | nt num | non in Dor | | | |
| 4 | Provide a description of the organization's co During the year, did the organization solicit o | | | | | | | ose in Par | | | |
| 5 | to be sold to raise funds rather than to be ma | | | | | | | | Yes | | |
| Par | t IV Escrow and Custodial Arran | | | | | | | | | | No |
| 1 41 | reported an amount on Form 990, Par | | | organizatio | in answered | res on re | onn 990 | Part IV, I | ne 9, or | | |
| 10 | Is the organization an agent, trustee, custodi | | nodian/ fo | r contributio | one or other (| ecote not i | ncludod | | | | |
| Ia | | | | | | | | | Yes | | No |
| h | on Form 990, Part X? If "Yes," explain the arrangement in Part XIII | and complete the | following | tabla: | | | | ······ └── | | | |
| b | | and complete the | lonowing | labie. | | | | | Amoun | t | |
| с | Beginning balance | | | | | | 1c | | , | - | |
| | Additions during the year | | | | | | | | | | |
| | Distributions during the year | | | | | | | | | | |
| f | | | | | | | 1f | | | | |
| | Ending balance Did the organization include an amount on Fe | | | | | | | | Yes | | No |
| | If "Yes," explain the arrangement in Part XIII. | | | | | | | ······ | | | |
| Par | | | | | | | | | | | |
| | | (a) Current year | | Prior year | (c) Two yea | | | ears back | (e) Four | vears | back |
| 1a | Beginning of year balance | (4) 5 41 5 11 9 5 41 | () | | (0) | (- | ", , | | (0) | , | |
| | Contributions | | | | | | | | | | |
| | | | | | | | | | | | |
| | Net investment earnings, gains, and losses | | | | | | | | | | |
| | Grants or scholarships | | | | | | | | | | |
| е | Other expenditures for facilities | | | | | | | | | | |
| | and programs | | | | | | | | | | |
| | Administrative expenses | | | | | | | | | | |
| - | End of year balance | | | | (-)) - | | | | | | |
| 2 | Provide the estimated percentage of the curr | rent year end bala | | ig, column | (a)) neid as: | | | | | | |
| | Board designated or quasi-endowment | 0/ | % | | | | | | | | |
| b | Permanent endowment | % | | | | | | | | | |
| С | | % | | | | | | | | | |
| • | The percentages on lines 2a, 2b, and 2c sho | | | | | | | | | | |
| За | Are there endowment funds not in the posse | ession of the orgar | hization th | at are held | and administ | ered for the | e | | Г | Yes | No |
| | organization by: | | | | | | | | | res | No |
| | (i) Unrelated organizations? | | | | | | | | | | |
| _ | (ii) Related organizations? | | | | ····· | | | | 3a(ii) | | |
| | If "Yes" on line 3a(ii), are the related organiza | | | | ? | | | | 3b | | |
| | Describe in Part XIII the intended uses of the | | dowment | funds. | | | | | | | |
| Par | t VI Land, Buildings, and Equipm | | | V 11 | C.a.a. F.a.maa 00 | | 10 | | | | |
| | Complete if the organization answere | | , | ŕ | | · · · | | . 1 | | | |
| | Description of property | (a) Cost o | | | t or other | | cumulate | d | (d) Boo | k valu | е |
| | | basis (inve | siment) | Dasis | s (other) | depr | eciation | | | | |
| | Land | | | | | | | | | | |
| | Buildings | | | | | | | | | | |
| | Leasehold improvements | | | ļ | | | | | | | |
| | Equipment | | | ļ | | | | | | | |
| | Other | | | | | | | | | | |
| Total | . Add lines 1a through 1e. (Column (d) must e | qual Form 990, Pa | art X, line 1 | 10c, colum | n (B)) | | | | | | 0. |
| | | | | | | | : | Schedule | D (Forn | n 990) | 2023 |

332052 09-28-23

| Part VII Investments - Other Securiti | | | |
|---|------------------------------------|--|------------------------|
| Complete if the organization answered (a) Description of security or category (including name of s | | (c) Method of valuation: Cost or en | d of your market yelue |
| | | (c) Method of Valuation. Cost of en | u-oi-year market value |
| (1) Financial derivatives (2) Closely held equity interests | | | |
| (2) Closely held equily interests | | | |
| (A) | | | |
| (B) | | | |
| (C) | | | |
| (D) | | | |
| (E) | | | |
| (F) | | | |
| (G) | | | |
| (H) | | | |
| Total. (Col. (b) must equal Form 990, Part X, line 12, col. | | | |
| Part VIII Investments - Program Relation | | | |
| Complete if the organization answered | | | |
| (a) Description of investment | (b) Book value | (c) Method of valuation: Cost or en | d-of-year market value |
| <u>(1)</u> | | | |
| (2) | | | |
| <u>(3)</u> | | | |
| (4) (5) | | | |
| (5) (6) | | | |
| (7) | | | |
| (8) | | | |
| (9) | | | |
| Total. (Col. (b) must equal Form 990, Part X, line 13, col. | (B)) | | |
| Part IX Other Assets | | | |
| Complete if the organization answered | | 11d. See Form 990, Part X, line 15. | |
| | (a) Description | | (b) Book value |
| (1) | | | |
| (2) | | | |
| (3) | | | |
| <u>(4)</u> | | | |
| (5) (6) | | | |
| (7) | | | |
| (8) | | | |
| (9) | | | |
| Total. (Column (b) must equal Form 990, Part X, line | e 15, col. (B)) | | |
| Part X Other Liabilities | | | |
| Complete if the organization answered | d "Yes" on Form 990, Part IV, line | 11e or 11f. See Form 990, Part X, line 2 | 5. |
| 1. (a) Description of liability | 1 | | (b) Book value |
| (1) Federal income taxes | | | |
| (2) | | | |
| (3) | | | |
| (4) | | | |
| (5) | | | |
| (6) | | | |
| (7) | | | |
| (8) (9) | | | |
| (9) Total. (Column (b) must equal Form 990, Part X, line | = 25 col (B) | | |
| Liability for uncertain tax positions. In Part XIII, | | | that reports the |
| organization's liability for uncertain tax position | - | - | |

332053 09-28-23

| (F) | | |
|--|----------------------------|---|
| (G) | | |
| (H) | | |
| Total. (Col. (b) must equal Form 990, Part X, line 12, col. (B)) | | |
| 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) | | |

| Schedule D |) (Form | 990) | 2023 | R | \mathbf{ETT} | SYNDROME | RESEARCH | TRUST, | INC | |
|------------|---------|------|------|---|----------------|----------|----------|--------|-----|--|
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| Sche | dule D (Form 990) 2023 RETT SYNDROME RESEARCH TRUS | ST, | INC | 26- | 0687439 Page 4 |
|--|---|----------------------------------|------------------|---------|-----------------------------|
| Pa | t XI Reconciliation of Revenue per Audited Financial Stateme | nts V | ith Revenue per | | |
| | Complete if the organization answered "Yes" on Form 990, Part IV, line 12a. | | | | |
| 1 | Total revenue, gains, and other support per audited financial statements | | | 1 | 8,531,815. |
| 2 | Amounts included on line 1 but not on Form 990, Part VIII, line 12: | | | | |
| а | Net unrealized gains (losses) on investments | 2a | | | |
| b | Donated services and use of facilities | 2b | 8,000 | • | |
| с | Recoveries of prior year grants | | | | |
| d | Other (Describe in Part XIII.) | | | | |
| е | Add lines 2a through 2d | | | 2e | 8,000. |
| 3 | Subtract line 2e from line 1 | | | | 8,523,815. |
| 4 | Amounts included on Form 990, Part VIII, line 12, but not on line 1: | | | | |
| а | Investment expenses not included on Form 990, Part VIII, line 7b | 4a | | | |
| b | Other (Describe in Part XIII.) | 4b | | | |
| | Add lines 4a and 4b | | | 4c | 0. |
| 5 | Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.) | | | 5 | 8,523,815. |
| Pa | rt XII Reconciliation of Expenses per Audited Financial Stateme | ents \ | With Expenses pe | er Retu | ırn |
| | | | | | |
| | Complete if the organization answered "Yes" on Form 990, Part IV, line 12a. | | | | |
| 1 | Complete if the organization answered "Yes" on Form 990, Part IV, line 12a. Total expenses and losses per audited financial statements | | | 1 | 12,346,304. |
| 1 2 | | | | | 12,346,304. |
| - | Total expenses and losses per audited financial statements | | | | 12,346,304. |
| 2 | Total expenses and losses per audited financial statements Amounts included on line 1 but not on Form 990, Part IX, line 25: | 2a | | | 12,346,304. |
| 2 a | Total expenses and losses per audited financial statements Amounts included on line 1 but not on Form 990, Part IX, line 25: Donated services and use of facilities | 2a 2b | | | 12,346,304. |
| 2 a b | Total expenses and losses per audited financial statements Amounts included on line 1 but not on Form 990, Part IX, line 25: Donated services and use of facilities Prior year adjustments | 2a 2b 2c | | | |
| 2 a b c | Total expenses and losses per audited financial statements Amounts included on line 1 but not on Form 990, Part IX, line 25: Donated services and use of facilities Prior year adjustments Other losses | 2a 2b 2c 2d | 8,000 | • • | 8,000. |
| 2 a b c d | Total expenses and losses per audited financial statements Amounts included on line 1 but not on Form 990, Part IX, line 25: Donated services and use of facilities Prior year adjustments Other losses Other (Describe in Part XIII.) Add lines 2a through 2d | 2a 2b 2c 2d | 8,000 | • 2e | |
| 2 a b c d e | Total expenses and losses per audited financial statements Amounts included on line 1 but not on Form 990, Part IX, line 25: Donated services and use of facilities Prior year adjustments Other losses Other (Describe in Part XIII.) | 2a 2b 2c 2d | 8,000 | • 2e | 8,000. |
| 2 a b c d e 3 | Total expenses and losses per audited financial statements Amounts included on line 1 but not on Form 990, Part IX, line 25: Donated services and use of facilities Prior year adjustments Other losses Other (Describe in Part XIII.) Add lines 2a through 2d Subtract line 2e from line 1 | 2a 2b 2c 2d | 8,000 | • 2e | 8,000. |
| 2 a b c d e 3 4 a | Total expenses and losses per audited financial statements Amounts included on line 1 but not on Form 990, Part IX, line 25: Donated services and use of facilities Prior year adjustments Other losses Other (Describe in Part XIII.) Add lines 2a through 2d Subtract line 2e from line 1 Amounts included on Form 990, Part IX, line 25, but not on line 1: | 2a 2b 2c 2d | 8,000 | • 2e | 8,000. |
| 2 a b c d e 3 4 a b | Total expenses and losses per audited financial statements Amounts included on line 1 but not on Form 990, Part IX, line 25: Donated services and use of facilities Prior year adjustments Other losses Other (Describe in Part XIII.) Add lines 2a through 2d Subtract line 2e from line 1 Amounts included on Form 990, Part IX, line 25, but not on line 1: Investment expenses not included on Form 990, Part VIII, line 7b | 2a 2b 2c 2d 4a 4b | 8,000 | • 2e | 8,000. 12,338,304. 0. |
| 2 a b c d e 3 4 a b c 5 | Total expenses and losses per audited financial statements Amounts included on line 1 but not on Form 990, Part IX, line 25: Donated services and use of facilities Prior year adjustments Other losses Other (Describe in Part XIII.) Add lines 2a through 2d Subtract line 2e from line 1 Amounts included on Form 990, Part IX, line 25, but not on line 1: Investment expenses not included on Form 990, Part VIII, line 7b Other (Describe in Part XIII.) Add lines 4a and 4b Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.) | 2a 2b 2c 2d 4a 4b | 8,000 | 2e 3 | 8,000. 12,338,304. |
| 2 a b c d e 3 4 a b c 5 | Total expenses and losses per audited financial statements Amounts included on line 1 but not on Form 990, Part IX, line 25: Donated services and use of facilities Prior year adjustments Other losses Other (Describe in Part XIII.) Add lines 2a through 2d Subtract line 2e from line 1 Amounts included on Form 990, Part IX, line 25, but not on line 1: Investment expenses not included on Form 990, Part VIII, line 7b Other (Describe in Part XIII.) Add lines 4a and 4b | 2a 2b 2c 2d 4a 4b | 8,000 | 2e 3 | 8,000. 12,338,304. 0. |

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; P lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

| Department of the Treasury | | | Attach to Form 990. | | | Open | to Public |
|--|---|---|---|----------------------|--|-----------|--|
| Internal Revenue Service | Go to w | ww.irs.gov/Form | 1990 for instructions and the latest in | formation. | | Inspec | |
| Name of the organization | | | | | Employer | identific | cation number |
| RETT SYNDROME | | | | | 26-06 | | |
| | nformation on A art IV, line 14b. | Activities Our | tside the United States. Complete | e if the organ | ization ansv | vered "Ye | es" on |
| | | n maintain recor | ds to substantiate the amount of its grar | nts and other | assistance, | | |
| the grantees' eligibil | ity for the grants or a | assistance, and | the selection criteria used to award the g | grants or ass | istance? | ···· □ • | Yes X No |
| 2 For grantmakers. D United States. | Describe in Part V the | e organization's | procedures for monitoring the use of its | grants and o | ther assista | nce outsi | ide the |
| | | | an be duplicated if additional space is ne | | | | |
| (a) Region | (b) Number of offices in the region | (c) Number of employees, agents, and independent contractors in the region | (d) Activities conducted in the region (by type) (such as, fundraising, pro- gram services, investments, grants to recipients located in the region) | is a pro describe | vity listed in gram service specific typ (s) in the rec | e, De | (f) Total expenditures for and investments in the region |
| EUROPE (INCLUDING | | - | | | | | |
| ICELAND & GREENLAND |) | | | | | | |
| - ALBANIA, ANDORRA, | | | GRANTS TO RECIPIENTS | | | | |
| AUSTRIA, BELGIUM | | | LOCATED IN THE REGION | | | | 403,502. |
| | | | | | | | |
| | | | | | | | |
| | | | GRANTS TO RECIPIENTS | | | | |
| NORTH AMERICA | | | LOCATED IN THE REGION | | | | 47,500. |
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| | | | | | | | |
| 3 a Subtotal | 0 | 0 | | | | | 451,002. |
| b Total from continuat | | | | | | | |
| sheets to Part I | | 0 | | | | | 0. |
| c Totals (add lines 3a | | | | | | | |
| and 3b) | 0 | 0 | | | | | 451,002. |

Statement of Activities Outside the United States

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

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

Schedule F (Form 990) 2023

OMB No. 1545-0047

LHA 332071 11-29-23

SCHEDULE F

(Form 990)

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

| 1 (a) Name of organization | (b) IRS code section and EIN (if applicable) | (c) Region | (d) Purpose of grant | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of noncash assistance | (h) Description of noncash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
|-------------------------------|---|----------------|-----------------------------|---------------------------------|---------------------------------|---|--|---|
| | | UNITED KINGDOM | | 402 502 | WIRE TRANSFER | | | |
| | | UNITED KINGDOM | | 403,502. | WIRE TRANSFER | 0. | | |
| | | CANADA | | 47,500. | | 0. | | |
| | | | | | | | | |
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| | | | | | | | | |
| | | | | | | | | |

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as a tax

exempt 501(c)(3) organization 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

Schedule F (Form 990) 2023

Page 2

26-0687439

Page 3

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.

| (a) Type of grant or assistance | (b) Region | (c) Number of recipients | (d) Amount of cash grant | (e) Manner of cash disbursement | (f) Amount of noncash assistance | (g) Description of noncash assistance | (h) Method of valuation (book, FMV, appraisal, other) |
|---------------------------------|------------|--------------------------|--------------------------|------------------------------------|--|---------------------------------------|--|
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Schedule F (Form 990) 2023

| | | | | SYNDROME | RESEARCH | TRUST, | INC |
|---------|---------|------|---|----------|----------|--------|-----|
| Part IV | Foreign | Form | s | | | | |

| 1 | Was the organization a U.S. transferor of property to a foreign corporation during the tax year? <i>If</i> "Yes," <i>the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see the Instructions for Form 926)</i> | Yes | X 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 the Instructions for Forms 3520 and 3520-A; don't file with Form 990) | Yes | X 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 the Instructions for Form 5471) | Yes | X 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? <i>If</i> "Yes," <i>the organization may be required to file Form</i> 8621, <i>Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund</i> (see the Instructions for Form 8621) | Yes | X 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 the Instructions for Form 8865) | Yes | X 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 the Instructions for Form 5713; don't file with Form 990) | Yes | X No |

Schedule F (Form 990) 2023

| | (Form 990) 2023 | RETT | SYNDROME | RESEARCH | TRUST, | INC | 26-0687439 | Page 5 |
|--------|--------------------|--------------|-----------------------|----------------------|--------------------|-----------------|---|--------|
| Part V | Supplemental | Inform | ation | | | | | |
| | Provide the inform | ation requ | iired by Part I, line | 2 (monitoring of fu | ınds); Part I, liı | ne 3, column | (f) (accounting method; amounts of | |
| | investments vs. ex | penditure | s per region); Part | II, line 1 (accounti | ng method); P | Part III (accou | nting method); and Part III, column (c) | |
| | (estimated numbe | r of recipie | ents), as applicable | e. Also complete th | nis part to prov | vide any add | itional information. See instructions. | |

PART I, LINE 2:

RSRT WORKS CLOSELY WITH THE UNIVERSITY OF EDINBURGH AND MONITORS FUNDING

AND PROGRESS OF THE RESEARCH IT PERFORMS.

332075 11-29-23

| SCHEDULE I (Form 990) Department of the Treasury Internal Revenue Service | Go | Grants and Oth vernments, an ete if the organizatio | nd Individual | ls in the Ŭni ' on Form 990, Pa n 990. | ted States rt IV, line 21 or 22. | | OMB No. 1545-0047 2023 Open to Public Inspection |
|--|------------------------------|---|-----------------------------|---|---|---------------------------------------|--|
| Name of the organization | | GO LO WWW.II'S | .gov/Form990101 | the fatest morn | | | Employer identification number |
| | ROME RESE | ARCH TRUST, | INC | | | | 26-0687439 |
| Part I General Information on Grants a | | · · · · | | | | | |
| Does the organization maintain records criteria used to award the grants or assi Describe in Part IV the organization's pro Part II Grants and Other Assistance to | stance? ocedures for moni | toring the use of grant | funds in the Unite | d States. | | | X Yes No |
| recipient that received more than | - | | | | | , | , , , , |
| 1 (a) Name and address of organization or government | (b) EIN | (c) IRC section (if applicable) | (d) Amount of cash grant | (e) Amount of noncash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of noncash assistance | (h) Purpose of grant or assistance |
| CHILDREN'S HOSPITAL OF MONTEFIORE 3415 BAINBRIDGE AVE BRONX, NY 10467 | | | 50,000. | 0. | | | RETT RESEARCH |
| UNIVERSITY OF CALIFORNIA DAVIS 1 SHIELDS AVENUE DAVIS, CA 95616 | 95-6006144 | | 390,506. | 0. | | | RNA EDITING |
| MASSACHUSETTS INSTITUTE OF TECHNOLOGY - 77 MASSACHUSETTS AVE - CAMBRIDGE, MA 02139 | 04-2103594 | 501(C)(3) | 3,734,738. | 0. | | | RNA EDITING |
| BOSTON CHILDREN'S HOSPITAL 300 LONGWOOD AVENUE BOSTON, MA 02115 | | | 69,088. | 0. | | | RETT RESEARCH |
| EMORY UNIVERSITY 201 DOWMAN DRIVE ATLANTA, GA 30322 | | | 1,254,085. | 0. | | | RNA EDITING |
| RETT SYNDROME GLOBAL REGISTRY C/O RSRT - 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 2 Enter total number of section 501(c)(3) a | and government of | ganizations listed in th | 100,000. ne line 1 table | 0. | | | RETT RESEARCH |

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

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

Schedule I (Form 990) 2023

RETT SYNDROME RESEARCH TRUST, INC Schedule I (Form 990)

| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of noncash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|--|----------------|----------------------------------|-----------------------------|--|---|---|---------------------------------------|
| HARVARD STEM CELL INSTITUTE | | | | | | | |
| 7 DIVINITY AVE | | | | | | | |
| CAMBRIDGE, MA 02138 | | | 101,887. | 0. | | | RETT RESEARCH |
| EMERALD 1 - VIVOSENSE | | | | | | | |
| C/O RETT SYNDROME | | | | | | | |
| TRUMBULL, CT 06611 | | | 20,075. | 0. | | | RETT RESEARCH |
| CORIELL INSTITUTE FOR MEDICAL | | | | | | | |
| RESEARCH - 403 HADDON AVENUE - | | | | | | | |
| CAMDEN, NJ 08103 | | | 105,826. | 0. | | | RETT RESEARCH |
| 1717AT TNV | | | | | | | |
| VIVALINK | | | | | | | |
| C/O RETT SYNDROME | | | 7 446 | 0 | | | |
| TRUMBULL, CT 06611 | | | 7,446. | 0. | | | RETT RESEARCH |
| CALIFORNIA INSTITUTE OF | | | | | | | |
| TECHNOLOGIES - 1200 E CALIFORNIA | | | | | | | |
| BLVD - PASADENA, CA 91125 | | | 500,000. | 0. | | | RETT RESEARCH |
| PROQR | | | | | | | |
| C/O RETT SYNDROME | | | | | | | |
| TRUMBULL, CT 06611 | | | 1,120,000. | 0. | | | RETT RESEARCH |
| UNIVERSITY OF MASSACHUSETTS | | | | | | | |
| MEDICAL SCHOOL - 55 N LAKE AVE - | | | | | | | |
| WORCESTER, MA 01655 | 54-2084125 | | 2,343,091. | 0. | | | RETT RESEARCH |
| ······································ | | | _, | | | | |
| NEW YORK UNIVERSITY | | | | | | | |
| C/O RETT SYNDROME | | | | | | | |
| TRUMBULL, CT 06611 | | | 50,000. | 0. | | | RETT RESEARCH |
| SAMPLED | | | | | | | |
| C/O RETT SYNDROME | | | | | | | |
| TRUMBULL, CT 06611 | | | 24,100. | ٥. | | | RETT RESEARCH |

Schedule I (Form 990)

RETT SYNDROME RESEARCH TRUST, INC

| | | EARCH TRUST, | | | | | 6-0687439 _{Ра} |
|---|---------|-----------------|------------------|--|--|--|--|
| Part II Continuation of Grants and Oth (a) Name and address of organization or government | (b) EIN | (c) IRC section | s and Domestic G | (e) Amount of noncash assistance | edule I (Form 990), Pa (f) Method of valuation (book, FMV, appraisal, other) | rt II.) (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
| ENETIC ALLIANCE /O RETT SYNDROME | | | | | | | |
| RUMBULL, CT 06611 | | | 750. | 0. | | | RETT RESEARCH |
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Schedule I (Form 990)

26-0687439

Page 2

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

| (a) Type of grant or assistance | (b) Number of recipients | (c) Amount of cash grant | (d) Amount of non- cash assistance | (e) Method of valuation (book, FMV, appraisal, other) | (f) Description of noncash assistance |
|---------------------------------|--------------------------|-----------------------------|---------------------------------------|---|---------------------------------------|
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Part IV Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

| sc | HEDULE J | Compensation Information | I | OMB No. 1 | 1545-00 | 47 | | |
|-----|---|---|--------------|-------------|-----------|--------|--|--|
| (Fo | rm 990) | For certain Officers, Directors, Trustees, Key Employees, and Highest | | 20 | <u>77</u> | 2 | | |
| • | , | Compensated Employees | | ΖU | ZJ |) | | |
| | | Complete if the organization answered "Yes" on Form 990, Part IV, line 23. Attach to Form 990. | | Open to | Publ | ic | | |
| | tment of the Treasury al Revenue Service | Go to www.irs.gov/Form990 for instructions and the latest information. | | Inspection | | | | |
| Nan | e of the organization | | Employer ide | entificatio | on nu | mber | | |
| | | RETT SYNDROME RESEARCH TRUST, INC | 26-06 | 58743 | 9 | | | |
| Pa | rt I Question | s Regarding Compensation | | | | | | |
| | | | | | Yes | No | | |
| 1a | Check the appropri | iate box(es) if the organization provided any of the following to or for a person listed on Form | ı 990, | | | | | |
| | Part VII, Section A, | line 1a. Complete Part III to provide any relevant information regarding these items. | | | | | | |
| | First-class or c | charter travel Housing allowance or residence for perso | nal use | | | | | |
| | Travel for com | panions Payments for business use of personal re | sidence | | | | | |
| | Tax indemnific | cation and gross-up payments Health or social club dues or initiation fee | S | | | | | |
| | Discretionary s | spending account Personal services (such as maid, chauffe | ur, chef) | | | | | |
| | | | | | | | | |
| b | • | on line 1a are checked, did the organization follow a written policy regarding payment or | | | | | | |
| | reimbursement or p | provision of all of the expenses described above? If "No," complete Part III to explain | | . 1b | | | | |
| 2 | Did the organization | n require substantiation prior to reimbursing or allowing expenses incurred by all directors, | | | | | | |
| | trustees, and office | rs, including the CEO/Executive Director, regarding the items checked on line 1a? | | 2 | | | | |
| | | | | | | | | |
| 3 | | ny, of the following the organization used to establish the compensation of the organization's | | | | | | |
| | CEO/Executive Dire | ector. Check all that apply. Do not check any boxes for methods used by a related organizat | ion to | | | | | |
| | establish compensat | ation of the CEO/Executive Director, but explain in Part III. | | | | | | |
| | Compensation | | | | | | | |
| | | compensation consultant Compensation survey or study | | | | | | |
| | X Form 990 of o | ther organizations | ommittee | | | | | |
| - | | | | | | | | |
| 4 | | any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing | | | | | | |
| | organization or a re | | | | | v | | |
| a | | e payment or change-of-control payment? | | | | X X | | |
| b | | ceive payment from a supplemental nonqualified retirement plan? | | | | A X | | |
| С | | ceive payment from an equity-based compensation arrangement? | | 4c | | | | |
| | If "Yes" to any of lir | nes 4a-c, list the persons and provide the applicable amounts for each item in Part III. | | | | | | |
| | Only postion Fod | (2) E01(a)(4) and E01(a)(20) argumentions must complete lines 5.0 | | | | | | |
| F | | c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9. In Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation | on | | | | | |
| J | contingent on the r | | 11 | | | | | |
| 9 | 0 | | | 5a | | x | | |
| h | Any related organiz | ation? | | . 5a 5b | | X | | |
| U. | | pr 5b, describe in Part III. | | | | | | |
| 6 | | on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation | on | | | | | |
| Ŭ | contingent on the r | | 511 | | | | | |
| а | - | | | 6a | | x | | |
| | | ation? | | | | X | | |
| - | | or 6b, describe in Part III. | | | | | | |
| 7 | | on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments | S | | | | | |
| | | nes 5 and 6? If "Yes," describe in Part III | | 7 | | X | | |
| 8 | | reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to t | | | | | | |
| - | | eption described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III | | 8 | | x | | |
| 9 | | id the organization also follow the rebuttable presumption procedure described in | | | | | | |
| - | | n 53.4958-6(c)? | | 9 | | | | |
| For | | ion Act Notice, see the Instructions for Form 990. | | le J (Forn | n 990 | 2023 | | |

LHA 332111 11-06-23

Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees. Use duplicate copies if additional space is needed.

For each individual whose compensation must be reported on Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii). Do not list any individuals that aren't listed on Form 990, Part VII.

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

| | (| B) Breakdown of W | /-2 and/or 1099-MIS compensation | C and/or 1099-NEC | (C) Retirement and other deferred | (D) Nontaxable benefits | (E) Total of columns (B)(i)-(D) | (F) Compensation in column (B) |
|------------------------------|------|--------------------------|---|---|-----------------------------------|-------------------------|------------------------------------|---|
| (A) Name and Title | | (i) Base compensation | (ii) Bonus & incentive compensation | (iii) Other reportable compensation | compensation | | | reported as deferred on prior Form 990 |
| (1) MONICA COENRAADS (i | i) | 220,000. | 0. | 0. | 0. | 0. | 220,000. | 0. |
| CHIEF EXECUTIVE OFFICER (i | | 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| (2) TIMOTHY FREEMAN (i | i) | 220,000. | 0. | 0. | 0. | 0. | 220,000. | 0. |
| CHIEF DEVELOPMENT OFFICER (i | | 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| (3) JANA VON HEHN (i | i) | 203,333. | 0. | 0. | 0. | 0. | 203,333. | 0. |
| CHIEF SCIENTIFIC OFFICER (i | | 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| (4) RANDALL CARPENTER (i | i) | 165,000. | 0. | 0. | 0. | 0. | 165,000. | 0. |
| CHIEF MEDICAL OFFICER (i | i) 🗌 | 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| (i | i) 🗋 | | | | | | | |
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Schedule J (Form 990) 2023

Page 3

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.

Schedule J (Form 990) 2023

SCHEDULE M (Form 990)

Noncash Contributions

OMB No. 1545-0047

Open to Public

. Inspection

Department of the Treasury Internal Revenue Service Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30. Attach to Form 990.

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

Name of the organization

RETT SYNDROME RESEARCH TRUST, IN Part I Types of Property

| | Employer | identification number |
|---|----------|-----------------------|
| C | 2 | 6-0687439 |
| | | |

| | | (a) | (b) Number of | (c) Noncash contri | ibution | (d) Mathad of da | | ina | |
|-------|--|---------------------|-------------------------|------------------------------|--------------|----------------------------------|---------|-------|------|
| | | Check if applicable | contributions or | amounts repor | ted on | Method of de noncash contribu | | • | s |
| | | approace | items contributed | Form 990, Part VI | II, line 1g | | | | - |
| 1 | Art - Works of art | | | | | | | | |
| 2 | Art - Historical treasures | | | | | | | | |
| 3 | Art - Fractional interests | | | | | | | | |
| 4 | Books and publications | | | | | | | | |
| 5 | Clothing and household goods | | | | | | | | |
| 6 | Cars and other vehicles | | | | | | | | |
| 7 | Boats and planes | | | | | | | | |
| 8 | Intellectual property | | | | | | | | |
| 9 | Securities - Publicly traded | | | | | | | | |
| 10 | Securities - Closely held stock | | | | | | | | |
| 11 | Securities - Partnership, LLC, or | | | | | | | | |
| | trust interests | | | | | | | | |
| 12 | Securities - Miscellaneous | | | | | | | | |
| 13 | Qualified conservation contribution - | | | | | | | | |
| | Historic structures | | | | | | | | |
| 14 | Qualified conservation contribution - Other | | | | | | | | |
| 15 | Real estate - Residential | | | | | | | | |
| 16 | Real estate - Commercial | | | | | | | | |
| 17 | Real estate - Other | | | | | | | | |
| 18 | Collectibles | | | | | | | | |
| 19 | Food inventory | | | | | | | | |
| 20 | Drugs and medical supplies | | | | | | | | |
| 21 | Taxidermy | | | | | | | | |
| 22 | Historical artifacts | | | | | | | | |
| 23 | Scientific specimens | | | | | | | | |
| 24 | Archeological artifacts | | | | | | | | |
| 25 | Other (AUCTION AND RAF) | Х | 0 | 299 | ,570. | | | | |
| 26 | Other (IN-KIND SERVICE) | X | 2 | | ,000. | | | | |
| 27 | Other () | | | | | | | | |
| 28 | Other () | | | | | | | | |
| 29 | Number of Forms 8283 received by the organi | ration during | the tax vear for c | ontributions | | | | | |
| | for which the organization completed Form 82 | | | | 29 | | | | |
| | | | | | | | | Yes | No |
| 30a | During the year, did the organization receive b | v contributio | on any property re | oorted in Part L line | es 1 throug | nh 28 that it | | | |
| | must hold for at least 3 years from the date of | - | • • • • | | - | | | | |
| | exempt purposes for the entire holding period | _ | | | | | 30a | | х |
| b | If "Yes," describe the arrangement in Part II. | | | | | | | | |
| 31 | | policy that re | equires the review | of any nonstandar | d contribu | tions? | 31 | | х |
| | Does the organization have a gift acceptance policy that requires the review of any nonstandard contributions? 2a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash | | | | | | | | |
| JE a | - | | - | | | | 32a | | х |
| h | contributions? If "Yes," describe in Part II. | | | | | | 02a | | |
| | If the organization didn't report an amount in c | olumn (c) fo | r a type of proport | y for which column |) (a) is cho | cked | | | |
| 33 | | | a type of propert | | | uneu, | | | |
| Eor B | describe in Part II. Paperwork Reduction Act Notice, see the Inst | tructions fo | r Eorm 990 | | | Schedule | L (Eorr | n 000 | 2022 |

16520624 759649 397-0001

| Part II | Supplemental Information. Provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also complete this part for any additional information. |
|---------------|--|
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| 332142 09-11- | 23 Schedule M (Form 990) 202 |
| 520624 | 43 759649 397-0001 2023.04000 RETT SYNDROME RESEARCH TRUS 397-0001 |

26 - 0687439

Page 2

Schedule M (Form 990) 2023 RETT SYNDROME RESEARCH TRUST, INC

SCHEDULE O (Form 990)

Department of the Treasury Internal Revenue Service

Name of the organization

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 Form 990-EZ. Go to www.irs.gov/Form990 for the latest information.

INC



26-0687439

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

RETT SYNDROME RESEARCH TRUST,

AND RELATED MECP2 DISORDERS.

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

THE ORGANIZATION PROVIDES FUNDING TO LEADING RESEARCH INSTITUTIONS

WORKING ON RETT SYNDROME AND RELATED MECP2 DISORDERS. RESEARCH IS AIMED

AT 1) RESTORING LEVELS OF MECP2 PROTEIN, 2) IDENTIFYING OBJECTIVE TOOLS

TO MEASURE RETT SYMPTOMS 3) ESTABLISH A CLINICAL TRIAL NETWORK 4)

IDENTIFY FUNCTION OF MECP2 PROTEIN.

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

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

LINE 11A EXPLANATION - A COPY OF FORM 990 IS GIVEN TO THE BOARD OF

DIRECTORS FOR REVIEW PRIOR TO ITS FILING.

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

THE ORGANIZATION MAINTAINS A CONFLICT OF INTEREST POLICY THAT MUST BE

SIGNED BY THE TRUSTEES ON AN ANNUAL BASIS.

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

THE COMPENSATION OF THE 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.

For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.Schedule O (Form 990) 2023LHA332211 11-14-23

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2023.04000 RETT SYNDROME RESEARCH TRUS 397-0001

Name of the organization

RETT SYNDROME RESEARCH TRUST, INC

26-0687439

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

332212 11-14-23

2023 TAX RETURN FILING INSTRUCTIONS

CALIFORNIA FORM 199

FOR THE YEAR ENDING

DECEMBER 31, 2023

| Prepared for | |
|--|--|
| | RETT SYNDROME RESEARCH TRUST, INC 67 UNDER CLIFF ROAD |
| | TRUMBULL, CT 06611 |
| Prepared by | |
| | ROLLERI & SHEPPARD CPAS, LLP 2150 POST ROAD, 5TH FL |
| | FAIRFIELD, CT 06824 |
| To be signed and dated by | NOT APPLICABLE |
| Amount of tax | Total tax \$ |
| | Less: payments and credits \$ 0.00 Plus: other amount \$ 0.00 |
| | Plus: interest and penalties \$ 0.00 |
| | NO PMT REQUIRED \$ |
| Overpayment | Credited to your estimated tax \$ 0.00 |
| | Other amount \$ 0.00 Refunded to you \$ 0.00 |
| | |
| Make check payable to | NOT APPLICABLE |
| Mail tax return and check (if applicable) to | THIS RETURN HAS BEEN PREPARED FOR ELECTRONIC FILING. IF YOU WISH TO HAVE IT TRANSMITTED ELECTRONICALLY TO THE FTB, PLEASE CONTACT OUR OFFICE. WE WILL THEN SUBMIT THE ELECTRONIC RETURN TO THE FTB. DO NOT MAIL THE PAPER COPY OF THE RETURN TO THE FTB. |
| Return must be mailed on or before | NOT APPLICABLE |
| Special Instructions | |
| | |
| | |
| | |
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| | |
| | |

TAXABLE YEARCalifornia Exempt Organization2023Annual Information Return

| 202 | 3 Annual Information Return | | | 199 |
|-------------------|--|---------------------|------------------------------------|----------------------------|
| Calendar Yea | 2023 or fiscal year beginning (mm/dd/yyyy) , and ending (mm/d | d/yyyy) | | |
| Corporation/Org | anization name | California c | corporation | number |
| ~ | | | | |
| | YNDROME RESEARCH TRUST, INC | 022 FEIN | 23183 | } |
| Additional inform | ation. See instructions. | | -0687 | 1120 |
| Street address (| uite or room) | <u> 20</u> - РМВ | | 439 |
| | ER CLIFF ROAD | | | |
| City | State | ZIP co | ode | |
| TRUMBU | LL CT | 066 | 511 | |
| Foreign country | name Foreign province/state/county | Foreig | gn postal co | ode |
| | | | | |
| A First retu | | | | |
| B Amendee | return • Yes X No not reported to the FTB? See in | nstructions | | • Yes X No |
| | on 4947(a)(1) trust Yes X No J If exempt under R&TC Section | | | |
| | mation return? engaged in political activities? Dissolved Surrendered (Withdrawn) Merged/Reorganized K Is the organization exempt und | | | |
| | (mm/dd/yyyy) • If "Yes," enter the gross receipt | | | 0 |
| | counting method: (1)Cash (2) X Accrual (3)Other L Is the organization a limited lia | | | |
| | turn filed? (1) ● 990T(2) ● 990PF (3) ● Sch H (990) M Did the organization file Form 1 | 100 or Forr | n 109 to | |
| | Other 990 series report taxable income? | | | • Yes X No |
| | roup filing? See instructions ● Yes LX No N Is the organization under audit | by the IRS | or has th | ie |
| | anization in a group exemption Yes X No IRS audited in a prior year? | | | |
| It "Yes," \ | hat is the parent's name? 0 Is federal Form 1023/1024 per | | | Yes X No |
| | Date filed with IRS | | _ | |
| Part I (| omplete Part I unless not required to file this form. See General Information B and C. | | | |
| | 1 Gross sales or receipts from other sources. From Side 2, Part II, line 8 | | • 1 | 791,753 00 |
| | 2 Gross dues and assessments from members and affiliates | | • 2 | 00 |
| | 3 Gross contributions, gifts, grants, and similar amounts receivedSTM | T 1 | • 3 | 8,080,684 ₀₀ |
| Receipts | 4 Total gross receipts for filing requirement test. Add line 1 through line 3. | | | |
| and | This line must be completed. If the result is less than \$50,000, see General Information B | | • 4 | 8,872,437 ₀₀ |
| Revenues | 556Cost or other basis, and sales expenses of assets sold6348 | 622 | 00 | |
| | | | | 348,622 00 |
| | 7 Total costs. Add line 5 and line 6 8 Total gross income. Subtract line 7 from line 4 | | • 8 | 8,523,815 00 |
| | 9 Total expenses and disbursements. From Side 2, Part II, line 18 | | • 9 | 12,338,304 00 |
| Expenses | 10 Excess of receipts over expenses and disbursements. Subtract line 9 from line 8 | | • 10 | -3,814,489 ₀₀ |
| | 11 Total payments | | • 11 | 00 |
| | 12 Use tax. See General Information K | | • 12 | 00 |
| _ | 13 Payments balance. If line 11 is more than line 12, subtract line 12 from line 11 | | • 13 | 00 |
| Payments | 14 Use tax balance. If line 12 is more than line 11, subtract line 11 from line 12 15 Penalties and interest. See General Information J | | 14 15 | 00 |
| | 15 Penalties and interest. See General Information J 16 Balance due. Add line 12 and line 15. Then subtract line 11 from the result | | | 00 |
| | Under penalties of perjury, 1 declaration of preparer (other than taxpayer) is based on all information of which preparer | and to the be | st of my kn | lowledge and belief, |
| Sign Here | I Title | Date | incago. | • Telephone |
| nere | Signature CHIEF EXECUTIV | | | 203-445-0041 |
| | | Check if | | ● PTIN |
| | Preparer's signature s | elf-employed | | P00182555 ● Firm's FEIN |
| Paid | Firm's name (or yours, POI.I.FRT & CHEDDARD CDAC I.I.D | | | |
| Preparer's | (or yours, if self- employed) ROLLERI & SHEPPARD CPAS, LLP 2150 POST ROAD, 5TH FL | | | 06-1156122 ● Telephone |
| Use Only | and address FAIRFIELD, CT 06824 | | | (203) 259-2727 |
| | May the FTB discuss this return with the preparer shown above? See instructions | • | X Yes | |

L

| | 1 | | | | | | | |
|-------------|---------------------|--|--------------------------|-----------|-------------------------------------|--------------------------|------------|-------------------------|
| | | Gross sales or receipts from all bus | | | | | 1 | 00 |
| | 2 1 | nterest | | | | • | 2 | 333,088 ₀₀ |
| | 3 D | Dividends | | | | • | 3 | 00 |
| Receipts | | | | | | | 4 | 00 |
| from | 5 0 | Gross royalties | | | ~~~~ | • | 5 | |
| Other | 6 6 | Gross amount received from sale of | assets (See instructions | s) | S'TA | TEMENT 2 • | 6 | 351,715 00 |
| Sources | |)ther income | · | | SEE STA | TEMENT $3 \bullet$ | 7 | 106,950 00 |
| | | otal gross sales or receipts from o | | | | | 8 | 791,753 00 |
| | 9 0 | Contributions, gifts, grants, and sim | ilar amounts paid | | STA | TEMENT 4 \bullet | 9 | 9,938,988 ₀₀ |
| | 10 D | Disbursements to or for members . Compensation of officers, directors | | | | • | 10 | 00 |
| | 11 0 | Compensation of officers, directors | , and trustees | | SEE STA | TEMENT 5 \bullet | 11 | 0 00 |
| | |)ther salaries and wages | | | | | 12 | 1,147,836 ₀₀ |
| Expenses | | nterest | | | | | 13 | 00 |
| and | 14 ⊺ | axes | | | | • | 14 | 80,841 ₀₀ |
| Disburse- | 15 R | Rents | | | | • | 15 | 00 |
| ments | 16 D | Depreciation and depletion (See ins | tructions) | | | • | 16 | 00 |
| | 17 C | Other expenses and disbursements | | | SEE STA | TEMENT 6 \bullet | 17 | 1,170,639 ₀₀ |
| | 18 T | fotal expenses and disbursements. | Add line 9 through line | 17. Enter | ⁻ here and on Side 1, Pa | art I, line 9 | 18 | 12,338,304 00 |
| Schedu | ile L | Balance Sheet | Beginning | of taxab | - | | l of taxab | - |
| Assets | | | (a) | | (b) | (c) | | (d) |
| | | | | _ | 13,831,961 | | • | 17,266,396 |
| | | eceivable | | | | | • | |
| | | ivable | | | | | • | |
| | | | | | | | • | |
| | | ate government obligations | | | | | • | |
| | | other bonds | | | | | • | |
| 7 Investr | ments in | stock | | | | | • | |
| 8 Mortga | | | | | | | • | |
| | | ents STMT 7 | | | 4,988 | | • | 1,078 |
| 10 a Dep | reciable | assets | | | | | | |
| | | ulated depreciation | | | | | | |
| 11 Land | | STMT 8 | | | | | • | |
| 12 Other a | assets _. | STMT 8 | | | 1,046,131 | | • | -,, |
| 13 Total a | assets | | | | 14,883,080 | | | 18,457,084 |
| Liabilities | | | | | | | | |
| 14 Accou | nts paya | ble | | | 13,000 | | • | |
| | | gifts, or grants payable | | | 3,919,779 | | • | 11,286,147 |
| 16 Bonds | and not | es payable | | | | | • | |
| 17 Mortga | ages pay | /able | | | | | • | |
| | | | | | | | | |
| | | r principal fund | | | | | • | |
| 20 Paid-in | or capital | surplus. Attach reconciliation | | | | | • | |
| 21 Retain | ed earnir | ngs or income fund | | | 10,950,301 | | • | ., |
| 22 Total I | liabilitie | s and net worth | | | 14,883,080 | | | 18,457,084 |
| Schedu | ile M- | 1 Reconciliation of income per | | | - 10 | a than \$50,000 | | |
| | | Do not complete this schedule | | - | | | | |
| | | r books | | ,489 | | • | . F | |
| | | e tax | | | | is return. Attach schedu | le 🖣 | • |
| 3 Excess | s of capit | tal losses over capital gains | | | 8 Deductions in this | s return not charged | | |

| 2 | Federal income tax | • | | not included in this return. Attach schedule | | |
|---|---|------------|----|--|---|------------|
| 3 | Excess of capital losses over capital gains | • | | 8 Deductions in this return not charged | | |
| 4 | Income not recorded on books this year. | | | against book income this year. | | |
| | Attach schedule | • | | Attach schedule | • | |
| 5 | Expenses recorded on books this year not | | 9 | Total. Add line 7 and line 8 | | |
| | deducted in this return. Attach schedule | • | 10 | Net income per return. | | |
| 6 | Total. Add line 1 through line 5 | -3,814,489 | | Subtract line 9 from line 6 | | -3,814,489 |

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| CA 199 | CASH CONTRIBUTIONS INCLUDED ON PART I, LINE 3 | S | tatement 1 |
|--------------------------|--|-----------------|------------|
| CONTRIBUTOR'S NAME | CONTRIBUTOR'S ADDRESS | DATE OF GIFT | AMOUNT |
| TULL FAMILY FOUNDATION | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | | 750,000. |
| LAWRENCE MATTIS | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | | 288,882. |
| MARC TESLER | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | | 203,200. |
| CRUSH RETT SYNDROME | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | | 200,000. |
| TOTAL INCLUDED ON LINE 3 | | | 1,442,082. |

| CA 199 GROSS AN | MOUNT FROM | SALE OF | ASSETS | S | TATEMENT | 2 |
|----------------------------------|--------------------|------------------|------------------|--------------------|-------------------------|-----|
| DESCRIPTION | - | DATE ACQUIREI | DA1 0 SOI | D ACQ | THOD UIRED CHASED | |
| | COST O OTHER BA | | PREC. | EXPENSE OF SALE | GROSS SALES PR | ICE |
| | 348,6 | 22. | 0. | 0. | 351,7 | 15. |
| TOTAL TO FORM 199, PAGE 2, LN 6 | 348,6 | 22. | 0. | 0. | 351,72 | 15. |
| CA 199 | OTHER I | NCOME | | S | TATEMENT | 3 |
| DESCRIPTION | | | | | AMOUNT | |
| LICENSING BIOREPOSITORY | | | | | 84,4 22,5 | |
| TOTAL TO FORM 199, PART II, LINH | E 7 | | | | 106,9 | 50. |

| CA 199 | CASH CONTRIBUTIONS, GIFTS, AND SIMILAR AMOUNTS PA | | TATEMENT 4 |
|--------------------------------------|---|--------------|------------|
| ACTIVITY CLASSIFICAT | ION: AWARDS AND GRANTS | | |
| DONEES NAME | DONEES ADDRESS | RELATIONSHIP | AMOUNT |
| UNIVERSITY OF EDINBURGH | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 | NONE | 403,352. |
| ΔΟΨΤΝΤΨΥ ΟΙ.ΔSSTFTCΔΨ | TOTAL FOR THIS ACTIVITY ION: AWARDS AND GRANTS | | 403,352. |
| DONEES NAME | DONEES ADDRESS | RELATIONSHIP | AMOUNT |
| CHILDREN'S HOSPITAL AT MONTEFIORE | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 | NONE | 50,000. |
| | TOTAL FOR THIS ACTIVITY ION: AWARDS AND GRANTS | | 50,000. |
| DONEES NAME | DONEES ADDRESS | RELATIONSHIP | AMOUNT |
| UNIVERSITY OF CALIFORNIA DAVIS | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 | NONE | 390,506. |
| | TOTAL FOR THIS ACTIVITY | | 390,506. |
| ACTIVITY CLASSIFICAT DONEES NAME | ION: AWARDS AND GRANTS DONEES ADDRESS | RELATIONSHIP | AMOUNT |
| <u></u> MIT | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 | NONE | 3,734,738. |

| | TOTAL FOR THIS ACTIVITY | | 3,734,738. |
|----------------------------------|---|--------------|------------|
| ACTIVITY CLASSIFICATI | ON: AWARDS AND GRANTS | | |
| DONEES NAME | DONEES ADDRESS | RELATIONSHIP | AMOUNT |
| BOSTON CHILDRENS HOSPITAL | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 | NONE | 69,088. |
| ACTIVITY CLASSIFICATI | TOTAL FOR THIS ACTIVITY | | 69,088. |
| DONEES NAME | DONEES ADDRESS | RELATIONSHIP | AMOUNT |
| RETT SYNDROME GLOBAL REGISTRY | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 | NONE | 100,000. |
| ACTIVITY CLASSIFICATI | TOTAL FOR THIS ACTIVITY | | 100,000. |
| DONEES NAME | DONEES ADDRESS | RELATIONSHIP | AMOUNT |
| RSRT BIOREPOSITORY | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 | NONE | 126,737. |

TOTAL FOR THIS ACTIVITY 126,737.

ACTIVITY CLASSIFICATION: AWARDS AND GRANTS

| DONEES NAME | DONEES ADDRESS | RELATIONSHIP | AMOUNT |
|---------------------|---|--------------|---------|
| EMERALD 1 VIVOSENSE | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 | NONE | 20,075. |

TOTAL FOR THIS ACTIVITY

ACTIVITY CLASSIFICATION: AWARDS AND GRANTS

| DONEES NAME | DONEES ADDRESS | RELATIONSHIP | AMOUNT |
|---|--|--------------|----------|
| CORIELL INSTITUTE FOR MEDICAL RESEARCH | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT | NONE | |
| | 06611 | | 105,826. |

TOTAL FOR THIS ACTIVITY

105,826.

20,075.

ACTIVITY CLASSIFICATION: AWARDS AND GRANTS

| DONEES NAME | DONEES ADDRESS | RELATIONSHIP | AMOUNT |
|-------------|---|--------------|--------|
| VIVALINK | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 | NONE | 7,446. |

TOTAL FOR THIS ACTIVITY

7,446.

ACTIVITY CLASSIFICATION: AWARDS AND GRANTS

| DONEES NAME | DONEES ADDRESS | RELATIONSHIP | AMOUNT | |
|-------------|---|--------------|------------|--|
| PROQR | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 | NONE | 1,120,000. | |

| | TOTAL FOR THIS ACTIVITY | | | |
|--|---|--------------|-----------|--|
| ACTIVITY CLASSIFICAT | ION: AWARDS AND GRANTS | | | |
| DONEES NAME | DONEES ADDRESS | RELATIONSHIP | AMOUNT | |
| UNIVERSITY OF MASSACHUSETTS MEDICAL SCHO | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 | NONE | 2,343,090 | |
| | TOTAL FOR THIS ACTIVITY | | 2,343,090 | |
| ACTIVITY CLASSIFICAT | ION: AWARDS AND GRANTS | | | |
| DONEES NAME | DONEES ADDRESS RELATIONSHIP | | | |
| NEW YORK UNIVERSITY | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 | NONE | 50,000 | |
| ΔΟΠΙΊΤΗΥ ΟΙ.ΔΟΟΙΕΙΟΔη | TOTAL FOR THIS ACTIVITY | | 50,000 | |
| DONEES NAME | DONEES ADDRESS | RELATIONSHIP | AMOUNT | |
| REFUNDS AND LONG TERM ADJUSTMENTS | C/O RETT SYNDROME, 67 UNDER CLIFF ROAD - TRUMBULL, CT 06611 | NONE | -335,955 | |
| | TOTAL FOR THIS ACTIVITY | | -335,955 | |
| TOTAL INCLUDED ON FO | ORM 199, PART II, LINE 9 | | 8,184,903 | |

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TRUMBULL, CT 06611

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| CA 199 | COMPENSATION OF | OFFICERS, | DIREC' | TORS AND | TRUSTEES | STATEMENT | 5 |
|--|-----------------|-----------|--------|-----------------------|----------------|-----------|-----|
| NAME AND ADDE | RESS | | AVERA | TITLE AN GE HRS WC | ID ORKED/WK | COMPENSAT | ION |
| MONICA COENRA 67 UNDER CLIM TRUMBULL, CT | FF ROAD | | CHIEF | EXECUTIV 50.00 | E OFFICER | | 0. |
| TIMOTHY FREEN 67 UNDER CLIN TRUMBULL, CT | FF ROAD | | CHIEF | DEVELOPM 50.00 | IENT OFFICER | | 0. |
| JANA VON HEHN 67 UNDER CLIN TRUMBULL, CT | FF ROAD | | CHIEF | SCIENTIF 50.00 | IC OFFICER | | 0. |
| RANDALL CARPH 67 UNDER CLIH TRUMBULL, CT | FF ROAD | | CHIEF | MEDICAL 25.00 | OFFICER | | 0. |
| ADRIAN BIRD 67 UNDER CLIM TRUMBULL, CT | | | TRUST | EE 2.00 | | | 0. |
| ALBA TULL 67 UNDER CLII TRUMBULL, CT | | | TRUST | EE 2.00 | | | 0. |
| BRAD ZELINGE 67 UNDER CLI TRUMBULL, CT | FF ROAD | | TRUST | EE 2.00 | | | 0. |
| BRIAN WHITMEN 67 UNDER CLIN TRUMBULL, CT | FF ROAD | | TRUST | EE 2.00 | | | 0. |
| HEIDI EPSTEIN 67 UNDER CLIN TRUMBULL, CT | FF ROAD | | VICE (| CHAIRMAN 2.00 | | | 0. |
| INGRID HARDIN 67 UNDER CLIN TRUMBULL, CT | FF ROAD | | CO-FO | UNDER AND 2.00 |) TRUSTEE | | 0. |
| LAWRENCE MATE | | | SECRE' | TARY 2.00 | | | 0. |

| RETT SYNDROME RESEARCH TRUST, IN | \mathbf{RETT} | SYNDROME | RESEARCH | TRUST, | INC |
|----------------------------------|-----------------|----------|----------|--------|-----|
|----------------------------------|-----------------|----------|----------|--------|-----|

| | TRUSTEE 2.00 | 0. |
|-------|-------------------|---|
| | TREASURER 2.00 | 0. |
| | TRUSTEE 2.00 | 0. |
| | TRUSTEE 2.00 | 0. |
| | TRUSTEE 2.00 | 0. |
| | CHAIRMAN 2.00 | 0. |
| E 11 | | 0. |
| OTHER | EXPENSES | STATEMENT 6 |
| | | |
| | | AMOUNT |
| | E 11 OTHER | 2.00 TREASURER 2.00 TRUSTEE 2.00 TRUSTEE 2.00 CHAIRMAN 2.00 |

TOTAL TO FORM 199, PART II, LINE 17

1,170,639.

| CA 199 | OTHER INVESTMENTS | 5 | STATEMENT 7 | |
|----------------------------------|-------------------|--------------|-------------|--|
| DESCRIPTION | | BEG. OF YEAR | END OF YEAR | |
| OTHER INVESTMENTS | | 4,988. | 1,078. | |
| TOTAL TO FORM 199, SCHEDULE L, | LINE 9 | 4,988. | 8. 1,078. | |
| CA 199 | OTHER ASSETS | | STATEMENT 8 | |
| DESCRIPTION | | BEG. OF YEAR | END OF YEAR | |
| PLEDGES AND GRANTS RECEIVABLE | | 1,046,131. | 1,189,610. | |
| TOTAL TO FORM 199, SCHEDULE L, | LINE 12 | 1,046,131. | 1,189,610. | |
| CA 199 | FUND BALANCES | | STATEMENT 9 | |
| DESCRIPTION | | BEG. OF YEAR | END OF YEAR | |
| NET ASSETS WITHOUT DONOR RESTRIC | CTIONS | 10,950,301. | 7,135,812. | |
| TOTAL TO FORM 199, SCHEDULE L, | LINE 21 | 10,950,301. | 7,135,812. | |

-

- ____

| TAXABLE YEAR 2023California e-file Return Authorization for Exempt Organizations | | | | | | | FORM 8453-EC | | | |
|--|--|---|--|--|---|---|---|---|--|---|
| Exempt Or | ganization na | me | | | | | | 10 | dentifying | number |
| | | | ESEARCH TRUS | - | | | | | 26-0 | 687439 |
| Part I | | | Information (whole dolla | | | | | | | |
| 1 Tot | al gross r | eceipts or u | nrelated business taxable | e income (Form 199, line | e 4 or Form | 109, line 5) | | | 1_ | 8 523 81 |
| 2 Tot 3 Tot | al gross ir | es and dish | tal tax (Form 199, line 8 c ursements (Form 199, lin | or Form 109, line 14) ⊙ 9) | | | | | ² | 12.338.30 |
| | - | | 23) | | | | | | | |
| | | | , line 24) | | | | | | | |
| Part II | Settle \ | our Accou | nt Electronically for Tax | able Year 2023 | | | | | | |
| 6 | Direct D | eposit of re | fund (Form 109 only.) | | | | | | | |
| 7 | | nic funds wit | | | 7 | b Withdrawal | date (mn | n/dd/yy | уу) | |
| Part III | Schedul | e of Estimate | d Tax Payments for Taxable | | | | | amount | | , |
| | | | First Payment | Second Paymer | it 👘 | Third Pa | iyment | | | Fourth Payment |
| 8 Amo | | ata . | | | | | | | | |
| | ndrawal Da Bankin | | on (Have you verified the | exempt organization's t | anking info | ormation?) | | | | |
| - | ting numb | - | | | j | , | | | | |
| | ount num | - | | | 12 Type | e of account: | | ecking | | Savings |
| Part V | Declara | ation of Offi | cer | | | | | | | |
| direct de | oosit refund | agrees with | n's account to be settled as the authorization stated on n nts listed on Part III, line 8 fi | ny return. If I check Part II, | box 7, I auth | norize an electror | | | | |
| a balance organizat statemen delayed, Sign | due return ion will rem ts be transi | , I understand nain liable for mitted to the F | best of my knowledge and that if the Franchise Tax Bo the tax liability and all applic TB by the ERO, transmitter, isclose to the ERO or intern | oard (FTB) does not receive able interest and penalties. or intermediate service pro | full and time I authorize to vider. If the ne reason(s) | ely payment of th he exempt organ processing of th | ie exempt ization ret e exempt the date | organiza urn and organiz when th | ation's ta accompa ation's r e refund | x liability, the exempt anying schedules and eturn or refund is |
| Here | Signa | ature of officer | | Date | Title | | | | | |
| Part VI | | | ctronic Return Originato | <u> </u> | | | | | | |
| am only a accuratel provided 1345, 20 the exem I declare | an intermec y reflects th the organiz 23 Handbo pt organiza that I have | liate service p ne data on the cation officer v ok for Authori tion return is examined the | above exempt organization's rovider, I understand that I a return.) I have obtained the with a copy of all forms and i ized e-file Providers. I will ke filed, whichever is later, and above exempt organization' e this declaration based on a | Im not responsible for revie organization officer's signa nformation that I will file wi ep form FTB 8453-EO on fi I will make a copy available s return and accompanying | ewing the ex ture on forn th the FTB, a le for four ye to the FTB g schedules a | empt organizatio n FTB 8453-EO b and I have follow ears from the du upon request. If and statements, | n's return efore tran ed all othe e date of t I am also f | . I declar smitting r require he returr he paid | e, howev this retu ements d or four preparer, | ver, that form FTB 8453-E0 rn to the FTB. I have escribed in FTB Pub. years from the date , under penalties of perjur |
| | ERO's | | | | Date | Check if also paid | | Check if self- | | ERO's PTIN |
| ERO | signature | | | | | preparer | X | employe | | P00182555 |
| Must | Firm's name if self-emple | | | HEPPARD CPAS | , LLP | | | | Firm's FE | N06-1156122 |
| Sign | and address | | 2150 POST R FAIRFIELD, | | | | | | 710 | 06824 |
| Under pe | nalties of p | erjury, I decla | re that I have examined the a and complete. I make this de | above organization's return | and accomp | panying schedul | es and sta | | | |
| Paid | Paid | arer's | | | | ate | Check if self- | a 🔽 | Paid | preparer's PTIN |
| Prepa Must | | s name (or yours | 6 | | I | | employe | - <u> </u> | J Firm's FEI | IN |
| Sign | | f-employed) address | ▶ | | | | | | | |
| J | | | | | | | | | ZIP code | |
| | | | | | | | | | | |
| 329021 12 | 2-27-23 | | | | 2 | | | | | FTB 8453-EO 202 |

16520624 759649 397-0001 2023.04000 RETT SYNDROME RESEARCH TRUS 397-0001

TAX RETURN FILING INSTRUCTIONS

CALIFORNIA FORM RRF-1

FOR THE YEAR ENDING

DECEMBER 31, 2023

| Prepared for | RETT SYNDROME RESEARCH TRUST, INC 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 |
|--|---|
| Prepared by | ROLLERI & SHEPPARD CPAS, LLP 2150 POST ROAD, 5TH FL FAIRFIELD, CT 06824 |
| Amount due or refund | BALANCE DUE OF \$400.00 |
| Make check payable to | DEPARTMENT OF JUSTICE |
| Mail tax return and check (if applicable) to | REGISTRY OF CHARITIES AND FUNDRAISERS P.O. BOX 903447 SACRAMENTO, CA 94203-4470 |
| Return must be mailed on or before | NOVEMBER 15, 2024 |
| Special Instructions | THE REPORT SHOULD BE SIGNED AND DATED BY THE AUTHORIZED INDIVIDUAL(S). |

| STATE OF CALIFORNIA RRF-1 (Rev. 01/2024) MAIL TO: Registry of Charities and Fundraisers P.O. Box 903447 Sacramento, CA 94203-4470 STREET ADDRESS: 1300 I Street Sacramento, CA 95814 WEBSITE ADDRESS: www.oag.ca.gov/charities | 024) ANNUAL REGISTRATION RENEWAL FEE REPORT TO ATTORNEY GENERAL OF CALIFORNIA (For Registry Use Only) 05 Charities and Fundraisers 903477 tot, CA 94203-4470 Sections 12586 and 12587, California Government Code 11 Cal. Code Regs. sections 301-307, and 310 Failure to submit this report annually no later than four months and fifteen days after the end of the organization's accounting period may result in the loss of tax exemption and the assessment of a minimum tax of \$800, plus interest, and/or fines or filing penalties. Revenue & Taxation Code section (For Registry Use Only) | | | | OF JU PAG | ISTICE | |
|---|---|---|--------------------------------|--|---|--------|----|
| RETT SYNDROME R Name of Organization | | | An 🗌 | ange of address nended report ganization requests e | mail notifications | | |
| 67 UNDER CLIFF | | | State Ch | arity Registration Nu | mber 0223183 | | |
| | 6611 | | | tion or Organization N | | | |
| City or Town, State, and ZIP Code State, and ZIP Code 203-445-0041 Federal Employer ID No. 26-0687439 | | | | | | | |
| Z03-445-0041 Telephone Number | E-mail Addres | ss | Federal E | Employer ID No. 20 | -0087439 | | |
| ANNUAL | REGISTRATIC | ON RENEWAL FEE SCHEDULE (11 C Make Check Payable to Departr | | | 07, and 310) | | |
| Total Revenue Less than \$50,000 Between \$50,000 and \$100,0 Between \$100,001 and \$250,000 and \$250,000 | | Total Revenue Between \$250,001 and \$1 million Between \$1,000,001 and \$5 millior Between \$5,000,001 and \$20 millior | <u>Fee</u> \$100 n \$200 | Total Revenue Between \$20,000, | 001 and \$100 million 0,001 and \$500 millior) million | | _ |
| PART A - ACTIVITIES | | | | | | | |
| | | g period (beginning $01/01/20$ 815 Noncash Contributions\$ 11,396,540 | | ding <u>12/31/2</u> 0 Total Asso penses \$ <u>12</u> | , | 7,0 | 84 |
| PART B - STATEMENTS REC | GARDING OR | GANIZATION DURING THE PERIOD | OF THIS R | EPORT | | | |
| | | f you answer "yes" to any of the que ils for each "yes" response. Please r | | | | Yes | No |
| | | e any contracts, loans, leases or other f eof, either directly or with an entity in w | | | • | | x |
| 2. During this reporting peri or funds? | od, was there | any theft, embezzlement, diversion or | misuse of t | he organization's cha | aritable property | | x |
| | od, were any c | organization funds used to pay any per | nalty, fine o | or judgment? | | | x |
| 4. During this reporting peri commercial coventurer u | | ervices of a commercial fundraiser, fur | ndraising co | ounsel for charitable p | ourposes, or | | x |
| 5. During this reporting peri | od, did the org | ganization receive any governmental fu | nding? | | | | x |
| 6. During this reporting peri | od, did the org | ganization hold a raffle for charitable pu | urposes? | | | | x |
| 7. Does the organization co | nduct a vehicle | le donation program? | | | | | x |
| 0 | • | endent audit and prepare audited finan es for this reporting period? | icial statem | ents in accordance v | vith | x | |
| 9. At the end of this reportir | ng period, did t | the organization hold restricted net as | sets, while | reporting negative un | restricted net assets? | | x |
| | | ave examined this report, including a d complete, and I am authorized to si | | ring documents, and | to the best of my kno | owled | ge |
| | | NICA COENRAADS | (| CHIEF EXECU OFFICER | | | |
| Signature of Authorized Agent | Pri | inted Name | | Fitle | Date | | |

TAX RETURN FILING INSTRUCTIONS

ILLINOIS FORM AG990-IL

FOR THE YEAR ENDING

DECEMBER 31, 2023

| Prepared for | RETT SYNDROME RESEARCH TRUST, INC 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 |
|--|---|
| Prepared by | ROLLERI & SHEPPARD CPAS, LLP 2150 POST ROAD, 5TH FL FAIRFIELD, CT 06824 |
| Amount due or refund | BALANCE DUE OF \$15.00 |
| Make check payable to | ILLINOIS CHARITY BUREAU FUND |
| Mail tax return and check (if applicable) to | OFFICE OF THE ATTORNEY GENERAL CHARITABLE TRUST BUREAU 115 S. LASALLE ST CHICAGO, IL 60603 |
| Return must be mailed on or before | JULY 1, 2024 |
| Special Instructions | THE REPORT SHOULD BE SIGNED AND DATED BY THE AUTHORIZED INDIVIDUAL(S). |

| For Off | fice Use Only ILLINOIS CHARITABLE ORGANIZATION ANNUAL REPORT | | Form AG990-IL Revised 1/24 |
|-----------------|---|-------------|--|
| PMT | | | |
| | Charitable Trust Bureau, 115 S. LaSalle St | CO | # 01-01070528 |
| | Chicago, IL 60603 | | Check all items attached: |
| AMT | · · · | | Copy of IRS Return |
| | Beginning 01/01/2023 Make Checks Payable to | X | Audited Financial Statements |
| | Illinois Charity | | Reviewed Financial Statements |
| INIT | & Ending 12/31/2023 Bureau Fund | | Copy of Form IFC \$15 Annual Report Filing Fee |
| | | | \$100 Late Report Filing Fee |
| Feder | al ID # 26-0687439 MO DAY YR Date organization was cr | reated | |
| | ontributions to the organization tax deductible? | | MO DAY YR |
| | Al Name: RETT SYNDROME RESEARCH TRUST, INC YEAR-END | | |
| - | AMOUNTS | | |
| | Address: 67 UNDER CLIFF ROAD A) ASSETS | | A) \$ 18,457,084. |
| | y, State: TRUMBULL, CT B) LIABILITIES | L | B) \$ 11,321,272. |
| Z | ip Code: 06611 C) NET ASSETS | S | C) \$ 7,135,812. |
| _ | | | |
| I . | SUMMARY OF ALL REVENUE ITEMS DURING THE YEAR:PERCENTAGD) PUBLIC SUPPORT, CONTRIBUTIONS AND PROGRAM SERVICE REV. (GROSS AMTS.)93.967 | | AMOUNT D) \$ 8,009,613. |
| | | | E) \$ 178,021. |
| | E) GOVERNMENT GRANTS AND MEMBERSHIP DUES2.089F) OTHER REVENUES3.944 | | L) \$ L 78,021. F) \$ 336,181. |
| | | ≚ /0 | ·, · · · · · · · · · · · · · · · · · · |
| | G) TOTAL REVENUES, INCOME AND CONTRIBUTIONS RECEIVED (ADD D, E, & F) 100 |)% | G) \$ 8,523,815. |
| п. | SUMMARY OF ALL EXPENDITURES DURING THE YEAR: | ,,, | ,, |
| | H) OPERATING CHARITABLE PROGRAM EXPENSE 11.813 | 3% | н) \$ 1,457,552. |
| | | | · · · |
| | I) EDUCATION PROGRAM SERVICE EXPENSE | % | I) \$ |
| | | | |
| | J) TOTAL CHARITABLE PROGRAM SERVICE EXPENSE (ADD H & I) 11.813 | 3% | J) \$ 1,457,552. |
| | | | |
| | J1) JOINT COSTS ALLOCATED TO PROGRAM SERVICES (INCLUDED IN J) | | |
| | K) GRANTS TO OTHER CHARITABLE ORGANIZATIONS 80.554 | 1% | к) \$ 9,938,988. |
| | | - /0 | κ) φ 3733673600 |
| | L) TOTAL CHARITABLE PROGRAM SERVICE EXPENDITURE (ADD J & K) 92.367 | 7% | L) \$ 11,396,540. |
| | -,, | | |
| | M) MANAGEMENT AND GENERAL EXPENSE 1.557 | 7% | M)\$ 192,149. |
| | | | |
| | N) FUNDRAISING EXPENSE 6.076 | 5% | N) \$ 749,615. |
| | | | 10 000 004 |
| | 0) TOTAL EXPENDITURES THIS PERIOD (ADD L, M & N) 100 |)% | 0) \$ 12,338,304. |
| III. | SUMMARY OF ALL PAID FUNDRAISER & CONSULTANT ACTIVITIES: | | |
| | (Attach Attorney General Report of Individual Fundraising Campaign (Form IFC). One for each PFR.) PROFESSIONAL FUNDRAISERS: | | |
| | P) TOTAL AMOUNT RAISED BY PAID PROFESSIONAL FUNDRAISERS 100 |)% | P) \$ 0. |
| | | , ,0 |) + • • • |
| | Q) TOTAL FUNDRAISERS FEES AND EXPENSES | % | Q) \$ |
| | | | |
| | R) NET RECEIVED BY THE CHARITY (P MINUS Q=R) | % | R) \$ |
| | PROFESSIONAL FUNDRAISING CONSULTANTS: | | |
| | S) TOTAL AMOUNT PAID TO PROFESSIONAL FUNDRAISING CONSULTANTS | ļ | S) \$ 0. |
| IV. | COMPENSATION TO THE (3) HIGHEST PAID PERSONS DURING THE YEAR: | | τ) Φ |
| | T) NAME, TITLE: | | T) \$ |
| | U) NAME, TITLE: | | U) \$ V) \$ |
| | V) NAME, TITLE: | | , |
| V. | CHARITABLE PROGRAM DESCRIPTION: CHARITABLE PROGRAM (3 HIGHEST BY \$ EXPENDED) CODE CATEGORIES | | List on back side of instructions CODE |
| -13-24 | W) DESCRIPTION: | · | W)# |
| 398091 02-13-24 | X) DESCRIPTION: | | X) # |
| 39805 | Y) DESCRIPTION: | | Y) # |
| | | | , |

| IF | THE ANSWER TO ANY OF THE FOLLOWING QUESTIONS IS YES, ATTACH A DETAILED EXPLANATION: | | YES | NO |
|-----|---|-----|-----|----|
| 1. | WAS THE ORGANIZATION THE SUBJECT OF ANY COURT ACTION, FINE, PENALTY OR JUDGMENT? | 1. | | X |
| 2. | HAS THE ORGANIZATION OR A CURRENT DIRECTOR, TRUSTEE, OFFICER OR EMPLOYEE THEREOF, EVER BEEN CONVICTED BY ANY COURT OF ANY MISDEMEANOR INVOLVING THE MISUSE OR MISAPPROPRIATION OF FUNDS OR ANY FELONY? | 2. | | X |
| 3. | DID THE ORGANIZATION MAKE A GRANT AWARD OR CONTRIBUTION TO ANY ORGANIZATION IN WHICH ANY OF ITS OFFICERS, DIRECTORS OR TRUSTEES OWNS AN INTEREST; OR WAS IT A PART TO ANY TRANSACTION IN WHICH ANY OF ITS OFFICERS, DIRECTORS OR TRUSTEES HAS A MATERIAL FINANCIAL INTEREST; OR DID ANY OFFICER, DIRECTOR OR TRUSTEE RECEIVE ANYTHING OF VALUE NOT REPORTED AS COMPENSATION? | 3. | | X |
| 4. | HAS THE ORGANIZATION INVESTED IN ANY CORPORATE STOCK IN WHICH ANY OFFICER, DIRECTOR OR TRUSTEE OWNS MORE THAN 10% OF THE OUTSTANDING SHARES? | 4. | | X |
| 5. | IS ANY PROPERTY OF THE ORGANIZATION HELD IN THE NAME OF OR COMMINGLED WITH THE PROPERTY OF ANY OTHER PERSON OR ORGANIZATION? | 5. | | X |
| 6. | DID THE ORGANIZATION USE THE SERVICES OF A PROFESSIONAL FUNDRAISER? (ATTACH FORM IFC) | 6. | | Х |
| | DID THE ORGANIZATION ALLOCATE THE COST OF ANY SOLICITATION, MAILING, ADVERTISEMENT OR LITERATURE COSTS BETWEEN PROGRAM SERVICE AND FUNDRAISING EXPENSES? IF "YES", ENTER | 7. | | X |
| | (I) THE AGGREGATE AMOUNT OF THESE JOINT COSTS \$; (II) THE AMOUNT ALLOCATED TO PROGRAM SERVICES \$; (III) THE AMOUNT ALLOCATED TO MANAGEMENT AND GENERAL \$; AND (IV) THE AMOUNT ALLOCATED TO FUNDRAISING \$. | | | |
| 8. | DID THE ORGANIZATION EXPEND ITS RESTRICTED FUNDS FOR PURPOSES OTHER THAN RESTRICTED PURPOSES? | 8. | | Х |
| 9. | HAS THE ORGANIZATION EVER BEEN REFUSED REGISTRATION OR HAD ITS REGISTRATION OR TAX EXEMPTION SUSPENDED OR REVOKED BY ANY GOVERNMENTAL AGENCY? | 9. | | X |
| 10. | WAS THERE OR DO YOU HAVE ANY KNOWLEDGE OF ANY KICKBACK, BRIBE, OR ANY THEFT, DEFALCATION, MISAPPROPRIATION, COMMINGLING OR MISUSE OF ORGANIZATIONAL FUNDS? | 10. | | X |
| 11. | LIST THE NAME AND ADDRESS OF THE FINANCIAL INSTITUTIONS WHERE THE ORGANIZATION MAINTAINS ITS THREE LARGEST ACCOUNTS: | | | |
| | | | | |
| | | | | |
| 12. | NAME AND TELEPHONE NUMBER OF CONTACT PERSON: MONICA COENRAADS - 203-445-0041 | | | |

\bullet All attachments must accompany this report - see instructions \bullet

UNDER PENALTY OF PERJURY, I (WE) THE UNDERSIGNED DECLARE AND CERTIFY THAT I (WE) HAVE EXAMINED THIS ANNUAL REPORT AND THE ATTACHED DOCUMENTS, INCLUDING ALL THE SCHEDULES AND STATEMENTS, AND THE FACTS THEREIN STATED ARE TRUE AND COMPLETE AND FILED WITH THE ILLINOIS ATTORNEY GENERAL FOR THE PURPOSE OF HAVING THE PEOPLE OF THE STATE OF ILLINOIS RELY THEREUPON. I HEREBY FURTHER AUTHORIZE AND AGREE TO SUBMIT MYSELF AND THE REGISTRANT HEREBY TO THE JURISDICTION OF THE STATE OF ILLINOIS.

| BE SURE TO INCLUDE ALL FEES DUE: | MONICA COENRAADS | | |
|--|-----------------------------------|-----------|------|
| 1.) REPORTS ARE DUE WITHIN SIX MONTHS OF YOUR FISCAL YEAR END. | PRESIDENT OR TRUSTEE (PRINT NAME) | SIGNATURE | DATE |
| 2.) FOR FEES DUE SEE INSTRUCTIONS. | MARCI VALNER | | |
| REPORTS THAT ARE LATE OR INCOMPLETE ARE SUBJECT TO A \$100.00 PENALTY. | TREASURER OF TRUSTEE (PRINT NAME) | SIGNATURE | DATE |
| • | JOHN M. ROLLERI, CPA | | |
| 398101 02-13-24 | PREPARER (PRINT NAME) | SIGNATURE | DATE |

TAX RETURN FILING INSTRUCTIONS

NEW YORK FORM CHAR500

FOR THE YEAR ENDING

DECEMBER 31, 2023

| Prepared for | RETT SYNDROME RESEARCH TRUST, INC |
|--|--|
| | 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 |
| Prepared by | |
| | ROLLERI & SHEPPARD CPAS, LLP 2150 POST ROAD, 5TH FL FAIRFIELD, CT 06824 |
| Amount due or refund | BALANCE DUE OF \$25.00 |
| Make check payable to | NOT APPLICABLE |
| Mail tax return and check (if applicable) to | THE NEW YORK FORM CHAR500 SHOULD BE FILED VIA THE WEB AT: HTTPS://CHARITIESNYS.COM/ANNUAL_FILING.HTML |
| Return must be mailed on or before | PLEASE MAIL AS SOON AS POSSIBLE. |
| Special Instructions | |
| | |
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| | |
| | |

CHAR500

NYS Annual Filing for Charitable Organizations www.CharitiesNYS.com

Open to Public Inspection

| 1.General Informat | | | | |
|---|--|--------------------------------|---|---|
| For Fiscal Year Beginning | g (mm/dd/yyyy) 01/01/ | 2023 and Ending (I | mm/dd/yyyy) 12/31/2 | 023 |
| Check if Applicable: Address Change | Name of Organization: RETT SYNDROME | RESEARCH TRUS | T, INC | $\begin{array}{c} \mbox{Employer Identification Number (EIN):} \\ 26-0687439 \end{array}$ |
| Name Change | Mailing Address: 67 UNDER CLIFF | ROAD | | NY Registration Number: $45 - 02 - 15$ |
| Final Filing | City / State / ZIP: TRUMBULL, CT | 06611 | | Telephone: 203 445-0041 |
| Reg ID Pending | Website: WWW • RSRT • ORG | | | Email: |
| Check your organization's | 3 | | | |
| registration category: | X 7A only EPTL o | only DUAL (7A & | | onfirm your Registration Category in the harities Registry at www.CharitiesNYS.com. |
| 2. Certification | | | | |
| See instructions for certif two signatories. | ication requirements. Improper | r certification is a violation | of law that may be subject t | to penalties. The certification requires |
| | enalties of perjury that we revie e true, correct and complete in | | | best of our knowledge and belief, oplicable to this report. |
| President or Authorized | Officer: | | MONICA COEN CHIEF EXECU | |
| | Signature | | Print Name | |
| Chief Financial Officer or | - | | | |
| | Signature | | Print Name | and Title Date |
| 3. Annual Reporting | g Exemption | | | |
| Check the exemption(s) t | hat apply to your filing. If your | organization is claiming ar | exemption under one cate | gory (7A or EPTL only filers) or both |
| categories (DUAL filers) the | nat apply to your registration, o | complete only parts 1, 2, a | nd 3, and submit the certifie | ed Char500. No fee, schedules, or |
| additional attachments an | e required. If you cannot claim | an exemption or are a DL | JAL filer that claims only one | e exemption, you must file applicable |
| schedules and attachmer | nts and pay applicable fees. | | | |
| exceed \$2 | <u>g exemption</u> : Total contributio 5,000 <u>and</u> the organization dic ons during the fiscal year. | | | vernment agencies, etc. did not aising counsel (FRC) to solicit |
| | iling exemption: Gross receipts fiscal year. | s did not exceed \$25,000 | and the market value of ass | ets did not exceed \$25,000 at any time |
| 4. Schedules and A | ttachments | | | |
| See the following page for a checklist of schedules and | | | fessional fund raiser, fund ra ? If yes, complete Schedule | aising counsel or commercial co-venturer 4a. |
| attachments to | | 0 , | | |
| | X Yes No 4b. Did th | ne organization receive gov | vernment grants? If yes, cor | nplete Schedule 4b. |
| 5. Fee | | | | |
| See the checklist on the | 7A filing fee: | EPTL filing fee: | Total fee: | |
| next page to calculate yo | - | Ŭ | | Make a single check or money order |
| fee(s). Indicate fee(s) you | | | | payable to: |
| are submitting here: | \$5. | \$ | \$ | "Department of Law" |
| - | r Charitable Organizations (Upo fers to an organization's NYS | • • | not refer to its IRS tax desi | gnation. |

368451 04-01-23 1019

Page 1

16520624 759649 397-0001

2 2023.04000 RETT SYNDROME RESEARCH TRUS 397-0001

| RETT SYNDROME RESE | ARCH TRUST, INC | |
|--|--|--|
| | Simply submit the certified CHAR500 | with no fee, schedule, or additional attachments IF: |
| CHAR500 | - Your organization is registered as 7A | only and you marked the 7A filing exemption in Part 3. |
| Annual Filing Checklist | - Your organization is registered as EP | TL only and you marked the EPTL filing exemption in Part 3. |
| Annual I ling Oneckist | - Your organization is registered as DU | JAL and you marked <u>both</u> the 7A and EPTL filing exemption in Part 3. |
| | | |
| Checklist of Schedules and | a Attachments | |
| | nit with your CHAR500 as described in F | |
| | 4a, submit Schedule 4a: Professional Fund 4b, submit Schedule 4b: Government Gr | d Raisers (PFR), Fund Raising Counsel (FRC), Commercial Co-Venturers (CCV) rants |
| Check the financial attachments you X IRS Form 990, 990-EZ, or 990- X All additional IRS Form 990 Sc | PF, and 990-T if applicable | le of Contributors). Schedule B of public charities is exempt from |
| disclosure and will not be avai | | |
| Our organization was eligible f | | ur revenue exceeded \$25,000 and/or our assets exceeded \$25,000 in the only. |
| | | ed Public Accountant's Review or Audit Report: |
| | total revenue and support greater than s | |
| | | I,000,000 and the fiscal year begins on or after July 1, 2021. |
| | port is required because total revenue a | total revenue and support is greater than \$750,000 |
| | ed box 3a, no Review Report or Audit R | |
| Calculate Your Fee | | |
| | | Is my Registration Category 7A, EPTL, DUAL or EXEMPT? |
| | | Organizations are assigned a Registration Category upon |
| For 7A and DUAL filers, calculate the | 3 /A fee: | registration with the NY Charities Bureau: |
| \$0, if you checked the 7A exer \$25, if you did not check the 7 | | 7A filers are registered to solicit contributions in New York under Article 7-A of the Executive Law ("7A") |
| | | EPTL filers are registered under the Estates, Powers & Trusts |

For EPTL and DUAL filers, calculate the EPTL fee:

| \$0, if you checked the EPTL exemption in Part 3b | a |
|--|----------|
| \$25, if the NET WORTH is less than \$50,000 | D |
| 50, if the NET WORTH is \$50,000 or more but less than \$250,000 | Е |
| \$100, if the NET WORTH is \$250,000 or more but less than \$1,000,000 | a |
| \$250, if the NET WORTH is \$1,000,000 or more but less than \$10,000,000 | <u>E</u> |
| \$750, if the NET WORTH is \$10,000,000 or more but less than \$50,000,000 | 0 |
| \$1500, if the NET WORTH is \$50,000,000 or more | b |

Send Your Filing

Send your CHAR500, all schedules and attachments, and total fee to:

NYS Office of the Attorney General Charities Bureau Registration Section 28 Liberty Street New York, NY 10005

Need Assistance?

Visit: www.CharitiesNYS.com Call: (212) 416-8401 Email: Charities.Bureau@ag.ny.gov **EPTL** filers are registered under the Estates, Powers & Trusts Law ("EPTL") because they hold assets and/or conduct activities for charitable purposes in NY.

DUAL filers are registered under both 7A and EPTL.

EXEMPT filers have registered with the NY Charities Bureau and meet conditions in <u>Schedule E - Registration</u> <u>Exemption for Charitable Organizations</u>. These organizations are not required to file annual financial reports but may do so voluntarily.

Confirm your Registration Category and learn more about NY law at <u>www.CharitiesNYS.com.</u>

Where do I find my organization's NET WORTH?

NET WORTH for fee purposes is calculated on:

- IRS Form 990 Part I, line 22
- IRS Form 990 EZ Part I, line 21
- IRS Form 990 PF, calculate the difference between Total Assets at Fair Market Value (Part II, line 16(c)) and Total Liabilities (Part II, line 23(b)).

³⁶⁸⁴⁶¹ ⁰⁴⁻⁰¹⁻²³ 1019 CHAR500 Annual Filing for Charitable Organizations (Updated January 2022)

16520624 759649 397-0001

2023.04000 RETT SYNDROME RESEARCH TRUS 397-0001

CHAR500

Open to Public Inspection

If you checked the box in question 4b in Part 4, complete this schedule and list EACH government grant award by a domestic (federal, state or local) agency; interstate or intergovernmental agency (for example Port Authority of New York and New Jersey); and state or local authorities. **Use additional pages if necessary.** Include this schedule with your certified CHAR500 NYS Annual Filing for Charitable Organizations.

| 1. Organization Information | |
|-----------------------------------|-------------------------|
| Name of Organization: | NY Registration Number: |
| RETT SYNDROME RESEARCH TRUST, INC | 45-02-15 |

2. Government Grants

| Name of Government Agency | Amount of Grant |
|---------------------------|-----------------|
| 1. ERC CREDIT | 1. 178,021. |
| 2. | 2. |
| 3. | 3. |
| 4. | 4. |
| 5. | 5. |
| 6. | 6. |
| 7. | 7. |
| 8. | 8. |
| 9. | 9. |
| 10. | 10. |
| 11. | 11. |
| 12. | 12. |
| 13. | 13. |
| 14. | 14. |
| 15. | 15. |
| Total Government Grants: | Total: 178,021. |

368481 04-01-23 1019 CHAR500 Schedule 4b: Government Grants (Updated January 2022)

2023.04000 RETT SYNDROME RESEARCH TRUS 397-0001

TAX RETURN FILING INSTRUCTIONS

PENNSYLVANIA FORM BCO-10

FOR THE YEAR ENDING

DECEMBER 31, 2023

| Prepared for | RETT SYNDROME RESEARCH TRUST, INC 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 |
|--|---|
| Prepared by | ROLLERI & SHEPPARD CPAS, LLP 2150 POST ROAD, 5TH FL FAIRFIELD, CT 06824 |
| Amount due or refund | BALANCE DUE OF \$250.00 |
| Make check payable to | COMMONWEALTH OF PENNSYLVANIA |
| Mail tax return and check (if applicable) to | BUREAU OF CHARITABLE ORGANIZATIONS 401 NORTH ST RM 207 HARRISBURG, PA 17120 |
| Return must be mailed on or before | NOVEMBER 15, 2024 |
| Special Instructions | THE REPORT SHOULD BE SIGNED AND DATED BY THE AUTHORIZED INDIVIDUAL(S). A COMPLETED AND SIGNED COPY OF FEDERAL FORM 990 (AND ALL APPLICABLE ATTACHMENTS) MUST BE INCLUDED WITH FORM BCO-10. |

| Mail to: Pennsylvania Department of State Bureau of Corporations and Charitable Organizations 401 North St Rm 207 Harrisburg, PA 17120 See <u>www.dos.pa.gov/charities</u> for more information | Charitable Organization Registration Statement BCO-10 (rev. 11/2023) Fee: See instructions | |
|--|---|--|
| Certificate number: $\frac{104197}{(N/A \text{ if initial registration})}$ Fiscal year ended: $\frac{12/31/2023}{MM DD YYYY}$ | If this is a voluntary registration, check and complete the applicable box(es). For a registration to be voluntary, at least one of the following must apply: Organization is exempt from registration because | |
| FEIN: 26-0687439 | Organization does not solicit contributions in Pennsylvania | |
| Legal name of organization: <u>RETT SYNDROME RE</u> Check if name change and give previous name All other names used to solicit contributions: <u>N/A</u> | SEARCH TRUST, INC | |
| 3. Contact person: MONICA COENRAADS 4. Principal address of organization: | Contact's e-mail: MONICA@RSRT.ORG Mailing address (if different than principal address): | |
| 67 UNDER CLIFF ROAD TRUMBULL | | |
| CT 06611 County: FAIRFIELD 800 number: | Phone number: <u>203-445-0041</u> Fax number: | |
| Website: WWW.RSRT.ORG | | |
| Item 5 to be completed 5. Type of organization (e.g. non-profit corporation, unincorpo NON-PROFIT CORPORATION | d by initial registrants only rated association, etc.): | |
| Where established: GEORGIA | Date established:* 08/09/2007 | |
| *Initial registrants must submit copies of organizational documents constitution or other organizational instrument and by-laws. | such as charter, articles of incorporation, | |

6. Name and addresses of all offices, chapters, branches, auxiliaries, affiliates or other subordinate units located in Pennsylvania, which share in the contributions or other revenue raised in the Commonwealth: (Attach a separate sheet if necessary)

| | Not Applicable |
|---|--|
| | N/A |
| | |
| | |
| | Short form registration applicability - Specified types of charitable organizations described in 1/462.7(a) of the Act may file a short form registration, which permits the organization to register without filing a financial report. Check the section that describes the organization. If the organization does not meet any of the criteria below for short form registration, check "Not Applicable": |
| Ľ | §162.7(a)(1) - Persons or organizations which solicit contributions for the relief of a specific individual, when all of the contributions collected are turned over to the named beneficiary for his/her use without any deductions and provided that all contributions collected shall be held in trust |
| E | \$162.7(a)(2) - Organizations which only solicit within the membership of the organization by other members of the organization. The term "membership" shall not include those persons who are granted a membership solely upon making a contribution as the result of solicitation. "Member" means a person having membership in a nonprofit corporation, or other organization, in accordance with the provisions of its articles of incorporation, bylaws or other instruments creating its form and organization and having bona fide rights and privileges in the organization such as the right to vote, to elect officers and directors, to hold office or position as ordinarily conferred on members of such organizations. |
| Ľ | §162.7(a)(3) - Organizations which receive gross contributions of no more than \$25,000 per fiscal year whose fundraising activities are carried on only by volunteers, members, officers or permanent employees and only permanent employees are compensated for those fundraising activities |
| [| §162.7(a)(4) - Veterans organizations chartered under Federal law, organizations of volunteer firemen, ambulance associations, rescue squad associations and their auxiliaries or affiliates, which are not exempt from |

X Not Applicable

Charitable organizations which check boxes 162.7(a)(1) - 162.7(a)(4) are not required to file a financial report with this registration. If "Not Applicable" is checked, the charitable organization must submit financial reports which are audited, reviewed, compiled or internally prepared. See Instructions.

registration, did not receive gross contributions in excess of \$100,000 and did not use a professional solicitor.

| Items 8 and 9 are required to be completed by initi | ial regis | trant | s only |
|--|-----------|-------|--------|
| 8. Date organization first solicited contributions from Pennsylvania residents: | MM | DD | YYYY |
| Other | | | |
| If organization solicited Pennsylvania residents and received gross* contribut \$25,000 in any given fiscal year, provide the date the organization first receive than \$25,000. | | - | |
| | MM | DD | 1000/ |
| | IVIIVI | 00 | YYYY |

| 10. | RETT SYNDROME RESEARCH TRUST, INC Has the organization been granted IRS tax-exempt status? X Yes No |
|-----|---|
| | A. If "Yes," under which IRS code section: <u>501(C)(3)</u> and attach a copy of the IRS exemption letter if not previously submitted. |
| | B. Has the organization's tax-exempt status ever been denied, revoked or modified? Yes X No (If "Yes," attach a copy of the denial, revocation or modification and subsequent reinstatement, if any, and if not previously submitted |
| 11. | Was the organization required to file any type of IRS 990 return, including 990, 990EZ, 990PF or 990N and applicable schedules, for its most recently completed fiscal year? |
| | (If "Yes," attach a copy of the most recently filed 990, 990EZ, 990PF or 990N and include all schedules. If "No," attach an explanation of why the organization is exempt from filing an IRS 990 return. An organization that is not required to file an IRS 990 return or an organization that files a 990N, 990EZ or 990PF, must file a Pennsylvania public disclosure form (BCO-23).) |
| 12. | Manner in which contributions are solicited (e.g. direct mail, telephone, internet, social media, etc.): |
| | X Does not solicit contributions |
| 13. | A clear description of the specific programs for which contributions are used or will be used, and a statement describing whether such programs are planned or in existence. |
| | |
| | |
| 14. | |
| | Is the organization registered to solicit contributions in any other state or municipality? |
| | Is the organization registered to solicit contributions in any other state or municipality? Yes X No (If "Yes," list all states and municipalities. Attach a separate sheet if necessary.) |
| 15 | Yes X No (If "Yes," list all states and municipalities. Attach a separate sheet if necessary.) |
| 15. | |
| 15. | Yes X No (If "Yes," list all states and municipalities. Attach a separate sheet if necessary.) Is any person compensated, or does the organization intend to compensate any person, who solicits contributions in Pennsylvania, including, but not limited to, employees of the organization and professional solicitors? (Do not check |
| | Yes X No (If "Yes," list all states and municipalities. Attach a separate sheet if necessary.) Is any person compensated, or does the organization intend to compensate any person, who solicits contributions in Pennsylvania, including, but not limited to, employees of the organization and professional solicitors? (Do not check "Yes" if the organizations only uses or intend to only use a professional fundraising counsel.) Yes X No If "Yes," give the date the person or entity started or will start soliciting contributions from Pennsylvania residents: |
| | Yes No (If "Yes," list all states and municipalities. Attach a separate sheet if necessary.) Is any person compensated, or does the organization intend to compensate any person, who solicits contributions in Pennsylvania, including, but not limited to, employees of the organization and professional solicitors? (Do not check "Yes" if the organizations only uses or intend to only use a professional fundraising counsel.) Yes X No If "Yes," give the date the person or entity started or will start soliciting contributions from Pennsylvania residents: |
| 15. | Yes No (If "Yes," list all states and municipalities. Attach a separate sheet if necessary.) Is any person compensated, or does the organization intend to compensate any person, who solicits contributions in Pennsylvania, including, but not limited to, employees of the organization and professional solicitors? (Do not check "Yes" if the organizations only uses or intend to only use a professional fundraising counsel.) Yes Yes No If "Yes," give the date the person or entity started or will start soliciting contributions from Pennsylvania residents: |

17. Names, addresses, and telephone numbers of all professional fundraising counsel the organizations uses or intends to use to provide services with respect to the solicitation of contributions from Pennsylvania residents. For each entry, include the beginning and ending dates of all contracts and dates services began, or will begin, with respect to soliciting contributions from Pennsylvania residents: (Attach a separate sheet if necessary)

| | Names, addresses, and telephone numbers of any commercial coventurers under contract with the organization: (Attach a separate sheet if necessary) |
|-----|---|
| | Not Applicable |
| 19. | If the registering charity is a parent organization located in Pennsylvania, does the organization elect to file a combined registration covering all of its Pennsylvania affiliates? (See note "Affiliate and Parent Organization") Yes No X Not Applicable |
| | If "Yes," give all names and certificate numbers of the affiliate organizations: (Each affiliate whose parent organization files an IRS 990 group return must submit a copy of the parent organization's 990 group return and file a public disclosure form (BCO-23) for each affiliate.) |
| | |
| 20. | Is the registering charity a Pennsylvania affiliate of a parent organization, which elected to file a combined registration on the registering charity's behalf? (See note "Affiliate and Parent Organization") Yes No X Not Applicable |
| 20. | on the registering charity's behalf? (See note "Affiliate and Parent Organization") Yes No X Not Applicable If "Yes," provide the name and, if available, certificate number of the parent organization. |
| 20. | on the registering charity's behalf? (See note "Affiliate and Parent Organization") Yes No X Not Applicable If "Yes," provide the name and, if available, certificate number of the parent organization. (Each affiliate whose parent organization files an IRS 990 group return must submit a copy of the parent organization's 990 group return |
| I | on the registering charity's behalf? (See note "Affiliate and Parent Organization") Yes No X Not Applicable If "Yes," provide the name and, if available, certificate number of the parent organization. (Each affiliate whose parent organization files an IRS 990 group return must submit a copy of the parent organization's 990 group return and file a public disclosure form (BCO-23) for each affiliate.) |

22. Names of the individuals or officers of the organization who: (Attach a separate sheet if necessary)

A. Are in charge of solicitation activities:

TIMOTHY FREEMAN, DIRECTOR OF DEVELOPMENT

B. Have final responsibility for the custody of contributions:

MONICA COENRAADS, CEO

C. Have final responsibility for final distribution of contributions:

BOARD OF TRUSTEES

D. Are responsible for custody of financial records:

MONICA COENRAADS, CEO

23. Are any officers, directors, trustees, or employees related by blood, marriage, or adoption to:

| A. Any other off | ficer, director, trustee, | or employee? | Yes | X No |
|------------------|---------------------------|--------------|-----|------|
|------------------|---------------------------|--------------|-----|------|

- B. Any officer, agent, or employee of any professional fundraising counsel or solicitor under contract with organization? ** Yes X No
- C. Any officers, agents or employees of any supplier or vendor providing goods or services? **

Yes X No

**(this includes any officer, director, trustee, or employee of the charitable organization who is also an officer, director, trustee, employee or owner of a professional fundraising counsel, professional solicitor, supplier or vendor)

If "Yes" is checked to any of the above, attach a list of related individuals including names, business, and residence addresses of related parties.

- 24. Has the organization or any of its present officers, directors, executive personnel or trustees ever:
 - A. Been found to have engaged in unlawful practices in the solicitation of contributions or administration of charitable assets or been enjoined from soliciting contributions or currently has such proceedings pending in this or any other jurisdiction? Yes X No
 - B. Had its registration or license to solicit contributions denied, suspended, or revoked by any governmental agency?
 - C. Entered into any legally enforceable agreement (such as a consent agreement, an assurance of voluntary compliance or discontinuance or any similar agreement) with any district attorney, Office of Attorney General, or other local or state governmental agency?

(If "Yes" is checked in response to any of the above, attach a written explanation, including the reasons for actions, and copies of all relevant documents.)

5

Page 5 of 6

Form BCO-10 (rev. 11/2023)

16520624 759649 397-0001

2023.04000 RETT SYNDROME RESEARCH TRUS 397-0001

Certification - This registration statement must be signed by two different officers of the organization, one of whom shall be the chief fiscal officer or the equivalent.

I certify that the information provided in this registration, including all statements and attached documentation, is true and correct to the best of my knowledge, information and belief. I understand that the falsification of any statement or documentation made is subject to the penalties of 18 Pa.C.S. §4904 (relating to unsworn falsification to authorities) and 10 P.S. §162.17 (relating to administrative enforcement and penalties).

| Signature of Chief Fiscal Officer Date | | | | |
|--|---|-----------------------|--|--|
| MONI | CA COENRAADS, CHIEF EXECUTIVE OFFICER | | | |
| Type or print name and title of Chief Fiscal Officer | | | | |
| <u></u> | | | | |
| Signatur | e of Other Authorized Officer | Date | | |
| Type or I | print name and title of Other Authorized Officer | | | |
| | | | | |
| Chec | klist for registration: | | | |
| | Completed registration statement properly signed and dated. | | | |
| | A copy of the IRS 990/990EZ/990PF/990N Return and required schedules, signed and dated by an authorized officer | | | |
| | Public Disclosure Form BCO-23 (if required) | | | |
| | Applicable Financial Statements (audited, reviewed, compiled or internally prepared) | | | |
| | Registration fee and any late filing fees | | | |
| | Initial Registrants Only: IRS determination letter, articles of incorport by-laws. | ration or charter and | | |
| See Instructions for more information on completing this form and attachments. | | | | |

375813 12-19-23

Form BCO-10 (rev. 11/2023)

16520624 759649 397-0001

_

PHONE NUMBER

| FORM BCO-10 | ALL PROFESSIONA | L SOLICITORS | STATEMENT | 1 |
|-------------|-----------------|--------------|-----------|---|
| | | | | |

NAME AND ADDRESS

N/A

CONTRACT BEGIN DATE CONTRACT END DATE SOLICIT DATE

| NAME AND ADDRESS N/A CONTRACT BEGIN DATE CONTRACT END DATE SERVICE DATE | NUMBER |
|---|--------|
| | |
| | |
| | |
| | |

| NAME AND ADDRESS | TITLE |
|--|---------------------------|
| NAME AND ADDRESS | |
| MONICA COENRAADS 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | CHIEF EXECUTIVE OFFICER |
| NAME AND ADDRESS | TITLE |
| TIMOTHY FREEMAN 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | CHIEF DEVELOPMENT OFFICER |
| NAME AND ADDRESS | TITLE |
| JANA VON HEHN 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | CHIEF SCIENTIFIC OFFICER |
| NAME AND ADDRESS | TITLE |
| RANDALL CARPENTER 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | CHIEF MEDICAL OFFICER |
| NAME AND ADDRESS | TITLE |
| ADRIAN BIRD 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | TRUSTEE |
| NAME AND ADDRESS | TITLE |
| ALBA TULL 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | TRUSTEE |

| NAME AND ADDRESS | TITLE |
|--|------------------------|
| BRAD ZELINGER 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | TRUSTEE |
| NAME AND ADDRESS | TITLE |
| BRIAN WHITMER 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | TRUSTEE |
| NAME AND ADDRESS | TITLE |
| HEIDI EPSTEIN 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | VICE CHAIRMAN |
| NAME AND ADDRESS | TITLE |
| INGRID HARDING 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | CO-FOUNDER AND TRUSTEE |
| NAME AND ADDRESS | TITLE |
| LAWRENCE MATTIS 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | SECRETARY |
| NAME AND ADDRESS | TITLE |
| MARC TESLER 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | TRUSTEE |
| NAME AND ADDRESS | TITLE |
| MARCI VALNER 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | TREASURER |
| NAME AND ADDRESS | TITLE |
| RACHAEL STEVENSON 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | TRUSTEE |
| NAME AND ADDRESS | TITLE |
| RACHEL ROTHSCHILD 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | TRUSTEE |

| NAME AND ADDRESS | TITLE |
|---|----------|
| STEPHANIE BOHN 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | TRUSTEE |
| NAME AND ADDRESS | TITLE |
| ANTHONY SCHOENER 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 | CHAIRMAN |

| Office Use Only: Fiscal Ye | Office | Use | Only: | Fiscal | Yea |
|----------------------------|--------|-----|-------|--------|-----|
|----------------------------|--------|-----|-------|--------|-----|

| OFFICE OF NON-PROFIT ORGANIZ ONE A | THE ATT ATIONS ASHBUR | OF MASSACHUSETTS FORNEY GENERAL /PUBLIC CHARITIES DIVISIO RTON PLACE CHUSETTS 02108 | | |
|--|--|---|--|------|
| | Form | n PC | | |
| Report for the Fiscal Period: $01/01/23$ to $12/31$ | Check all items attact (<i>if applicable</i>) Filing Fee or Prin | | | |
| AG Account #: 058530 Federal ID #: | Electronic Payme Confirmation | ent | | |
| Electronic Payment Confirmation #: Attach printout of electron | nic paymer | nt confirmation. | Copy of IRS Retu Audited Financia Statements/Revi | zl 🛛 |
| Electronic Payment Date: | | | Amended Article By-Laws | is/ |
| When did the organization first engage in charitable work in Massachusetts? $10/01/2015$ | | | Schedule A-1 Schedule A-2 Schedule RO Schedule RO | |
| Has the organization applied for or been granted IRS tax exempt status? | | X Yes No | Probate Account | t |
| If yes, date of application OR date of determination letter: | | 02/25/2008 | L | |
| IRS Exemption under 501(c): | | 3 | | |
| If exempt under 501(c), are contributions to the organization tax deductible as charitable contributions? | n | Yes X No | | |
| Organization Data | | | | |
| Name: RETT SYNDROME RESEARCH TRUST | , INC | | | |
| Mailing Address: 67 UNDER CLIFF ROAD | | | | |
| City: TRUMBULL | S ^r | tate: CT | ZIP: 06611 | |
| Phone Number: 203-445-0041 | | Fax Number: | | _ |
| Email: | | Website: WWW.RSRT.ORG | | |
| | | <u></u> | | |
| In the table below, please enter the appropriate codes from the c Enter up to 2 codes from Table 3 for your organization's main pu | - | ing tables found in the instructions. | | |
| Category | Code | Categor | / | Code |
| County (Table 1) | | Organization Purpose Code 1 | ; | 21 |
| Type of Organization (Table 2) | 8 | Organization Purpose Code 2 | | |
| Please check box if final return prior to dissolution: | | | | |

26-0687439

All questions must be completed in their entirety whether or not similar questions are answered in an attached federal form. See instructions and definition section for guidance.

1. On what date was the organization created? 08/09/2007

2. Where was the organization created? GEORGIA

3. What is the form of organization? (check one)

| Corporation | X | Testamentary Trust | |
|----------------------------|---|--------------------|--|
| Unincorporated Association | | Inter Vivos Trust | |

Other (please describe):

4. Was your organization related to any other organization(s) during the reporting year (see definition "Related Organization")? If yes, please complete the Schedule RO on pages 13 and 14.

5. Enter your summary of financial data:

| | Financial Data | Amounts |
|----|--|-------------|
| Α. | Contributions, gifts, grants, and similar amounts received | 8,080,684. |
| в. | Gross support and revenue | 8,520,722. |
| c. | Program services and similar amounts paid out | 11,396,540. |
| D. | Fundraising expenses | 749,615. |
| E. | Management and general expenses | 192,149. |
| F. | Payments to affiliates | 0. |
| G. | Total expenses | 12,338,304. |
| н. | Net assets or fund balances at the end of the year | 7,135,812. |

6. List the total compensation you provided to your five highest paid employees:

| | Name/Title | Hrs/ Week | Salary and Other Income | Benefit Plans | Other Compensation |
|----|------------|--------------|----------------------------|---------------|-----------------------|
| 1. | NONE | | | | |
| 2. | | | | | |
| 3. | | | | | |
| 4. | | | | | |
| 5. | | | | | |

7. Was any compensation provided to any of the individuals listed in question 6 above not quantified in your response to 6? If yes, please provide explanation (attach separate sheet).

26-0687439

8. List the name, amount of compensation paid, and the nature of services rendered by each of the organization's five highest paid consultants providing professional services (e.g. attorneys, architects, accountants, management companies, investment advisors, professional solicitors, professional fundraising counsel).

| | Name/Title | Amount of Compensation | Type(s) of Service |
|----|------------|------------------------|--------------------|
| 1. | NONE | | |
| 2. | | | |
| 3. | | | |
| 4. | | | |
| 5. | | | |

9. Bank(s) in which the organization's funds are deposited (include bank addresses and phone number):

| | Bank | Address | | Phone Number |
|-----|--|--|--------|--------------|
| | | | | |
| | | | | |
| | | | | |
| 10. | What is the organization's accounting method? | Cash X Accrual | | |
| | | Other (specify): | | |
| 11. | If organization's mailing address is a P.O. Box, lis | t the organization's full street address | : | |
| | Address: | | | |
| | City: | | State: | ZIP Code: |
| 12. | Contact Person Name: | | | |
| | Street Address: | | | |
| | City: | | State: | ZIP Code: |
| | Phone Number: | | | |

- 13. During the fiscal year reported here, did your organization solicit contributions or have funds solicited on its behalf?
- 14. At any time during the fiscal year following the year reported here, will your organization, or others acting on its behalf, solicit contributions? Yes X No If you answered yes to Question 13 or 14, you must complete Schedule A-1 and/or Schedule A-2 unless you are exempt from the solicitation certificate regularement.
- 15. If you are claiming an exemption from the solicitation certificate requirement, please indicate by checking the box below to identify which exemption applies to your organization.

| a religious organization | |
|--|--|
| an organization which: (a) does not raise more than \$5,000 during a calendar year OR does not receive contributions from | |
| more than ten persons during a calendar year; AND (b) carries out all of its activities, including fundraising, through unpaid | |
| volunteers. (The conditions at both (a) and (b) must be met for your organization to qualify for this exemption.) | |

- 16. Attach a list of names, addresses (street and/or mailing), and telephone numbers of other offices/chapters/branches/affiliates.
- 17. Attach a list of names, titles, and addresses (street and/or mailing) of officers, directors, trustees, and the principal salaried executives of organization.

STATEMENT 1

- 18. Attach a list of names, titles, and addresses (street and/or mailing) of any individual(s) authorized to sign checks, and any individual(s) responsible for: custody of funds; distribution of funds; fundraising; and custody of financial records.
- 19. Has this organization or any of its officers, directors, employees or fundraisers solicited funds in any other state?

If yes attach list of states where solicitation was conducted, including registered agency, dates of registration, registration numbers, any other names under which the organization was/is registered, and the dates and type (mail, telephone, door to door, special events, etc.) of the solicitation conducted.

Page 4 of 15

26-0687439

Yes X No

Yes 🗶 No

| 20. | | RETT SYNDROME RESEARCH TRUST, INC 26-0687439 this organization or any of its officers, directors, or employees: 5, please attach an explanation. | | |
|-----|------|--|-----|------|
| | (a) | Been enjoined or otherwise prohibited by a government agency/court from operating or soliciting contributions? | Yes | X No |
| | (b) | Ever been refused registration or had its registration or tax exemption denied, suspended, modified or revoked by a governmental agency? | Yes | X No |
| | (c) | Been the subject of a proceeding regarding any solicitation or registration? | Yes | X No |
| | (d) | Entered into a voluntary agreement of compliance or consent judgment with, any government agency or in a case before a court or administrative agency? | Yes | X No |
| 21. | | e any restrictions been removed during the year from donor-restricted funds? s, please attach an explanation. | Yes | X No |
| 22. | | e donor-restricted funds been loaned to unrestricted funds? s, please attach an explanation. | Yes | X No |
| 23. | Part | question involves "Termination of Employment or Changes of Control Compensatory Arrangements" with certain "Re ies" (see <i>instructions and definition sections</i>). Report only if payments made or promised to any individual are in exces our months salary or \$100,000, whichever dollar amount is less. | | |
| | (a) | Did you make actual payments or otherwise transfer value under such an arrangement to any individual described in Related Party definition, sections (a) or (b), which payments are not reported in Question 6 or 7 above? | Yes | X No |
| | (b) | Do you have such an agreement with any individual described in Related Party definition, sections (a) or (b)? | Yes | X No |

If you answered yes for Question 23(a) or 23(b) above, please attach an explanation identifying the individual(s) involved, stating the amount of any payments made or value transferred, and describing the terms of each agreement.

26-0687439

24. This question applies to related party transactions, which include transactions with officers, directors, trustees, certain employees, relatives, and organizations they own or control. Please consult the instructions and definition sections for the definition of a "Related Party" and "Indebtedness" before answering. Note that transactions involving related parties must be reported even when there is no accounting recognition (e.g. in-kind gifts, waiver or interest not otherwise reported).

If the answer to any part of Question 24 is **yes**, attach a schedule stating the name and address of the related party, the nature of the transaction, the value or the amounts involved in the transaction, and the procedure followed in authorizing the transaction.

| | During the year: | | |
|----------|--|------|------|
| A. | Has your organization sold or transferred assets to or purchased assets from or exchanged assets with a related party? | Yes | X No |
| в. | Has your organization leased assets to or leased assets from a related party? | Yes_ | X No |
| c. | Has your organization been indebted to a related party? | Yes | X No |
| D. | Has your organization allowed a related party to be indebted to it? | Yes_ | X No |
| Е. | Has your organization made or held an investment in a related party? | Yes_ | X No |
| F. | Has your organization furnished goods, services, or facilities to a related party? | Yes | X No |
| G. | Has your organization acquired goods, services, or facilities from a related party who received compensation or other value in return? | Yes | X No |
| н. | Has your organization paid or become obligated to pay wages, salary, or other compensation to a related party? | Yes | X No |
| <u> </u> | Has your organization transferred income or assets to or for use by a related party? | Yes_ | X No |
| J. | Was your organization a party to any transaction in which any of its officers, directors, or trustees has a material financial interest, or did any officer, director or trustee receive anything of value not reported as compensation? | Yes | X No |
| к. | Has your organization invested in any corporate stock of a company in which any officer, director, or trustee owns more than 10% of the outstanding shares? | Yes | X No |
| L. | Is any property of the organization held in the name of or commingled with the property of any other person or organization? | Yes | X No |
| м. | Did your organization make a grant award or contribution to any other organization in which any of this organization's officers, directors or trustees has a relationship? | Yes | X No |

| Signature Required | | | | |
|--|----------------------|--------------------|--|--|
| Under penalty of perjury, I declare that the information furnished in this report, in correct to the best of my knowledge. | ncluding all attachn | nents, is true and | | |
| Signature: | . | Date: | | |
| Printed Name: MONICA COENRAADS | | | | |
| Title: CHIEF EXECUTIVE OFFICER | | | | |
| Name of Preparer: ROLLERI & SHEPPARD CPAS, LLP | | | | |
| Address 2150 POST ROAD, 5TH FL | | | | |
| City FAIRFIELD | State <u>CT</u> | ZIP Code 06824 | | |
| Phone Number (203) 259-2727 | | | | |
| | | | | |

26-0687439

Schedule A-1

A-1

Solicitation Activities During Fiscal Year Covered By This Report

List any names which will be used by the organization in connection with the solicitation of funds, other than the official name which appears on page 1.

Types of solicitation activities in which you expect to engage (check all that apply):

RETT SYNDROME RESEARCH TRUST, INC

| Mass Mailing | Via the Internet | |
|--|---------------------------------------|--|
| Door-to-door | Raffle, beano, bingo or gaming event | |
| Entertainment event | Sale of goods other than by telephone | |
| Telemarketing without sale of goods or ads | Individual Mailings | |
| Telemarketing with sale of goods | Corporate solicitations | |
| Telemarketing with sale of ads | Grant Proposals | |
| Other (enceifil): | | |

_ Other (specify): ____

.

Identify the method or methods you expect to use for the fundraising (check all that apply):

| Professional solicitor* | Own employees | |
|-----------------------------------|---------------|--|
| Professional fundraising counsel* | Volunteers | |
| Commercial co-venturer* | | |

* Provide applicable names and addresses:

| Professional Solicitor Name: | | | |
|--|-------|----------|--|
| Address | | | |
| City | | ZIP Code | |
| Professional Fundraising Counsel Name: | | | |
| Address | | | |
| City | | | |
| Commercial Co-Venturer Name: | | | |
| Address | | | |
| City | State | ZIP Code | |

Solicitation Activities During Fiscal Year Covered By This Report

Identify the individuals who will have final responsibility for the charity's custody of contributions:

| | Name and Title: | | |
|-------|--|-------|----------|
| | Address | | |
| | City | State | ZIP Code |
| | Name and Title: | | |
| | Name and Title: | | |
| | Address | | |
| | City | State | ZIP Code |
| | Name and Title: | | |
| | Address | | |
| | City | | |
| ident | ify the individuals who will have final responsibility for the charity's distrib | | |
| | Name and Title: | | |
| | Address | | |
| | City | | |
| | | | |
| | Name and Title: | | |
| | Address | | |
| | City | State | ZIP Code |
| | | | |
| | Name and Title: | | |
| | Address | | |
| | City | State | ZIP Code |

26-0687439

Schedule A-2 Solicitation Activities Planned for Fiscal Year Which Follows the Reporting Year

List any names which will be used by the organization in connection with the solicitation of funds, other than the official name which appears on page 1.

Types of solicitation activities in which you expect to engage (check all that apply):

| Mass Mailing | Via the Internet | |
|--|---------------------------------------|--|
| Door-to-door | Raffle, beano, bingo or gaming event | |
| Entertainment event | Sale of goods other than by telephone | |
| Telemarketing without sale of goods or ads | Individual Mailings | |
| Telemarketing with sale of goods | Corporate solicitations | |
| Telemarketing with sale of ads | Grant Proposals | |
| Other (enceited) | | |

__ Other (specify): ____

.

Identify the method or methods you expect to use for the fundraising (check all that apply):

| Professional solicitor* | Own employees | |
|-----------------------------------|---------------|--|
| Professional fundraising counsel* | Volunteers | |
| Commercial co-venturer* | | |

* Provide applicable names and addresses:

| Professional Solicitor Name: | | | ·· |
|--|-------|----------|----|
| Address | | | |
| City | State | ZIP Code | |
| Professional Fundraising Counsel Name: | | | |
| Address | | | |
| City | State | ZIP Code | |
| Commercial Co-Venturer Name: | | | |
| Address | | | |
| City | State | ZIP Code | |

Schedule A-2 ctd.

Solicitation Activities Planned for Fiscal Year Which Follows the Reporting Year

Identify the individuals who will have final responsibility for the charity's custody of contributions:

| | Name and Title: | | |
|--------|---|--------------------------|----------|
| | Address | | |
| | City | State | ZIP Code |
| | Name and Title: | | |
| | Address | | |
| | City | State | ZIP Code |
| | Name and Title: | | |
| | Address | | |
| | City | | ZIP Code |
| Identi | fy the individuals who will have final responsibility for the charity's distrib | pution of contributions: | |
| | Name and Title: | | |
| | Address | | |
| | City | State | ZIP Code |
| | Name and Title: | | |
| | Address | | |
| | City | State | ZIP Code |
| | Name and Title: | | |
| | Address | | |
| | City | State | ZIP Code |

Certification by Organization

Two different signatures required. Signers must be organization president or other authorized officer or trustee.

Under penalty of perjury, we declare that the information furnished in this report, including all attachments, is true and correct to the best of our knowledge.

| Signature: | Date: |
|--------------------------------|---------|
| Printed Name: MONICA COENRAADS | |
| Title: CHIEF EXECUTIVE OFFICER | |
| | |
| Signature: | _ Date: |
| Printed Name: | |
| Title: | |

Schedule RO

1. Please read the instructions and definition of "Related Organization" carefully before completing this section. (If you have more than five Related Organizations, please attach a list.)

| Name: | | Primary purpose or activity: | | |
|-------|--|---|--|--------------------------------|
| FYE | A. Donor restricted funds (·) liabilities | B. 3rd party restricted funds C. Unrestricted funds | | D. Total net assets (A+B+C) |

| Name: | | Primary purpose or activity: | | | |
|-------|---------------------------|-------------------------------|-----------------------|---------------------|--|
| FYE | A. Donor restricted funds | B. 3rd party restricted funds | C. Unrestricted funds | D. Total net assets | |
| | (·) liabilities | (·) liabilities | (·) liabilities | (A+B+C) | |

| Name: | | Primary purpose or activity: | | | |
|-------|---------------------------|-------------------------------|-----------------------|---------------------|--|
| FYE | A. Donor restricted funds | B. 3rd party restricted funds | C. Unrestricted funds | D. Total net assets | |
| | (·) liabilities | (·) liabilities | (-) liabilities | (A+B+C) | |

| Name: | | Primary purpose or activity: | | |
|-------|---------------------------|-------------------------------|-----------------------|---------------------|
| FYE | A. Donor restricted funds | B. 3rd party restricted funds | C. Unrestricted funds | D. Total net assets |
| | (·) liabilities | (·) liabilities | (·) liabilities | (A+B+C) |

| Name: | | Primary purpose or activity: | | | |
|-------|---------------------------|-------------------------------|-----------------------|---------------------|--|
| FYE | A. Donor restricted funds | B. 3rd party restricted funds | C. Unrestricted funds | D. Total net assets | |
| | (·) liabilities | (·) liabilities | (•) liabilities | (A+B+C) | |

Schedule RO ctd.

2. List the total compensation paid by your organization and/or any other related organization to your chief executive (e.g., executive director) and to the four other current or former directors, trustees, officers, or employees within the system of related organizations identified at question 1, on page 13, receiving the highest aggregate compensation (see *instructions*). Use additional lines below to itemize by compensation source.

| Name: | | Title: | | |
|---|--|-----------------------------------|--|--|
| Income Source: Salary and Other Income: | | Benefits Plan: Other Compensation | | |
| | | | | |
| | | | | |

| Name: | | Title: | | |
|----------------|--------------------------|----------------|--------------------|--|
| Income Source: | Salary and Other Income: | Benefits Plan: | Other Compensation | |
| | | | | |
| | | | | |

| Name: | | Title: | | |
|---|--|----------------|--------------------|--|
| Income Source: Salary and Other Income: | | Benefits Plan: | Other Compensation | |
| | | | | |
| | | | | |

| Name: | | Title: | | | |
|---|--|-----------------------------------|--|--|--|
| Income Source: Salary and Other Income: | | Benefits Plan: Other Compensation | | | |
| | | | | | |
| | | | | | |

| Name: | | Title: | | | |
|---|--|-----------------------------------|--|--|--|
| Income Source: Salary and Other Income: | | Benefits Plan: Other Compensation | | | |
| | | | | | |
| | | | | | |

| З. | Is asset and/or compensation information for religious organizations and/or certain non-charitable entities related to | |
|----|--|--|
| | foundations excluded pursuant to instructions? | |

X No

Yes

Schedule VCO Application for Designation As Veterans' Charitable Organization PLEASE NOTE THAT ORGANIZATIONS DESIGNATED AS VETERANS' CHARITABLE ORGANIZATIONS ("VCOs") MAY NOT RETAIN PAID FUNDRAISERS

| Schedule VCO is an application for designation as a veterans' charitable organization. Schedule VCO may be submitted by |
|---|
| certain charitable organizations. To determine whether your organization is eligible to be designated as a VCO, and thus may file |
| a schedule VCO, please answer questions 1 and 2, below. |

| 1. | Was your organization established for an advocacy, benevolent, educational, humane, patriotic, philanthropic, scientific or social welfare purpose on behalf of veterans or the military? | Yes | X No |
|----|---|-----|------|
| 2. | Does your organization intend to solicit contributions from persons within the commonwealth itself or to have contributions solicited on its behalf only by other charitable organizations? | Yes | X No |

ORGANIZATIONS THAT ANSWER "NO" TO EITHER QUESTION MAY NOT SUBMIT A SCHEDULE VCO. ORGANIZATIONS THAT ANSWER "YES" TO BOTH QUESTIONS MAY CONTINUE AND SUBMIT A SCHEDULE VCO.

Identify your organization's purpose, as recorded in its by-laws, articles of organization, agreement of association, or instrument of trust, or otherwise in its written statement of purpose.

Provide the charitable purposes for which solicited contributions shall be used.

IMPORTANT INFORMATION, PLEASE READ

- VCO designation is valid for three (3) years.
- By applying for this designation, this organization agrees that its retention of a paid fundraiser while it is designated as a VCO will operate to forfeit its VCO status.
- An organization designated as a VCO must still comply with annual filing requirements pursuant to G.L. c. 12, §8F and G.L. c. 68, §19; however, otherwise applicable fees for those filings will be waived for designated VCOs.
- Organizations designated as VCOs that fail to comply with annual filing requirements pursuant to G.L. c. 12, §8F and G.L. c. 68, §19 may not solicit contributions from persons within the commonwealth.

| Signature: | | | | | Date: | | |
|---------------|--------|-----------|--|------|-------|--|--|
| _ | | | | | | | |
| Printed Name: | MONICA | COENRAADS | | | | | |

| FORM PC | OFFICERS, | DIRECTORS, | TRUSTEES | AND EXECUTIVES | STATEMENT | 1 |
|--|-----------|------------|----------|----------------|-----------|---|
| NAME AND ADDRES | S | | | TITLE | | |
| MONICA COENRAAD 67 UNDER CLIFF TRUMBULL, CT 0 | ROAD | | | CHIEF EXECUTIV | E OFFICER | |
| ADRIAN BIRD 67 UNDER CLIFF 1 TRUMBULL, CT 0 | | | | TRUSTEE | | |
| ALBA TULL 67 UNDER CLIFF 1 TRUMBULL, CT 00 | | | | TRUSTEE | | |
| BRAD ZELINGER 67 UNDER CLIFF I TRUMBULL, CT 00 | | | | TRUSTEE | | |
| BRIAN WHITMER 67 UNDER CLIFF I TRUMBULL, CT 00 | | | | TRUSTEE | | |
| HEIDI EPSTEIN 67 UNDER CLIFF 1 TRUMBULL, CT 00 | | | | VICE CHAIRMAN | | |
| INGRID HARDING 67 UNDER CLIFF 1 TRUMBULL, CT 00 | | | | CO-FOUNDER AND | TRUSTEE | |
| LAWRENCE MATTIS 67 UNDER CLIFF 1 TRUMBULL, CT 00 | | | | SECRETARY | | |
| MARC TESLER 67 UNDER CLIFF I TRUMBULL, CT 00 | | | | TRUSTEE | | |
| MARCI VALNER 67 UNDER CLIFF I TRUMBULL, CT 00 | | | | TREASURER | | |
| RACHAEL STEVENS 67 UNDER CLIFF I TRUMBULL, CT 00 | ROAD | | | TRUSTEE | | |
| RACHEL ROTHSCHI 67 UNDER CLIFF 1 TRUMBULL, CT 00 | ROAD | | | TRUSTEE | | |

STEPHANIE BOHN 67 UNDER CLIFF ROAD TRUMBULL, CT 06611 TRUSTEE

ANTHONY SCHOENER 67 UNDER CLIFF ROAD TRUMBULL, CT 06611

.

,

CHAIRMAN

RETURN MUST BE FILED ONLINE. This form cannot be paper filed - this copy is for informational purposes only.

Form CRI-200 Short-Form Registration/Verification Statement

(Revised April 2008)

All questions must be answered.

Charitable organizations, domiciled or doing business in the State of New Jersey, which receive gross contributions of \$25,000 or less per year, are required to submit an initial registration and to renew registration annually. In both circumstances this form may be used. In the event an organization receives gross contributions of less than \$10,000 per year and does not compensate anyone to solicit or perform fund-raising activities on its behalf, the organization is exempt from registration, but may still choose to register. The registration fee for charities with gross contributions between \$0 and \$25,000 is \$30, whether the fee is for an initial or renewal registration. Payment is to be made by check or money order, made payable to the "New Jersey Division of Consumer Affairs," and is due at the time of submission of the form.

| 1a. | This statement is an Initial Initial Renewal Registration (check one only.) | | | | | | |
|-----|--|--|--|--|--|--|--|
| 1b. | This statement contains the facts and financial information for the fiscal year ending: $\frac{12/31/2023}{\text{month day year}}$ | | | | | | |
| 2. | Federal ID Number (EIN) 26-0687439 2a. N.J. Charities Registration Number: CH- 3077500 | | | | | | |
| 3. | (Leave blank ONLY if this is an initial registration., Full legal name of the registering organization: | | | | | | |
| 4. | Mailing Address: 67 Under Cliff Road, Trumbull, CT 06611 Change of Address | | | | | | |
| NO | Street Address City State ZIP Code NOTE: If "in care of," a postal, private or rural delivery mail box number is used, the street address of the charity must be given below. | | | | | | |
| 5. | The principal street address of the registering organization Street Address City State ZIP Code | | | | | | |
| 6. | Does the organization have any offices in New Jersey in addition to the one listed above? Yes X No If "Yes," attach a list giving the street address and telephone number of each office in New Jersey. Yes X No | | | | | | |
| 6a. | If the street address listed above is not where the organization's official records are kept, or if the organization does not maintain an office in New Jersey, indicate the name, full address, phone and fax number of the person having custody of the organization's records, and to whom correspondence should be addressed. Monica Coenraads 67 Under Cliff Road Trumbull, CT 06611 | | | | | | |
| | Contact person Street address City State ZIP Code | | | | | | |
| | 203-445-0041 Telephone number (include area code) Fax number (include area code) | | | | | | |
| 7. | Organization's contact information: 203-445-0041 | | | | | | |
| | Telephone number (include area code) Fax number (include area code) | | | | | | |
| | E-mail address Www.RSRT.org | | | | | | |

| 8. | The | organization is eligible to file a Short Form Registration because: |
|-------|-------|--|
| | a) | It did not receive gross contributions in excess of \$25,000 in the preceding fiscal year, AND all of the organization's functions, including fund-raising, are conducted by volunteers, members, officers or persons who are not compensated for soliciting contributions. |
| | b) | It is a fraternal, patriotic, social or alumni organization, historical society or similar organization organized under the provisions of Title 15 |
| | 0) | of the New Jersey Revised Statutes or Title 15A of the New Jersey Statutes, AND solicitation of contributions is confined to the |
| | | organization's membership and performed by members of the organization. |
| | | |
| | c) | It solicits on behalf of a specified individual, and all contributions, without any deductions whatsoever, will be turned over to this beneficiary. |
| | d) | It is a local post, camp, chapter or similarly designated element or county unit, of a bona fide veterans' organization which issues charters to the local elements throughout New Jersey or to any veterans' organization chartered under federal law or a service foundation of such |
| | | an organization recognized in the organization's by-laws. |
| | e) | It is a private foundation that raised less than \$25,000 in public contributions. |
| not e | ligit | uestion 8: If after reviewing the answers to questions 8a through 8e, none of the statements can be answered "Yes," the charity is le to use the Short-Form CRI-200 and instead must use the Long-Form Initial Registration Statement CRI-150-I or the Long-Form Statement CRI-300R. |
| 9. | Hav | ve there been changes in the organization's name, address, Internal Revenue Service (I.R.S.) status, etc. since the date of your last reporting? |
| | lf "` | Yes," please provide the details on a separate sheet of paper, and provide copies of the documentary proof of a name change (example: |
| | | endment to incorporation) and/or a copy of the letter of determination from the I.R.S. regarding the tax-exempt-status changes. |
| | | |
| 9a. | ls t | ne organization a chapter or local unit of a parent organization? |
| | | Yes, " write in the full name, address and phone number (include the area code) of the parent organization. Please do not use abbreviations. |
| | | |
| | | |
| 10. | Pur | pose for which the organization was created (write in or attach a statement to this registration): |
| | | E IRS FORM 990, PAGE 2. |
| | | |
| 10a. | | es the organization solicit or intend to solicit contributions from the general public in the State of New Jersey (including through the sale of rchandise)? INO |
| | lf "` | Yes," explain the purpose for which solicited funds are being raised (write in or attach a statement to this registration): |
| | S | olicited funds are for the development of treatments and cures for Rett Syndrome. |
| | | |
| 10b. | Doe | es the organization solicit funds under any other name(s)? Yes X No |
| | lf "` | Yes," please attach to this registration a list of all other names used: |
| | | |
| 11. | Doe | es the organization register or solicit in other states? |
| | lf "` | Yes," please indicate other states here or, if necessary, attach to this registration a list of those states. CA, CT, IL, MA, MD, NJ, NY, PA |
| | | |
| 11a. | Has | the organization ever been enjoined in any jurisdiction from soliciting contributions or has it been found to have engaged in unlawful |
| | pra | ctices in the solicitation of contributions or the administration of charitable assets? |
| | lf "` | Yes," list the jurisdiction and attach copies of all the relevant documents. |
| | | |
| 11b. | Has | s the organization's charity registration been denied, suspended or revoked by any jurisdiction or state? Yes X No |
| | | |
| 11c. | Has | s the organization voluntarily entered into an assurance of voluntary compliance agreement or any similar order or legal agreement with |
| | | jurisdiction, state or federal agency or officer? |
| | | |

| 12. | If the answer to 11a, 11b or 11c is "Yes," please attach to this registration a statement that provides the details of the action, together with the reason(s) for that denial, suspension, revocation, injunction, compliance agreement etc., including the state or jurisdiction involved, the dates and full copies of all related documents. |
|-------|---|
| | Indicate the attachment of documents to this Registration/Verification Statement by checking this box: |
| 13. | Is the organization currently I.R.S. tax-exempt? X Yes No If "Yes," under which section of the code? $501(c)(3)$ |
| 14. | Has the organization's tax-exempt status been revoked, changed, or refused by the I.R.S.? Yes X No If "Yes," please attach to this registration a statement providing an explanation, including all of the facts, dates, and all letters and notices received from the I.R.S. |
| 15. | Has the organization used an independent paid fund-raiser, fund-raising counsel or commercial co-venturer? Yes X No If "Yes," for what purpose(s) are funds being raised? |
| 15a. | If the answer to question 15 is "Yes," write in or provide a separate listing of the name(s) of all independent paid fund-raiser(s), fund-raising counsel and/or commercial co-venturer(s): |
| 16. | Provide on a separate sheet of paper the name, title, street address, telephone number and salary of each officer, director and trustee, and the five most-highly compensated employees in the organization. Indicate the attachment of documents to this Registration/Verification Statement by checking this box: |
| 16a. | Has any person listed in the response to question 16 been adjudged liable in any administrative or civil action, or been convicted in a criminal action involving theft, fraud or deceptive business practices? Yes No If the response is "Yes," please provide all of the details on a separate sheet and also attach to this registration a copy of the order, judgment or other document(s) indicating final disposition of the matter. |
| deen | se note: For the purpose of question 16a, a plea of guilty, non vult, nolo contendere or any similar disposition of the alleged activity shall be ned a conviction. A judgment of liability in an administrative or civil action would include a finding or admission that the individual engaged in nlawful practice relating to the solicitation of contributions or the administration of charitable assets. |
| may | nderstand that this registration is being issued at the discretion of the Division of Consumer Affairs and agree that employees of the Division inspect the records in the possession of this organization in order to ascertain compliance with the statute and all pertinent regulations. We understand that we may be required to provide additional information if requested. |
| | ereby certify that the above information and the attached financial schedule(s) and statement(s) are true. We are aware that if any of the e statements are willfully false, we are subject to punishment. |
| Signa | ature Name Title Date |
| Signa | ature Name Title Date |
| | This form must be signed by two (2) authorized officers of the organization, including the chief financial officer. |

CRI-200 Short-Form Registration Verification Financial Statement

Note: If the financial value of a line item = 0, place a zero in the space provided. Please report all figures as GROSS, not NET.

| Full legal name and street address of the organization | | | | | | | | |
|---|---|------|-------|-----------------|--|--|--|--|
| Full legal name: | | | | | | | | |
| Fiscal year-end being reported: | Fiscal year-end being reported: Federal ID Number (EIN) | | | | | | | |
| Mailing address: | | | | | | | | |
| Mailing Address | P.O. Box Number or Suite | City | State | ZIP Code | | | | |
| Street address of the registering organiz | Street address of the registering organization: | | | | | | | |
| Street Address City State ZIP Code New Jersey Charities Registration number: CH 00 Telephone number: | | | | | | | | |
| | | | (inc | lude area code) | | | | |

A. Revenue

| | Line A1. | | butions & Donations: Includes but is not limited to individual and corporate receipts from fundraising: | contributions, donations, legacies, bequests and |
|------|-----------|--------------|---|--|
| | | A1a. | Direct Public Support | |
| | | A1b. | Indirect Public Support (including donations from other charities) | |
| | | A1c. | Gross Contributions (add lines 1a and 1b) | |
| | Line A2. | Gover | nment Grants | |
| | Line A3. | Other | Income | |
| | | АЗа. | Membership dues and assessments | |
| | | A3b. | Interest and dividends | |
| | | A3c. | Program service revenue | |
| | | A3d. | Gain from sale of assets | |
| | | A3e. | Other income (please specify on a separate statement): | |
| | | A3f. | Donations from founder(s) of private foundation | |
| | | A3g. | Total other income | |
| | Line A4. | <u>Total</u> | Gross Revenue (add lines A1c, A2 and A3g) | |
| B. I | Expenses | | | |
| | Line B1. | Progra | am | |
| | Line B2. | | gement, office and general expenses | |
| | Line B3. | | raising expenses | |
| | Line B4. | | ents to state/national affiliates (if applicable) | |
| | Line B5. | <u>Total</u> | Expenses (add lines B1, B2, B3 and B4) | |
| C. I | Excess or | Defic | sit | |

Line C1. Excess or deficit for the year-end noted above (subtract line B5 from A4):

Please Note: The amount of Gross Contributions (line A1c on this form) determines the registration fee which must be paid and the form which should be used. July 2006 revisions to the Charities Registration Act now require all charities to pay a registration fee, including charities whose Gross Contributions are less than \$10,000. Further information for charity registrants may be found on our Web site: http://www.njconsumeraffairs.gov/ocp/charities.htm

RETURN MUST BE FILED ONLINE. This form cannot be paper filed - this copy is for informational purposes only.

Form CRI-300R Long-Form Renewal Registration/Verification Statement

(Revised April 2008)

All questions must be answered.

 Pursuant to the New Jersey Charitable Registration and Investigation Act (also known as "the C.R.I. Act" (N.J.S.A. 45:17A-18 et seq.), and prior to operating or commencing solicitation activity in the State, a charitable organization unless exempted from registration requirements (or qualified to file a Short-Form Registration Statement, CRI-200) shall file a Long-Form Initial Registration Statement, CRI-150-I. Charities submitting their annual long-form renewal registration must use Form CRI-300R. Please see the checklist at the end of this form for a discussion of fees, financial statements, documents to be attached, and other requirements for registration.

 1. This statement contains the facts and financial information for the fiscal year ending:

 <u>12/31/2023</u> <u>month day year</u>
 2a. N.J. Charities Registration Number: CH- <u>3077500</u>

| 3. | Full legal name of the registering organization: | Rett Syndrome Research Trust, Inc. |
|----|---|------------------------------------|
| | In care of: (if necessary, otherwise leave this line bl | ank) |

4. Mailing Address: 67 Under Cliff Road, Trumbull, CT 06611

NOTE: If "in care of," a postal, private or rural delivery mail box number is used, the street address of the charity must be given below.

| 5. | The principal street address of the registering organization | | | | |
|----|--|----------------|------|-----------|--------|
| | X Same as Mailing Address | Street Address | City | State ZIF | P Code |

Does the organization have any offices in New Jersey in addition to the one listed above?
 If "Yes," attach a list giving the street address and telephone number of each office in New Jersey.

6a. If the street address listed above is not where the organization's official records are kept, or if the organization does not maintain an office in New Jersey, indicate the name, full address, phone and fax number of the person having custody of the organization's records, and to whom correspondence should be addressed.

| | Monica Coenraads | 67 Un | der Cliff Rd Street address | <u>Trumbull</u> | CT 06611 State ZIP Code | e |
|----|--|------------------|--------------------------------|--------------------------------|----------------------------|---|
| | 203-445-0041 Telephone number (include area code | ə) | Fax number (include area cod | (e) | | |
| 7. | Organization's contact information: 203-445-0041 Telephone number (include area code | e) | | Fax number (include area code) | | |
| | E-mail a | ddress | www | RSRT.org | ite | |
| | | luciess | | Web S | ile - | |
| 8. | Type of organization (check one): | | | | | |
| | X Nonprofit corporation | Foundation Trust | Individual Other (Specify) | Association | Society | |
| | | | | | | |
| | | | | | | |

State

Change of Address

X No

Yes

| 9. | 9. Where and when was the organization legally established? Date: $08/09$ | /2007 | State: | GA | | | |
|------|--|---------------------|---------------|----------------------------|----------------------|--|--|
| | As required by the C.R.I. Act (N.J.S.A. 45:17A-24c(1)), attach to this registration a copy of the organization's bylaws and instrument of organization (that is, the organization's charter, articles of incorporation or organization, agreement of association, instrument of trust, or constitution) only if the document has been issued or amended during the fiscal year being reported. | | | | | | |
| 10. | 10. Does the organization solicit funds under any name or names other than as indicated on I If "Yes," indicate all of the other names used: | ine 3 of this form | ? | Yes | X No | | |
| 11. | 11. Does the organization intend to solicit contributions from the general public? | | | X Yes | No No | | |
| 12. | 12. Is the organization authorized by any other state or jurisdiction to solicit contributions? If "Yes," please provide a list of those states or jurisdictions, below or on a separate sheet <u>CA, CT, IL, MA, MD, NJ, NY, PA</u> . | t of paper. | | X Yes | No | | |
| 13. | Does the organization have affiliates which share the contributions or other revenue it rais If "Yes," provide a separate listing of those affiliates indicating the name, street address a | | | Yes Ach one. | X No | | |
| 14. | 14. What is the charitable purpose or purposes for which the organization was formed? If nec registration. <u>SEE IRS FORM 990, PAGE 2.</u> | cessary, attach a | separate s | tatement to th | is | | |
| | | | | | | | |
| | | | | | | | |
| 14a. | 14a. What are the specific programs and charitable purposes for which contributions are used is planned. Only major program categories need be listed. If necessary, attach a separate <u>ALREADY EXISTS-SEE IRS FORM 990, PAGE 2.</u> | | | | dy exists or | | |
| 15. | 15. Does the organization use an independent paid fund-raiser or fund-raising counsel? If "Yes," please attach to this registration a list of paid fund-raiser(s) or fund-raising counse number, registration number in New Jersey, and a contact person's name. | el(s), including th | eir full addı | Yes ress, telephone | X No Nomber, fax | | |
| 15a. | 15a. Does the independent paid fund-raiser or fund-raising counsel have custody, control or ac If "Yes," please describe the situation. | ccess to the orga | nization's f | unds? | X No | | |
| 16. | 16. Has the organization permitted a charitable sales promotion to be conducted on its behale end being reported? If "Yes," please explain: | f by a commercia | al co-ventur | rer during the f | iscal year- X No | | |
| 17. | 17. Has the Internal Revenue Service (I.R.S.) determined that the organization is tax exempt u a. If "No," has an application been filed which is still pending? If so, please attach a copy I.R.S. 1023 form filed. b. Has a tax exemption been granted under another I.R.S. code? If "Yes," advise which one: C. Has an I.R.S. tax exemption been refused, changed or revoked? | y of the | | X Yes Yes Yes Yes | No No No No | | |
| | If an exemption has been refused, changed or revoked, attach to this registration a co and provide a detailed explanation of the circumstances on a separate sheet of paper | | Jerenningli | | meanon | | |

| 18. | Has the organization ever had its authority to conduct charitable activities denied, suspended, or revoked in any jurisdiction or has the organization ever entered into any voluntary agreement of discontinuance with any governmental entity? Yes X No If "Yes," attach to this registration a copy of the denial, suspension, revocation or voluntary agreement of discontinuance. If the document does not explain the reasons for the denial, suspension or revocation, attach to this registration on a separate sheet of paper. |
|-----|--|
| 19. | Has the organization voluntarily entered into an assurance of voluntary compliance or similar order or agreement (including, but not limited to, a settlement of an administrative investigation or proceeding, with or without an admission of liability) with any jurisdiction, state or federal agency or officer? Yes X No If "Yes," please attach to this registration the relevant document. |
| 20. | Has the organization or any of its present officers, directors, executive personnel or trustees ever been found to have engaged in unlawful practices in the solicitation of contributions or administration of charitable assets or been enjoined from soliciting contributions, or are such proceedings pending in this or any other jurisdiction? Yes X No If "Yes," attach to this registration photocopies of any and all written documentation (such as a court order, administrative order, judgment, formal notice, written assurance or other document) which show the final disposition of the matter. |
| 21. | Has the organization or any of its present officers, directors, trustees or principal salaried executive staff employees ever been convicted of any criminal offense committed in connection with the performance of activities regulated under this act or any criminal or civil offense involving untruthfulness or dishonesty or any criminal offense relating adversely to the registrant's fitness to perform activities regulated by this Act? A plea of guilty, non vult, nolo contendere or any similar disposition of alleged criminal activity shall be deemed a conviction. |
| 22. | Has the organization or any of its officers, directors, trustees or principal salaried executive staff employees been adjudged liable in any administrative or civil action involving theft, fraud, or deceptive business practices? For purposes of this question a judgment of liability in an administrative or civil action shall include, but is not limited to, any finding or admission that the individual engaged in an unlawful practice in relation to the solicitation of contributions or the administration of charitable assets. |

23. Provide the following information for each officer, director, trustee and the five most-highly compensated executive staff employees:

| Name | Business address | Telephone number (include area code) | Title | Salary |
|--------------|------------------|---|-------|--------|
| See Attached | | () | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |

CRI-300R Long-Form Registration Renewal Financial Statement

Note: If the financial value of a line item = 0, place a zero in the space provided. Please report all figures as GROSS, not NET

| | Thease report all rightes as direct | 00, NULNET. | | | | | | |
|---|--|---------------|--------------------------------------|--------------------------|--|--|--|--|
| Full legal name and street address of the organiza | Full legal name and street address of the organization | | | | | | | |
| Full legal name: <u>Rett Syndrome Research</u> | Trust, Inc. | | | | | | | |
| Fiscal year-end being reported: $\frac{12/31/2022}{\text{month day year}}$ | Federal ID Number (EIN) | 26-0687439 | | | | | | |
| Mailing address: <u>67 Under Cliff Road, Trumbull, CT</u> Mailing Address | P.O. Box Number or Suite | City | State | ZIP Code | | | | |
| Street address of the registering organization: | Street Address | City | State | ZIP Code | | | | |
| New Jersey Charities Registration number: CH | 3077500 | -00 Telephone | e number <u>: 203-44</u> (inclue) | 45-0041 de area code) | | | | |

Attach to this registration the most recent Internal Revenue Service Form 990 and Schedule A (990), if the organization has filed those forms. Attach a copy if the organization's annual financial report included an audited financial statement, or if the organization received gross revenue in excess of \$500,000. **Note:** If the organization received gross revenue of less than \$500,000, the financial reports must be certified by the organization's president or other authorized officer of the organization's board.

In lieu of completing the CRI-300R Financial Statement pages, attached please find a copy of the I.R.S. 990 filing for the fiscal year-end indicated above.

A. Receipts

| Line A1a. | Direct Public | Support received from the following sources: |
|-----------|----------------|--|
| | (1) | Direct mail |
| | (2) | Telephone solicitation |
| | (3) | Commercial co-venture |
| | (4) | Gross receipts from fund-raising events |
| | (5) | Canisters, counter cards, door to door etc |
| | (6) | Corporations and other businesses |
| | (7) | Foundations and trusts |
| | (8) | Donated land, buildings, property, equipment |
| | | and materials |
| | (9) | Legacies and bequests |
| | (10) | Membership dues solely resulting from |
| | | solicitations |
| | (11) | Other support (specify) |
| Line A1b. | Total Direct P | ublic Support (add lines A1a(1) through A1a(11)) |
| Line A1c. | Indirect Publi | c Support received from the following sources: |
| | (1) | Federated fund-raising organization |
| | (2) | From an affiliated organization |
| | (3) | From another fund-raising organization |
| Line A1d. | Total Indirect | Public Support (add lines A1c(1) thru A1c(3)) |
| Line A1e. | Total Gross (| Contributions (add lines A1b and A1d) |

| Line A2. | Government grants including purchase of service contracts (specify agency) | |
|----------------|--|--|
| | a | |
| | b | |
| | C | |
| Lina A2a | d. | |
| Line Aze. | Total Government Grants (add lines 2a thru 2d) | |
| Line A3. | Other Support | |
| | a. Bona fide membership | |
| | b. Program service revenue | |
| | c. Professional services rendered by volunteers | |
| | d. Miscellaneous income (specify) | |
| Line A3e. | Total Other Support (add the total of lines A3a thru A3d) | |
| Line A4. | Total Gross Revenue (add lines A1e, A2e and A3e) | |
| B. Expenses | 6 | |
| Line B1. | Program expenses | |
| Line B2. | Management and general expenses | |
| Line B3. | Fund-raising expenses | |
| Line B4. | Payments to state/national affiliates (if applicable) | |
| Line B5. | Total Expenses (add the totals of line B1 thru B4) | |
| C. Excess or | r Deficit | |
| For the fisca | l year-end (subtract line B5 from line A4) | |
| D. Fund Bala | ance | |
| Line D1. | Net assets or fund balances at beginning of year | |
| Line D2. | Other changes in net assets or fund balances (attach explanation) | |
| Line D3. | Net assets or fund balances at end of year (Combine line C, D1 and D2) | |
| Please Note: ⊺ | he amount of Gross Contributions (line A1e on this form) determines the registration | fee which must be paid and the form wh |
| should be used | . July 2006 revisions to the Charities Registration Act now require all charities to pay | a registration fee, including charities wh |

Gross Contributions are less than \$10,000. Further information for charity registrants may be found on our

Web site: http://www.njconsumeraffairs.gov/ocp/charities.htm.

Long-Form Renewal Registration Statement Form CRI-300RC Confidential Information

| Organization's Name: <u>Rett Syndrome Research Trust, Inc</u> | | | | | | | |
|--|--|--|--|--|--|--|--|
| N.J. Charities Registration Number: CH- <u>3077500</u> -00 Federal ID Number (EIN) <u>26-0687439</u> | | | | | | | |
| Fiscal Year-End being reported: <u>12/31/2022</u> month day year | | | | | | | |
| 24. Are any of the organization's officers, directors, trustees or the five most-highly compensated employees related by blood, marriage or adoption to: | | | | | | | |
| a. each other? Yes X No b. any officers, agents or employees of any fund-raising counsel or independent paid fund-raiser under contract to the organization? Yes X No c. any chief executive, employee, any other employee of the organization with a direct financial interest in the transaction, or any partner, proprietor, director, officer, trustee, or to any shareholder of the organization with more than two (2) percent interest in any supplier or vendor providing goods or services to the organization? d. If you answered "Yes," to questions 24a, b, or c, please provide a statement explaining these relationships. | | | | | | | |
| 25. Do any of the organization's officers, directors, trustees or the five most-highly compensated employees have a financial interest in any activities engaged in by a fund-raising counsel or independent paid fund-raiser under contract to the organization, or any supplier or vendor providing goods or services to the organization? Yes X No If "Yes," please detail these relationships below or on a separate sheet of paper, and provide the name, business address and telephone number of all interested parties. | | | | | | | |
| We understand that this registration is being issued at the discretion of the Division of Consumer Affairs and agree that employees of the Division may inspect the records in the possession of this organization in order to ascertain compliance with the statute and all pertinent regulations. We also understand that we may be required to provide additional information if requested. | | | | | | | |
| We hereby certify that the above information and the attached financial schedule(s) and statement(s) are true. We are aware that if any of the above statements are willfully false, we are subject to punishment. | | | | | | | |
| SignatureNameNameNonica Coenraads Title Chief Executive OfficerDate | | | | | | | |
| Signature Name Title Date | | | | | | | |
| This form must be signed by two (2) authorized officers of the organization, including the chief financial officer. | | | | | | | |

Note: Form CRI-300RC must be filed with Form CRI-300R.

Form CRI-300R: List of officers, directors, and trustees

| Name | Title | Address |
|-------------------|-------------------------|---|
| Monica Coenraads | Chief Executive Officer | 67 Under Cliff Road Trumbull, CT 06611 |
| Heidi Epstein | Vice Chairman | 67 Under Cliff Road Trumbull, CT 06611 |
| Anthony Schoener | Chairman | 67 Under Cliff Road Trumbull, CT 06611 |
| Lawrence Mattis | Secretary | 67 Under Cliff Road Trumbull, CT 06611 |
| Marci Valner | Treasurer | 67 Under Cliff Road Trumbull, CT 06611 |
| Adrian Bird | Trustee | 67 Under Cliff Road Trumbull, CT 06611 |
| Stephanie Bohn | Trustee | 67 Under Cliff Road Trumbull, CT 06611 |
| Ingrid Harding | Trustee | 67 Under Cliff Road Trumbull, CT 06611 |
| Rachel Rothschild | Trustee | 67 Under Cliff Road Trumbull, CT 06611 |
| Rachael Stevenson | Trustee | 67 Under Cliff Road Trumbull, CT 06611 |
| Marc Tesler | Trustee | 67 Under Cliff Road Trumbull, CT 06611 |
| Alba Tull | Trustee | 67 Under Cliff Road Trumbull, CT 06611 |
| Brian Whitmer | Trustee | 67 Under Cliff Road Trumbull, CT 06611 |
| Brad Zelinger | Trustee | 67 Under Cliff Road Trumbull, CT 06611 |

Form CRI-300R: Five most highly paid employees

| Name | Title | Address |
|-------------------|---------------------------|---|
| Monica Coenraads | CEO | 67 Under Cliff Road Trumbull, CT 06611 |
| Tim Freeman | Chief Development Officer | 67 Under Cliff Road Trumbull, CT 06611 |
| Jana von Hehn | Chief Scientific Officer | 67 Under Cliff Road Trumbull, CT 06611 |
| Randall Carpenter | Chief Medical Officer | 67 Under Cliff Road Trumbull, CT 06611 |
| Bob Deans | Chief Technology Officer | 67 Under Cliff Road Trumbull, CT 06611 |