



See a Social Security Number? Say Something!  
Report Privacy Problems to <https://public.resource.org/privacy>  
Or call the IRS Identity Theft Hotline at 1-800-908-4490



Form 990

Department of the Treasury  
Internal Revenue Service

## Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except black lung  
benefit trust or private foundation)

The organization may have to use a copy of this return to satisfy state reporting requirements.

OMB No 1545-0047

2009

Open to Public  
Inspection

## A For the 2009 calendar year, or tax year beginning

and ending

B Check if  
applicable:

- ☐ Address  
change  
☐ Name  
change  
☐ Initial  
return  
☐ Termi-  
nated  
return  
☐ Amend-  
ed return  
☐ Applica-  
tion  
pending

Please  
use IRS  
label or  
print or  
typeSee  
Specific  
Instruc-  
tions.

## C Name of organization

International Rett Syndrome Foundation

Doing Business As

Number and street (or P.O. box if mail is not delivered to street address) Room/suite

4600 Devitt Drive

City or town, state or country, and ZIP + 4

Cincinnati, OH 45246

F Name and address of principal officer: Stephen E. Bajardi  
same as C above

## D Employer identification number

31-1682518

## E Telephone number

513-874-3020

## G Gross receipts \$

4,699,528.

H(a) Is this a group return  
for affiliates? ☐ Yes ☒ NoH(b) Are all affiliates included? ☐ Yes ☐ No  
If "No," attach a list. (see instructions)

H(c) Group exemption number ▶

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

J Website: ▶ www.rett Syndrome.org

K Form of organization: ☒ Corporation ☐ Trust ☐ Association ☐ Other ▶

L Year of formation: 1999 M State of legal domicile: OH

## Part I Summary

| Activities & Governance |                                                                                                                                                                                        |
|-------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1                       | Briefly describe the organization's mission or most significant activities: <u>To fund research for treatments and a cure for Rett Syndrome while enhancing the overall quality of</u> |
| 2                       | Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.                                                |
| 3                       | Number of voting members of the governing body (Part VI, line 1a) 3 14                                                                                                                 |
| 4                       | Number of independent voting members of the governing body (Part VI, line 1b) 4 14                                                                                                     |
| 5                       | Total number of employees (Part V, line 2a) 5 9                                                                                                                                        |
| 6                       | Total number of volunteers (estimate if necessary) 6 100                                                                                                                               |
| 7a                      | Total gross unrelated business revenue from Part VIII, column (C), line 12 7a 0.                                                                                                       |
| b                       | Net unrelated business taxable income from Form 990-T, line 34 7b 0.                                                                                                                   |

  

| Revenue |                                                                                                          |
|---------|----------------------------------------------------------------------------------------------------------|
| 8       | Contributions and grants (Part VIII, line 1h) 3,861,502. 3,588,547.                                      |
| 9       | Program service revenue (Part VIII, line 2g) 68,264. 40,965.                                             |
| 10      | Investment income (Part VIII, column (A), lines 3, 4, and 7d) 101,605. 10,050.                           |
| 11      | Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) 16,508. 202,640.                |
| 12      | Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12) 4,047,879. 3,842,202. |
| 13      | Grants and similar amounts paid (Part IX, column (A), lines 1-3) 1,729,809. 2,014,902.                   |
| 14      | Benefits paid to or for members (Part IX, column (A), line 4)                                            |
| 15      | Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) 550,183. 579,058.      |
| 16a     | Professional fundraising fees (Part IX, column (A), line 11e)                                            |
| b       | Total fundraising expenses (Part IX, column (D), line 25) 154,092.                                       |
| 17      | Other expenses (Part IX, column (A), lines 11a-11d, 11f-24f) 1,146,772. 895,836.                         |
| 18      | Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) 3,426,764. 3,489,796.          |
| 19      | Revenue less expenses. Subtract line 18 from line 12 621,115. 352,406.                                   |

  

| Net Assets or Fund Balances |                                                                                  |
|-----------------------------|----------------------------------------------------------------------------------|
| 20                          | Total assets (Part X, line 16) 3,693,539. 4,187,959.                             |
| 21                          | Total liabilities (Part X, line 26) 1,933,009. 2,072,323.                        |
| 22                          | Net assets or fund balances. Subtract line 21 from line 20 1,760,530. 2,115,636. |

## Part II Signature Block

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

Sign  
Here

Signature of officer

Date

Stephen E. Bajardi, Executive Director  
Type or print name and titlePaid  
Preparer's  
Use OnlyPreparer's  
signatureFirm's name (or  
yours if  
self-employed),  
address, and  
ZIP + 4Barnes, Dennig & Co., LTD.  
150 East Fourth Street  
Cincinnati, OH 45202

Date

6/8/10

Check if  
self-  
employed ☐Preparer's identifying number  
(see instructions)

EIN ▶

Phone no. ▶ 513-241-8313

May the IRS discuss this return with the preparer shown above? (see instructions)

☒ Yes ☐ No

932001 02-04-10

LHA For Privacy Act and Paperwork Reduction Act Notice, see the separate instructions.

Form 990 (2009)

See Schedule O for Organization Mission Statement Continuation

**Part III** Statement of Program Service Accomplishments

1 Briefly describe the organization's mission:

The core mission of the IRSF is to fund research for treatments and a cure for Rett Syndrome while enhancing the overall quality of life for those living with Rett Syndrome by providing information, programs and services.

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

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

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

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

4 Describe the exempt purpose achievements for each of the organization's three largest program services by expenses.

Section 501(c)(3) and 501(c)(4) organizations and section 4947(a)(1) trusts are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code: ) (Expenses \$ 2,607,354. including grants of \$ 2,014,902. ) (Revenue \$ )

Research programs include activities focused on finding treatments and a cure for Rett Syndrome and include items such as research grants, medical symposiums and support of Rett Clinics.

4b (Code: ) (Expenses \$ 219,235. including grants of \$ ) (Revenue \$ )

The family support program includes activities focused on enhancing the overall lives of those afflicted with Rett Syndrome and their families and includes such items as an 800 phone number, 2 staff members devoted to connecting with families and offering information support, regional representatives program and a family advisory board.

4c (Code: ) (Expenses \$ 248,571. including grants of \$ ) (Revenue \$ 40,965. )

Education activities focused on providing information about and raising awareness of Rett Syndrome and includes activities such as the website, newsletters and the annual family conference.

4d Other program services. (Describe in Schedule O )

(Expenses \$ including grants of \$ ) (Revenue \$ )

4e Total program service expenses ► \$ 3,075,160.

**Part IV Checklist of Required Schedules**

|                                                                                                                                                                                                                                                       | Yes      | No      |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------|---------|
| 1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)?<br>If "Yes," complete Schedule A                                                                                                                | X        |         |
| 2 Is the organization required to complete Schedule B, Schedule of Contributors?                                                                                                                                                                      | X        |         |
| 3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I                                                                |          | X       |
| 4 <b>Section 501(c)(3) organizations.</b> Did the organization engage in lobbying activities? If "Yes," complete Schedule C, Part II                                                                                                                  |          | X       |
| 5 <b>Section 501(c)(4), 501(c)(5), and 501(c)(6) organizations.</b> Is the organization subject to the section 6033(e) notice and reporting requirement and proxy tax? If "Yes," complete Schedule C, Part III                                        | N/A      |         |
| 6 Did the organization maintain any donor advised funds or any similar funds or accounts where donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I  |          | X       |
| 7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II                                      |          | X       |
| 8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III                                                                                                   |          | X       |
| 9 Did the organization report an amount in Part X, line 21; 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 |          | X       |
| 10 Did the organization, directly or through a related organization, hold assets in term, permanent, or quasi-endowments? If "Yes," complete Schedule D, Part V                                                                                       | X        |         |
| 11 Is the organization's answer to any of the following questions "Yes"? If so, complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable                                                                                                      | X        |         |
| • Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI.                                                                                                                |          |         |
| • 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.                                            |          |         |
| • 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.                                            |          |         |
| • 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.                                                               |          |         |
| • Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X.                                                                                                                              |          |         |
| • Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48? If "Yes," complete Schedule D, Part X.               |          |         |
| 12 Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI, XII, and XIII.                                                                                           | X        |         |
| 12A Was the organization included in consolidated, independent audited financial statements for the tax year?<br>If "Yes," completing Schedule D, Parts XI, XII, and XIII is optional                                                                 | Yes<br>X | No<br>X |
| 13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E                                                                                                                                                  |          | X       |
| 14a Did the organization maintain an office, employees, or agents outside of the United States?                                                                                                                                                       |          | X       |
| b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, and program service activities outside the United States? If "Yes," complete Schedule F, Part I                             | X        |         |
| 15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization or entity located outside the United States? If "Yes," complete Schedule F, Part II                                      | X        |         |
| 16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or assistance to individuals located outside the United States? If "Yes," complete Schedule F, Part III                                          |          | X       |
| 17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I                                                         |          | X       |
| 18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II                                                                     | X        |         |
| 19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III                                                                                               |          | X       |
| 20 Did the organization operate one or more hospitals? If "Yes," complete Schedule H                                                                                                                                                                  |          | X       |

Form 990 (2009)

**Part IV Checklist of Required Schedules** (continued)

|                                                                                                                                                                                                                                                                                   | Yes | No |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|----|
| 21 Did the organization report more than \$5,000 of grants and other assistance to governments and organizations in the United States on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II                                                               | X   |    |
| 22 Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III                                                                                |     | 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                           | X   |    |
| 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 25 |     | X  |
| b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?                                                                                                                                                                               |     |    |
| c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?                                                                                                                                      |     |    |
| d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?                                                                                                                                                                         |     |    |
| 25a Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I                                                                                 |     | 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             |     | X  |
| 26 Was a loan to or by a current or former officer, director, trustee, key employee, highly compensated employee, or disqualified person outstanding as of the end of the organization's tax year? If "Yes," complete Schedule L, Part II                                         |     | X  |
| 27 Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor, or a grant selection committee member, or to a person related to such an individual? If "Yes," complete Schedule L, Part III                 | X   |    |
| 28 Was the organization a party to a business transaction with one of the following parties, (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):                                                                                 |     |    |
| a A current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV                                                                                                                                                                         |     | X  |
| b A family member of a current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV                                                                                                                                                      |     | X  |
| c An entity of which a current or former officer, director, trustee, or key employee of the organization (or a family member) was an officer, director, trustee, or direct or indirect owner? If "Yes," complete Schedule L, Part IV                                              |     | X  |
| 29 Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M                                                                                                                                                                       | X   |    |
| 30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If "Yes," complete Schedule M                                                                                                       |     | X  |
| 31 Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I                                                                                                                                                             |     | X  |
| 32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete Schedule N, Part II                                                                                                                                           |     | X  |
| 33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I                                                                                           |     | X  |
| 34 Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Parts II, III, IV, and V, line 1                                                                                                                                              |     | X  |
| 35 Is any related organization a controlled entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2                                                                                                                                        |     | X  |
| 36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? If "Yes," complete Schedule R, Part V, line 2                                                                                                       |     | X  |
| 37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI                                                  |     | X  |
| 38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11 and 19?                                                                                                                                                                  | X   |    |

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

Form 990 (2009)

**Part V. Statements Regarding Other IRS Filings and Tax Compliance**

|            |                                                                                                                                                                                                                                                                                  | Yes | No |
|------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|----|
| <b>1a</b>  | Enter the number reported in Box 3 of Form 1096, Annual Summary and Transmittal of U.S. Information Returns. Enter -0- if not applicable                                                                                                                                         | 34  |    |
| <b>1b</b>  | Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable                                                                                                                                                                                                  | 0   |    |
| <b>c</b>   | Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?                                                                                                                         | X   |    |
| <b>2a</b>  | 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                                                                                                    | 9   |    |
| <b>b</b>   | If at least one is reported on line 2a, did the organization file all required federal employment tax returns?<br><b>Note.</b> If the sum of lines 1a and 2a is greater than 250, you may be required to e-file this return. (see instructions)                                  | X   |    |
| <b>3a</b>  | Did the organization have unrelated business gross income of \$1,000 or more during the year covered by this return?                                                                                                                                                             |     | X  |
| <b>b</b>   | If "Yes," has it filed a Form 990-T for this year? If "No," provide an explanation in Schedule O                                                                                                                                                                                 |     |    |
| <b>4a</b>  | At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?                                       |     | X  |
| <b>b</b>   | If "Yes," enter the name of the foreign country:<br>See the instructions for exceptions and filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.                                                                                            |     |    |
| <b>5a</b>  | Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?                                                                                                                                                                            |     | X  |
| <b>b</b>   | Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?                                                                                                                                                                 |     | X  |
| <b>c</b>   | If "Yes," to line 5a or 5b, did the organization file Form 8886-T, Disclosure by Tax-Exempt Entity Regarding Prohibited Tax Shelter Transaction?                                                                                                                                 |     |    |
| <b>6a</b>  | Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible?                                                                                                      | X   |    |
| <b>b</b>   | If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?                                                                                                                                    | X   |    |
| <b>7</b>   | <b>Organizations that may receive deductible contributions under section 170(c).</b>                                                                                                                                                                                             |     |    |
| <b>a</b>   | 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?                                                                                                                                  |     | X  |
| <b>b</b>   | If "Yes," did the organization notify the donor of the value of the goods or services provided?                                                                                                                                                                                  |     |    |
| <b>c</b>   | Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?                                                                                                                                             |     | X  |
| <b>d</b>   | If "Yes," indicate the number of Forms 8282 filed during the year                                                                                                                                                                                                                | 7d  |    |
| <b>e</b>   | Did the organization, during the year, receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?                                                                                                                                                |     | X  |
| <b>f</b>   | Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?                                                                                                                                                                     |     | X  |
| <b>g</b>   | For all contributions of qualified intellectual property, did the organization file Form 8899 as required?                                                                                                                                                                       |     |    |
| <b>h</b>   | For contributions of cars, boats, airplanes, and other vehicles, did the organization file a Form 1098-C as required?                                                                                                                                                            |     |    |
| <b>8</b>   | <b>Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations.</b> Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year? N/A | 8   |    |
| <b>9</b>   | <b>Sponsoring organizations maintaining donor advised funds.</b>                                                                                                                                                                                                                 |     |    |
| <b>a</b>   | Did the organization make any taxable distributions under section 4966? N/A                                                                                                                                                                                                      | 9a  |    |
| <b>b</b>   | Did the organization make a distribution to a donor, donor advisor, or related person? N/A                                                                                                                                                                                       | 9b  |    |
| <b>10</b>  | <b>Section 501(c)(7) organizations.</b> Enter                                                                                                                                                                                                                                    |     |    |
| <b>a</b>   | Initiation fees and capital contributions included on Part VIII, line 12 N/A                                                                                                                                                                                                     | 10a |    |
| <b>b</b>   | Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities                                                                                                                                                                                      | 10b |    |
| <b>11</b>  | <b>Section 501(c)(12) organizations.</b> Enter.                                                                                                                                                                                                                                  |     |    |
| <b>a</b>   | Gross income from members or shareholders N/A                                                                                                                                                                                                                                    | 11a |    |
| <b>b</b>   | Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them)                                                                                                                                                      | 11b |    |
| <b>12a</b> | <b>Section 4947(a)(1) non-exempt charitable trusts.</b> Is the organization filing Form 990 in lieu of Form 1041?                                                                                                                                                                | 12a |    |
| <b>b</b>   | If "Yes," enter the amount of tax-exempt interest received or accrued during the year                                                                                                                                                                                            | 12b |    |

Form 990 (2009)

**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 in Schedule O. See instructions.

### Section A. Governing Body and Management

|                                                                                                                                                                                                                              | Yes | No |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|----|
| <b>1a</b> Enter the number of voting members of the governing body                                                                                                                                                           | 1a  | 14 |
| <b>b</b> Enter the number of voting members that are independent                                                                                                                                                             | 1b  | 14 |
| <b>2</b> Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?                                               | 2   | X  |
| <b>3</b> Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person? | 3   | X  |
| <b>4</b> Did the organization make any significant changes to its organizational documents since the prior Form 990 was filed?                                                                                               | 4   | X  |
| <b>5</b> Did the organization become aware during the year of a material diversion of the organization's assets?                                                                                                             | 5   | X  |
| <b>6</b> Does the organization have members or stockholders?                                                                                                                                                                 | 6   | X  |
| <b>7a</b> Does the organization have members, stockholders, or other persons who may elect one or more members of the governing body?                                                                                        | 7a  | X  |
| <b>b</b> Are any decisions of the governing body subject to approval by members, stockholders, or other persons?                                                                                                             | 7b  | X  |
| <b>8</b> Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:                                                                                   |     |    |
| <b>a</b> The governing body?                                                                                                                                                                                                 | 8a  | X  |
| <b>b</b> Each committee with authority to act on behalf of the governing body?                                                                                                                                               | 8b  | X  |
| <b>9</b> Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O        | 9   | X  |

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

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

### Section C. Disclosure

**17** List the states with which a copy of this Form 990 is required to be filed ► OH, AL, CT, IL, MA, NJ, NY, PA, WA, CO, FL, GA

**18** Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you make these available. Check all that apply.  
☐ Own website    ☐ Another's website    ☒ Upon request

**19** Describe in Schedule O whether (and if so, how), the organization makes its governing documents, conflict of interest policy, and financial statements available to the public

**20** State the name, physical address, and telephone number of the person who possesses the books and records of the organization: ►  
Mary Joyce Griffin - 513-874-3020  
4600 Devitt Drive, Cincinnati, OH 45246

Form 990 (2009)

**Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors**
**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. Use Schedule J-2 if additional space is needed.

• 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. See instructions for definition of "key employee."

• List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.

• List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations

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

List persons in the following order: individual trustees or directors; institutional trustees; officers; key employees; highest compensated employees; and former such persons.

☐ Check this box if the organization did not compensate any current officer, director, or trustee.

| (A)<br>Name and Title                          | (B)<br>Average hours per week | (C)<br>Position (check all that apply) |                       |         |              |                              |        | (D)<br>Reportable compensation from the organization (W-2/1099-MISC) | (E)<br>Reportable compensation from related organizations (W-2/1099-MISC) | (F)<br>Estimated amount of other compensation from the organization and related organizations |
|------------------------------------------------|-------------------------------|----------------------------------------|-----------------------|---------|--------------|------------------------------|--------|----------------------------------------------------------------------|---------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------|
|                                                |                               | Individual trustee or director         | Institutional trustee | Officer | Key employee | Highest compensated employee | Former |                                                                      |                                                                           |                                                                                               |
| Ed Draves<br>Board Member                      | 2.00                          | X                                      |                       |         |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| Rick Altschuler<br>Board Member                | 5.00                          | X                                      |                       |         |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| Dan Brinkhaus<br>Board Member                  | 5.00                          | X                                      |                       |         |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| Michael Joyce<br>Board Member                  | 5.00                          | X                                      |                       |         |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| Sean Lebson<br>Board Member                    | 5.00                          | X                                      |                       |         |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| Karen Nussle<br>Board Member                   | 5.00                          | X                                      |                       |         |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| Barry Rinehart<br>Board Member                 | 5.00                          | X                                      |                       |         |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| Kenna Seiler<br>Board Member                   | 5.00                          | X                                      |                       |         |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| Rajat Shah<br>Board Member                     | 5.00                          | X                                      |                       |         |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| Jeffrey Stelmach<br>Board Member               | 5.00                          | X                                      |                       |         |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| Christian McMahan<br>Secretary                 | 5.00                          | X                                      |                       | X       |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| John Corpus<br>Treasurer                       | 5.00                          | X                                      |                       | X       |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| Stephen Gallucci<br>Vice Chair                 | 5.00                          | X                                      |                       | X       |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| Kathryn Kissam<br>Chairperson                  | 10.00                         | X                                      |                       | X       |              |                              |        | 0.                                                                   | 0.                                                                        | 0.                                                                                            |
| Stephen Bajardi arr 8/09<br>Executive Director | 60.00                         |                                        |                       | X       |              |                              |        | 57,827.                                                              | 0.                                                                        | 944.                                                                                          |
| Charles Curly, left 3/09<br>Executive Director | 60.00                         |                                        |                       | X       |              |                              |        | 34,618.                                                              | 0.                                                                        | 1,482.                                                                                        |
| Antony Horton<br>Chief Scientific Officer      | 50.00                         |                                        |                       |         | X            |                              |        | 151,188.                                                             | 0.                                                                        | 5,667.                                                                                        |

**Part VII** Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees (continued)

| (A)<br>Name and title | (B)<br>Average<br>hours<br>per<br>week | (C)<br>Position<br>(check all that apply) |                       |         |              |                              |        | (D)<br>Reportable<br>compensation<br>from<br>the<br>organization<br>(W-2/1099-MISC) | (E)<br>Reportable<br>compensation<br>from related<br>organizations<br>(W-2/1099-MISC) | (F)<br>Estimated<br>amount of<br>other<br>compensation<br>from the<br>organization<br>and related<br>organizations |
|-----------------------|----------------------------------------|-------------------------------------------|-----------------------|---------|--------------|------------------------------|--------|-------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------|
|                       |                                        | Individual trustee or director            | Institutional trustee | Officer | Key employee | Highest compensated employee | Former |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
|                       |                                        |                                           |                       |         |              |                              |        |                                                                                     |                                                                                       |                                                                                                                    |
| <b>1b Total</b>       |                                        |                                           |                       |         |              |                              |        | <b>243,633.</b>                                                                     | <b>0.</b>                                                                             | <b>8,093.</b>                                                                                                      |

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 in reportable compensation from the organization **1**

- 3 Did the organization list any **former** officer, director or trustee, key employee, or highest compensated employee on line 1a? If "Yes," complete Schedule J for such individual **3**
- 4 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? If "Yes," complete Schedule J for such individual **4**
- 5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization for services rendered to the organization? If "Yes," complete Schedule J for such person **5**

|          | Yes      | No       |
|----------|----------|----------|
| <b>3</b> |          | <b>X</b> |
| <b>4</b> | <b>X</b> |          |
| <b>5</b> |          | <b>X</b> |

**Section B. Independent Contractors**

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. **NONE**

| (A)<br>Name and business address                                                                                                                                          | (B)<br>Description of services | (C)<br>Compensation |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------|---------------------|
|                                                                                                                                                                           |                                |                     |
|                                                                                                                                                                           |                                |                     |
|                                                                                                                                                                           |                                |                     |
|                                                                                                                                                                           |                                |                     |
|                                                                                                                                                                           |                                |                     |
|                                                                                                                                                                           |                                |                     |
|                                                                                                                                                                           |                                |                     |
|                                                                                                                                                                           |                                |                     |
| <b>2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 in compensation from the organization</b> | <b>0</b>                       |                     |

**Part VIII Statement of Revenue**

|                                                               |                                                                                                                                          |                            | (A)<br>Total revenue    | (B)<br>Related or<br>exempt function<br>revenue | (C)<br>Unrelated<br>business<br>revenue | (D)<br>Revenue<br>excluded from<br>tax under<br>sections 512,<br>513, or 514 |
|---------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------|----------------------------|-------------------------|-------------------------------------------------|-----------------------------------------|------------------------------------------------------------------------------|
| Contributions, gifts, grants<br>and other similar amounts     | 1 a Federated campaigns                                                                                                                  | 1a                         |                         |                                                 |                                         |                                                                              |
|                                                               | b Membership dues                                                                                                                        | 1b                         | 9,740.                  |                                                 |                                         |                                                                              |
|                                                               | c Fundraising events                                                                                                                     | 1c                         | 2,227,403.              |                                                 |                                         |                                                                              |
|                                                               | d Related organizations                                                                                                                  | 1d                         |                         |                                                 |                                         |                                                                              |
|                                                               | e Government grants (contributions)                                                                                                      | 1e                         | 65,152.                 |                                                 |                                         |                                                                              |
|                                                               | f All other contributions, gifts, grants, and<br>similar amounts not included above                                                      | 1f                         | 1,286,252.              |                                                 |                                         |                                                                              |
|                                                               | g Noncash contributions included in lines 1a-1f: \$                                                                                      |                            | 327,770.                |                                                 |                                         |                                                                              |
|                                                               | h Total. Add lines 1a-1f                                                                                                                 |                            | 3,588,547.              |                                                 |                                         |                                                                              |
|                                                               | Program Service<br>Revenue                                                                                                               | 2 a Conference Registratio | Business Code<br>611710 | 39,665.                                         | 39,665.                                 |                                                                              |
| b Conference Sponsorship                                      |                                                                                                                                          | 900099                     | 1,300.                  | 1,300.                                          |                                         |                                                                              |
| c                                                             |                                                                                                                                          |                            |                         |                                                 |                                         |                                                                              |
| d                                                             |                                                                                                                                          |                            |                         |                                                 |                                         |                                                                              |
| e                                                             |                                                                                                                                          |                            |                         |                                                 |                                         |                                                                              |
| f All other program service revenue                           |                                                                                                                                          |                            |                         |                                                 |                                         |                                                                              |
| g Total. Add lines 2a-2f                                      |                                                                                                                                          |                            | 40,965.                 |                                                 |                                         |                                                                              |
| Other Revenue                                                 | 3 Investment income (including dividends, interest, and<br>other similar amounts)                                                        |                            | 10,054.                 |                                                 |                                         | 10,054.                                                                      |
|                                                               | 4 Income from investment of tax-exempt bond proceeds                                                                                     |                            |                         |                                                 |                                         |                                                                              |
|                                                               | 5 Royalties                                                                                                                              |                            |                         |                                                 |                                         |                                                                              |
|                                                               | 6 a Gross Rents                                                                                                                          | (i) Real (ii) Personal     |                         |                                                 |                                         |                                                                              |
|                                                               | b Less: rental expenses                                                                                                                  |                            |                         |                                                 |                                         |                                                                              |
|                                                               | c Rental income or (loss)                                                                                                                |                            |                         |                                                 |                                         |                                                                              |
|                                                               | d Net rental income or (loss)                                                                                                            |                            |                         |                                                 |                                         |                                                                              |
|                                                               | 7 a Gross amount from sales of<br>assets other than inventory                                                                            | (i) Securities (ii) Other  | 2,524.                  |                                                 |                                         |                                                                              |
|                                                               | b Less: cost or other basis<br>and sales expenses                                                                                        |                            | 2,528.                  |                                                 |                                         |                                                                              |
|                                                               | c Gain or (loss)                                                                                                                         |                            | <4.>                    |                                                 |                                         |                                                                              |
|                                                               | d Net gain or (loss)                                                                                                                     |                            | <4.>                    |                                                 |                                         | <4.>                                                                         |
|                                                               | 8 a Gross income from fundraising events (not<br>including \$ 2227403. of<br>contributions reported on line 1c). See<br>Part IV, line 18 | a                          | 997,078.                |                                                 |                                         |                                                                              |
|                                                               | b Less: direct expenses                                                                                                                  | b                          | 802,115.                |                                                 |                                         |                                                                              |
|                                                               | c Net income or (loss) from fundraising events                                                                                           |                            | 194,963.                |                                                 |                                         | 194,963.                                                                     |
|                                                               | 9 a Gross income from gaming activities. See<br>Part IV, line 19                                                                         | a                          |                         |                                                 |                                         |                                                                              |
|                                                               | b Less: direct expenses                                                                                                                  | b                          |                         |                                                 |                                         |                                                                              |
|                                                               | c Net income or (loss) from gaming activities                                                                                            |                            |                         |                                                 |                                         |                                                                              |
| 10 a Gross sales of inventory, less returns<br>and allowances | a                                                                                                                                        | 60,360.                    |                         |                                                 |                                         |                                                                              |
| b Less: cost of goods sold                                    | b                                                                                                                                        | 52,683.                    |                         |                                                 |                                         |                                                                              |
| c Net income or (loss) from sales of inventory                |                                                                                                                                          | 7,677.                     | 7,677.                  |                                                 |                                         |                                                                              |
| Miscellaneous Revenue                                         |                                                                                                                                          | Business Code              |                         |                                                 |                                         |                                                                              |
| 11 a                                                          |                                                                                                                                          |                            |                         |                                                 |                                         |                                                                              |
| b                                                             |                                                                                                                                          |                            |                         |                                                 |                                         |                                                                              |
| c                                                             |                                                                                                                                          |                            |                         |                                                 |                                         |                                                                              |
| d All other revenue                                           |                                                                                                                                          |                            |                         |                                                 |                                         |                                                                              |
| e Total. Add lines 11a-11d                                    |                                                                                                                                          |                            |                         |                                                 |                                         |                                                                              |
| 12 Total revenue. See instructions.                           |                                                                                                                                          | 3,842,202.                 | 48,642.                 | 0.                                              | 205,013.                                |                                                                              |

**Part IX Statement of Functional Expenses**

Section 501(c)(3) and 501(c)(4) organizations must complete all columns.

All other organizations must complete column (A) but are not required to complete columns (B), (C), and (D).

| Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.                                                                                                                                              | (A)<br>Total expenses | (B)<br>Program service expenses | (C)<br>Management and general expenses | (D)<br>Fundraising expenses |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|---------------------------------|----------------------------------------|-----------------------------|
| 1 Grants and other assistance to governments and organizations in the U.S. See Part IV, line 21                                                                                                                             | 2,014,902.            | 2,014,902.                      |                                        |                             |
| 2 Grants and other assistance to individuals in the U.S. See Part IV, line 22                                                                                                                                               |                       |                                 |                                        |                             |
| 3 Grants and other assistance to governments, organizations, and individuals outside the U.S. See Part IV, lines 15 and 16                                                                                                  |                       |                                 |                                        |                             |
| 4 Benefits paid to or for members                                                                                                                                                                                           |                       |                                 |                                        |                             |
| 5 Compensation of current officers, directors, trustees, and key employees                                                                                                                                                  | 251,726.              | 232,752.                        | 9,487.                                 | 9,487.                      |
| 6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)                                                                             |                       |                                 |                                        |                             |
| 7 Other salaries and wages                                                                                                                                                                                                  | 299,880.              | 145,805.                        | 82,282.                                | 71,793.                     |
| 8 Pension plan contributions (include section 401(k) and section 403(b) employer contributions)                                                                                                                             | 644.                  | 442.                            | 107.                                   | 95.                         |
| 9 Other employee benefits                                                                                                                                                                                                   |                       |                                 |                                        |                             |
| 10 Payroll taxes                                                                                                                                                                                                            | 26,808.               | 18,396.                         | 4,461.                                 | 3,951.                      |
| 11 Fees for services (non-employees):                                                                                                                                                                                       |                       |                                 |                                        |                             |
| a Management                                                                                                                                                                                                                |                       |                                 |                                        |                             |
| b Legal                                                                                                                                                                                                                     |                       |                                 |                                        |                             |
| c Accounting                                                                                                                                                                                                                | 27,391.               | 15,988.                         | 11,403.                                |                             |
| d Lobbying                                                                                                                                                                                                                  |                       |                                 |                                        |                             |
| e Professional fundraising services. See Part IV, line 17                                                                                                                                                                   |                       |                                 |                                        |                             |
| f Investment management fees                                                                                                                                                                                                |                       |                                 |                                        |                             |
| g Other                                                                                                                                                                                                                     | 144,219.              | 93,442.                         | 38,876.                                | 11,901.                     |
| 12 Advertising and promotion                                                                                                                                                                                                |                       |                                 |                                        |                             |
| 13 Office expenses                                                                                                                                                                                                          | 132,126.              | 49,877.                         | 66,875.                                | 15,374.                     |
| 14 Information technology                                                                                                                                                                                                   | 53,275.               | 40,157.                         | 1,476.                                 | 11,642.                     |
| 15 Royalties                                                                                                                                                                                                                |                       |                                 |                                        |                             |
| 16 Occupancy                                                                                                                                                                                                                | 62,328.               | 44,708.                         | 17,620.                                |                             |
| 17 Travel                                                                                                                                                                                                                   | 210,593.              | 199,246.                        | 6,299.                                 | 5,048.                      |
| 18 Payments of travel or entertainment expenses for any federal, state, or local public officials                                                                                                                           |                       |                                 |                                        |                             |
| 19 Conferences, conventions, and meetings                                                                                                                                                                                   | 168,436.              | 167,639.                        | 298.                                   | 499.                        |
| 20 Interest                                                                                                                                                                                                                 |                       |                                 |                                        |                             |
| 21 Payments to affiliates                                                                                                                                                                                                   |                       |                                 |                                        |                             |
| 22 Depreciation, depletion, and amortization                                                                                                                                                                                | 8,658.                |                                 |                                        | 8,658.                      |
| 23 Insurance                                                                                                                                                                                                                | 10,260.               |                                 | 10,260.                                |                             |
| 24 Other expenses. Itemize expenses not covered above. (Expenses grouped together and labeled miscellaneous may not exceed 5% of total expenses shown on line 25 below.)                                                    |                       |                                 |                                        |                             |
| a <u>Research Expense</u>                                                                                                                                                                                                   | 27,844.               | 27,844.                         |                                        |                             |
| b <u>Repairs and Maintenance</u>                                                                                                                                                                                            | 27,754.               | 8,562.                          | 5,662.                                 | 13,530.                     |
| c <u>Miscellaneous</u>                                                                                                                                                                                                      | 22,952.               | 15,400.                         | 5,438.                                 | 2,114.                      |
| d                                                                                                                                                                                                                           |                       |                                 |                                        |                             |
| e                                                                                                                                                                                                                           |                       |                                 |                                        |                             |
| f All other expenses                                                                                                                                                                                                        |                       |                                 |                                        |                             |
| 25 Total functional expenses. Add lines 1 through 24f                                                                                                                                                                       | 3,489,796.            | 3,075,160.                      | 260,544.                               | 154,092.                    |
| 26 Joint costs. Check here <input type="checkbox"/> if following SOP 98-2. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation |                       |                                 |                                        |                             |

**Part X** Balance Sheet

|                                                                     |                                                                                                                                                                         | (A)<br>Beginning of year |            | (B)<br>End of year |
|---------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|------------|--------------------|
| <b>Assets</b>                                                       | 1 Cash - non-interest-bearing                                                                                                                                           | 619,558.                 | 1          | 428,966.           |
|                                                                     | 2 Savings and temporary cash investments                                                                                                                                | 2,932,181.               | 2          | 3,557,670.         |
|                                                                     | 3 Pledges and grants receivable, net                                                                                                                                    | 32,013.                  | 3          | 70,589.            |
|                                                                     | 4 Accounts receivable, net                                                                                                                                              |                          | 4          |                    |
|                                                                     | 5 Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L                   |                          | 5          |                    |
|                                                                     | 6 Receivables from other disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B). Complete Part II of Schedule L      |                          | 6          |                    |
|                                                                     | 7 Notes and loans receivable, net                                                                                                                                       |                          | 7          |                    |
|                                                                     | 8 Inventories for sale or use                                                                                                                                           | 30,145.                  | 8          | 39,327.            |
|                                                                     | 9 Prepaid expenses and deferred charges                                                                                                                                 | 19,925.                  | 9          | 37,707.            |
|                                                                     | 10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D                                                                                 | 10a 47,491.              |            |                    |
|                                                                     | b Less: accumulated depreciation                                                                                                                                        | 10b 13,870.              | 10c        | 33,621.            |
|                                                                     | 11 Investments - publicly traded securities                                                                                                                             | 1,000.                   | 11         | 1,000.             |
|                                                                     | 12 Investments - other securities. See Part IV, line 11                                                                                                                 |                          | 12         |                    |
|                                                                     | 13 Investments - program-related. See Part IV, line 11                                                                                                                  |                          | 13         |                    |
|                                                                     | 14 Intangible assets                                                                                                                                                    |                          | 14         |                    |
|                                                                     | 15 Other assets. See Part IV, line 11                                                                                                                                   | 16,438.                  | 15         | 19,079.            |
| 16 <b>Total assets.</b> Add lines 1 through 15 (must equal line 34) | 3,693,539.                                                                                                                                                              | 16                       | 4,187,959. |                    |
| <b>Liabilities</b>                                                  | 17 Accounts payable and accrued expenses                                                                                                                                | 47,643.                  | 17         | 59,862.            |
|                                                                     | 18 Grants payable                                                                                                                                                       | 1,885,366.               | 18         | 2,012,461.         |
|                                                                     | 19 Deferred revenue                                                                                                                                                     |                          | 19         |                    |
|                                                                     | 20 Tax-exempt bond liabilities                                                                                                                                          |                          | 20         |                    |
|                                                                     | 21 Escrow or custodial account liability. Complete Part IV of Schedule D                                                                                                |                          | 21         |                    |
|                                                                     | 22 Payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L |                          | 22         |                    |
|                                                                     | 23 Secured mortgages and notes payable to unrelated third parties                                                                                                       |                          | 23         |                    |
|                                                                     | 24 Unsecured notes and loans payable to unrelated third parties                                                                                                         |                          | 24         |                    |
|                                                                     | 25 Other liabilities. Complete Part X of Schedule D                                                                                                                     |                          | 25         |                    |
|                                                                     | 26 <b>Total liabilities.</b> Add lines 17 through 25                                                                                                                    | 1,933,009.               | 26         | 2,072,323.         |
| <b>Net Assets or Fund Balances</b>                                  | Organizations that follow SFAS 117, check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.                               |                          |            |                    |
|                                                                     | 27 Unrestricted net assets                                                                                                                                              | 1,728,144.               | 27         | 2,025,968.         |
|                                                                     | 28 Temporarily restricted net assets                                                                                                                                    | 15,948.                  | 28         | 70,589.            |
|                                                                     | 29 Permanently restricted net assets                                                                                                                                    | 16,438.                  | 29         | 19,079.            |
|                                                                     | Organizations that do not follow SFAS 117, check here <input type="checkbox"/> and complete lines 30 through 34.                                                        |                          |            |                    |
|                                                                     | 30 Capital stock or trust principal, or current funds                                                                                                                   |                          | 30         |                    |
|                                                                     | 31 Paid-in or capital surplus, or land, building, or equipment fund                                                                                                     |                          | 31         |                    |
|                                                                     | 32 Retained earnings, endowment, accumulated income, or other funds                                                                                                     |                          | 32         |                    |
|                                                                     | 33 <b>Total net assets or fund balances</b>                                                                                                                             | 1,760,530.               | 33         | 2,115,636.         |
| 34 <b>Total liabilities and net assets/fund balances</b>            | 3,693,539.                                                                                                                                                              | 34                       | 4,187,959. |                    |

Form 990 (2009)

**Part XI Financial Statements and Reporting**

1 Accounting method used to prepare the Form 990: ☐ Cash ☒ Accrual ☐ Other \_\_\_\_\_

If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.

2a Were the organization's financial statements compiled or reviewed by an independent accountant? .....

b Were the organization's financial statements audited by an independent accountant? .....

c If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? .....

If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.

d If "Yes" to line 2a or 2b, check a box below to indicate whether the financial statements for the year were issued on a consolidated basis, separate basis, or both:

☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis

3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133? .....

b If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits. ....

Yes No

2a X

2b X

2c X

3a X

3b

Form 990 (2009)

Department of the Treasury  
Internal Revenue Service

**Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.**

▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

OMB No. 1545-0047

2009

**Open to Public Inspection**

Name of the organization

Employer identification number

31-1682518

International Rett Syndrome Foundation

|        |                                                                                                 |  |
|--------|-------------------------------------------------------------------------------------------------|--|
| Part I | Reason for Public Charity Status (All organizations must complete this part.) See instructions. |  |
|--------|-------------------------------------------------------------------------------------------------|--|

The organization is not a private foundation because it is: (For lines 1 through 11, check only one box.)

- 1 ☐ A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i).**

2 ☐ A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E.)

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

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

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

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

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

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

9 ☐ An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions - subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2).** (Complete Part III.)

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

11 ☐ An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2).** See **section 509(a)(3).** Check the box that describes the type of supporting organization and complete lines 11e through 11h.

a ☐ Type I      b ☐ Type II      c ☐ Type III - Functionally integrated      d ☐ Type III - Other

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

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

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

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

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

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

h Provide the following information about the supported organization(s).

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

[illegible]

**LHA For Privacy Act and Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.**

Schedule A (Form 990 or 990-EZ) 2009

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

(Complete only if you checked the box on line 5, 7, or 8 of Part I.)

**Section A. Public Support**

| Calendar year (or fiscal year beginning in) ▶                                                                                                                                                         | (a) 2005 | (b) 2006 | (c) 2007 | (d) 2008 | (e) 2009 | (f) Total |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------|----------|----------|----------|----------|-----------|
| 1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")                                                                                                  | 2369694. | 2925887. | 3952569. | 3837630. | 3588547. | 16674327. |
| 2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf                                                                                                     |          |          |          |          |          |           |
| 3 The value of services or facilities furnished by a governmental unit to the organization without charge                                                                                             |          |          |          |          |          |           |
| 4 <b>Total.</b> Add lines 1 through 3                                                                                                                                                                 | 2369694. | 2925887. | 3952569. | 3837630. | 3588547. | 16674327. |
| 5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f) |          |          |          |          |          |           |
| 6 <b>Public support.</b> Subtract line 5 from line 4.                                                                                                                                                 |          |          |          |          |          | 16674327. |

**Section B. Total Support**

| Calendar year (or fiscal year beginning in) ▶                                                                                                                                           | (a) 2005 | (b) 2006 | (c) 2007 | (d) 2008 | (e) 2009 | (f) Total                  |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------|----------|----------|----------|----------|----------------------------|
| 7 Amounts from line 4                                                                                                                                                                   | 2369694. | 2925887. | 3952569. | 3837630. | 3588547. | 16674327.                  |
| 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources                                                        | 39,592.  | 76,551.  | 115,298. | 101,605. | 10,113.  | 343,159.                   |
| 9 Net income from unrelated business activities, whether or not the business is regularly carried on                                                                                    |          |          |          |          |          |                            |
| 10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)                                                                                      |          |          |          |          |          |                            |
| 11 <b>Total support.</b> Add lines 7 through 10                                                                                                                                         |          |          |          |          |          | 17017486.                  |
| 12 Gross receipts from related activities, etc. (see instructions)                                                                                                                      |          |          |          |          | 12       | 3,962,780.                 |
| 13 <b>First five years.</b> If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here |          |          |          |          |          | ▶ <input type="checkbox"/> |

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

|                                                                                                                                                                                                                                                                                                                                                                                                       |    |       |                                       |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|-------|---------------------------------------|
| 14 Public support percentage for 2009 (line 6, column (f) divided by line 11, column (f))                                                                                                                                                                                                                                                                                                             | 14 | 97.98 | %                                     |
| 15 Public support percentage from 2008 Schedule A, Part II, line 14                                                                                                                                                                                                                                                                                                                                   | 15 | 96.65 | %                                     |
| 16a <b>33 1/3% support test - 2009.</b> If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization                                                                                                                                                                           |    |       | ▶ <input checked="" type="checkbox"/> |
| b <b>33 1/3% support test - 2008.</b> If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization                                                                                                                                                                        |    |       | ▶ <input type="checkbox"/>            |
| 17a <b>10% -facts-and-circumstances test - 2009.</b> If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test The organization qualifies as a publicly supported organization    |    |       | ▶ <input type="checkbox"/>            |
| b <b>10% -facts-and-circumstances test - 2008.</b> If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test The organization qualifies as a publicly supported organization |    |       | ▶ <input type="checkbox"/>            |
| 18 <b>Private foundation.</b> If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions                                                                                                                                                                                                                                                          |    |       | ▶ <input type="checkbox"/>            |

Schedule A (Form 990 or 990-EZ) 2009

**Part III Support Schedule for Organizations Described in Section 509(a)(2)** (Complete only if you checked the box on line 9 of Part I.)**Section A. Public Support**

| Calendar year (or fiscal year beginning in) ▶                                                                                                                                     | (a) 2005 | (b) 2006 | (c) 2007 | (d) 2008 | (e) 2009 | (f) Total |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------|----------|----------|----------|----------|-----------|
| <b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")                                                                       |          |          |          |          |          |           |
| <b>2</b> Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose |          |          |          |          |          |           |
| <b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513                                                                             |          |          |          |          |          |           |
| <b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf                                                                          |          |          |          |          |          |           |
| <b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge                                                                  |          |          |          |          |          |           |
| <b>6 Total.</b> Add lines 1 through 5                                                                                                                                             |          |          |          |          |          |           |
| <b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons                                                                                                |          |          |          |          |          |           |
| <b>b</b> Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year           |          |          |          |          |          |           |
| <b>c</b> Add lines 7a and 7b                                                                                                                                                      |          |          |          |          |          |           |
| <b>8 Public support</b> (Subtract line 7c from line 6)                                                                                                                            |          |          |          |          |          |           |

**Section B. Total Support**

| Calendar year (or fiscal year beginning in) ▶                                                                                             | (a) 2005 | (b) 2006 | (c) 2007 | (d) 2008 | (e) 2009 | (f) Total |
|-------------------------------------------------------------------------------------------------------------------------------------------|----------|----------|----------|----------|----------|-----------|
| <b>9</b> Amounts from line 6                                                                                                              |          |          |          |          |          |           |
| <b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources |          |          |          |          |          |           |
| <b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975                          |          |          |          |          |          |           |
| <b>c</b> Add lines 10a and 10b                                                                                                            |          |          |          |          |          |           |
| <b>11</b> Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on     |          |          |          |          |          |           |
| <b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)                                 |          |          |          |          |          |           |
| <b>13 Total support</b> (Add lines 9, 10c, 11, and 12)                                                                                    |          |          |          |          |          |           |

**14 First five years.** If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here ☐

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

|                                                                                                  |           |   |
|--------------------------------------------------------------------------------------------------|-----------|---|
| <b>15</b> Public support percentage for 2009 (line 8, column (f) divided by line 13, column (f)) | <b>15</b> | % |
| <b>16</b> Public support percentage from 2008 Schedule A, Part III, line 15                      | <b>16</b> | % |

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

|                                                                                                       |           |   |
|-------------------------------------------------------------------------------------------------------|-----------|---|
| <b>17</b> Investment income percentage for 2009 (line 10c, column (f) divided by line 13, column (f)) | <b>17</b> | % |
| <b>18</b> Investment income percentage from 2008 Schedule A, Part III, line 17                        | <b>18</b> | % |

**19a 33 1/3% support tests - 2009.** If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization ☐

**b 33 1/3% support tests - 2008.** If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization ☐

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

Schedule A (Form 990 or 990-EZ) 2009

**Schedule D**  
(Form 990)

Department of the Treasury  
Internal Revenue Service

**Supplemental Financial Statements**

- ▶ Complete if the organization answered "Yes," to Form 990,  
Part IV, line 6, 7, 8, 9, 10, 11, or 12.  
▶ Attach to Form 990. ▶ See separate instructions.

OMB No 1545-0047

**2009**

Open to Public  
Inspection

Name of the organization

International Rett Syndrome Foundation

Employer identification number

31-1682518

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

|                                                                                                                                                                                                                                                                       | (a) Donor advised funds | (b) Funds and other accounts                             |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------|----------------------------------------------------------|
| 1 Total number at end of year                                                                                                                                                                                                                                         |                         |                                                          |
| 2 Aggregate contributions to (during year)                                                                                                                                                                                                                            |                         |                                                          |
| 3 Aggregate grants from (during year)                                                                                                                                                                                                                                 |                         |                                                          |
| 4 Aggregate value at end of year                                                                                                                                                                                                                                      |                         |                                                          |
| 5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control?                                                            |                         | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? |                         | <input type="checkbox"/> Yes <input type="checkbox"/> No |

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

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

|                                                                                             |                                                                              |
|---------------------------------------------------------------------------------------------|------------------------------------------------------------------------------|
| <input type="checkbox"/> Preservation of land for public use (e.g., recreation or pleasure) | <input type="checkbox"/> Preservation of an historically important land area |
| <input type="checkbox"/> Protection of natural habitat                                      | <input type="checkbox"/> Preservation of a certified historic structure      |
| <input type="checkbox"/> Preservation of open space                                         |                                                                              |

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

|                                                                                      | Held at the End of the Tax Year |
|--------------------------------------------------------------------------------------|---------------------------------|
| a Total number of conservation easements                                             | 2a                              |
| b Total acreage restricted by conservation easements                                 | 2b                              |
| c Number of conservation easements on a certified historic structure included in (a) | 2c                              |
| d Number of conservation easements included in (c) acquired after 8/17/06            | 2d                              |

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

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

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

6 Staff and volunteer hours devoted to monitoring, inspecting, and enforcing conservation easements during the year ▶

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

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

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

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

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

1a If the organization elected, as permitted under SFAS 116, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIV, the text of the footnote to its financial statements that describes these items

b If the organization elected, as permitted under SFAS 116, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items:

(i) Revenues included in Form 990, Part VIII, line 1 ▶ \$

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

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 relating to these items:

a Revenues included in Form 990, Part VIII, line 1 ▶ \$

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

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

3 Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items

(check all that apply):

a ☐ Public exhibitiond ☐ Loan or exchange programsb ☐ Scholarly researche ☐ Other \_\_\_\_\_c ☐ Preservation for future generations

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

5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets

to be sold to raise funds rather than to be maintained as part of the organization's collection?

☐ Yes☐ No**Part IV Escrow and Custodial Arrangements.** Complete if organization answered "Yes" to Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?

☐ Yes☐ No

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

c Beginning balance

d Additions during the year

e Distributions during the year

f Ending balance

|    | Amount |
|----|--------|
| 1c |        |
| 1d |        |
| 1e |        |
| 1f |        |

2a Did the organization include an amount on Form 990, Part X, line 21?

☐ Yes☐ No

b If "Yes," explain the arrangement in Part XIV.

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

|                                                  | (a) Current year | (b) Prior year | (c) Two years back | (d) Three years back | (e) Four years back |
|--------------------------------------------------|------------------|----------------|--------------------|----------------------|---------------------|
| 1a Beginning of year balance                     | 16,438.          | 25,876.        |                    |                      |                     |
| b Contributions                                  |                  |                |                    |                      |                     |
| c Net investment earnings, gains, and losses     | 2,641.           | <9,438.>       |                    |                      |                     |
| d Grants or scholarships                         |                  |                |                    |                      |                     |
| e Other expenditures for facilities and programs |                  |                |                    |                      |                     |
| f Administrative expenses                        |                  |                |                    |                      |                     |
| g End of year balance                            | 19,079.          | 16,438.        |                    |                      |                     |

2 Provide the estimated percentage of the year end balance held as:

a Board designated or quasi-endowment ▶ .00 %

b Permanent endowment ▶ 100.00 %

c Term endowment ▶ .00 %

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

(i) unrelated organizations

(ii) related organizations

|        | Yes | No |
|--------|-----|----|
| 3a(i)  | X   |    |
| 3a(ii) |     | X  |
| 3b     |     |    |

b If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?

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

**Part VI Investments - Land, Buildings, and Equipment.** See Form 990, Part X, line 10.

| Description of investment                                                                        | (a) Cost or other basis (investment) | (b) Cost or other basis (other) | (c) Accumulated depreciation | (d) Book value |
|--------------------------------------------------------------------------------------------------|--------------------------------------|---------------------------------|------------------------------|----------------|
| 1a Land                                                                                          |                                      |                                 |                              |                |
| b Buildings                                                                                      |                                      |                                 |                              |                |
| c Leasehold improvements                                                                         |                                      |                                 |                              |                |
| d Equipment                                                                                      |                                      |                                 |                              |                |
| e Other                                                                                          |                                      | 47,491.                         | 13,870.                      | 33,621.        |
| Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c)) |                                      |                                 |                              | 33,621.        |

Schedule D (Form 990) 2009

**Part VII Investments - Other Securities.** See Form 990, Part X, line 12.

| (a) Description of security or category<br>(including name of security) | (b) Book value | (c) Method of valuation:<br>Cost or end-of-year market value |
|-------------------------------------------------------------------------|----------------|--------------------------------------------------------------|
| Financial derivatives .....                                             |                |                                                              |
| Closely-held equity interests .....                                     |                |                                                              |
| Other .....                                                             |                |                                                              |
|                                                                         |                |                                                              |
|                                                                         |                |                                                              |
|                                                                         |                |                                                              |
|                                                                         |                |                                                              |
|                                                                         |                |                                                              |
|                                                                         |                |                                                              |
|                                                                         |                |                                                              |
|                                                                         |                |                                                              |
|                                                                         |                |                                                              |
|                                                                         |                |                                                              |
| <b>Total.</b> (Col (b) must equal Form 990, Part X, col (B) line 12.) ▶ |                |                                                              |

|                  |                                                                      |
|------------------|----------------------------------------------------------------------|
| <b>Part VIII</b> | <b>Investments - Program Related.</b> See Form 990, Part X, line 13. |
|------------------|----------------------------------------------------------------------|

| (a) Description of investment type                               | (b) Book value | (c) Method of valuation:<br>Cost or end-of-year market value |
|------------------------------------------------------------------|----------------|--------------------------------------------------------------|
|                                                                  |                |                                                              |
|                                                                  |                |                                                              |
|                                                                  |                |                                                              |
|                                                                  |                |                                                              |
|                                                                  |                |                                                              |
|                                                                  |                |                                                              |
|                                                                  |                |                                                              |
|                                                                  |                |                                                              |
|                                                                  |                |                                                              |
|                                                                  |                |                                                              |
|                                                                  |                |                                                              |
| Total. (Col (b) must equal Form 990, Part X, col (B) line 13.) ▶ |                |                                                              |

|                |                                                     |
|----------------|-----------------------------------------------------|
| <b>Part IX</b> | <b>Other Assets.</b> See Form 990, Part X, line 15. |
|----------------|-----------------------------------------------------|

[illegible]

|               |                                                          |
|---------------|----------------------------------------------------------|
| <b>Part X</b> | <b>Other Liabilities.</b> See Form 990, Part X, line 25. |
|---------------|----------------------------------------------------------|

| 1 | (a) Description of liability                                             | (b) Amount |
|---|--------------------------------------------------------------------------|------------|
|   | Federal income taxes                                                     |            |
|   |                                                                          |            |
|   |                                                                          |            |
|   |                                                                          |            |
|   |                                                                          |            |
|   |                                                                          |            |
|   |                                                                          |            |
|   |                                                                          |            |
|   |                                                                          |            |
|   |                                                                          |            |
|   |                                                                          |            |
|   | <b>Total.</b> (Column (b) must equal Form 990, Part X, col (B) line 25.) |            |

2. FIN 48 Footnote. In Part XIV, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48

**Part XI Reconciliation of Change in Net Assets from Form 990 to Audited Financial Statements**

|    |                                                                                          |    |            |
|----|------------------------------------------------------------------------------------------|----|------------|
| 1  | Total revenue (Form 990, Part VIII, column (A), line 12)                                 | 1  | 3,842,202. |
| 2  | Total expenses (Form 990, Part IX, column (A), line 25)                                  | 2  | 3,489,796. |
| 3  | Excess or (deficit) for the year. Subtract line 2 from line 1                            | 3  | 352,406.   |
| 4  | Net unrealized gains (losses) on investments                                             | 4  | 59.        |
| 5  | Donated services and use of facilities                                                   | 5  |            |
| 6  | Investment expenses                                                                      | 6  |            |
| 7  | Prior period adjustments                                                                 | 7  |            |
| 8  | Other (Describe in Part XIV.)                                                            | 8  | 2,641.     |
| 9  | Total adjustments (net). Add lines 4 through 8                                           | 9  | 2,700.     |
| 10 | Excess or (deficit) for the year per audited financial statements. Combine lines 3 and 9 | 10 | 355,106.   |

**Part XII Reconciliation of Revenue per Audited Financial Statements With Revenue per Return**

|   |                                                                                 |    |            |
|---|---------------------------------------------------------------------------------|----|------------|
| 1 | Total revenue, gains, and other support per audited financial statements        | 1  | 4,667,867. |
| 2 | Amounts included on line 1 but not on Form 990, Part VIII, line 12:             |    |            |
| a | Net unrealized gains on investments                                             | 2a | 59.        |
| b | Donated services and use of facilities                                          | 2b | 20,850.    |
| c | Recoveries of prior year grants                                                 | 2c |            |
| d | Other (Describe in Part XIV.)                                                   | 2d | 2,641.     |
| e | Add lines 2a through 2d                                                         | 2e | 23,550.    |
| 3 | Subtract line 2e from line 1                                                    | 3  | 4,644,317. |
| 4 | Amounts included on Form 990, Part VIII, line 12, but not on line 1:            |    |            |
| a | Investment expenses not included on Form 990, Part VIII, line 7b                | 4a |            |
| b | Other (Describe in Part XIV.)                                                   | 4b | <802,115.> |
| c | Add lines 4a and 4b                                                             | 4c | <802,115.> |
| 5 | Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.) | 5  | 3,842,202. |

**Part XIII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return**

|   |                                                                                  |    |            |
|---|----------------------------------------------------------------------------------|----|------------|
| 1 | Total expenses and losses per audited financial statements                       | 1  | 4,312,761. |
| 2 | Amounts included on line 1 but not on Form 990, Part IX, line 25:                |    |            |
| a | Donated services and use of facilities                                           | 2a | 20,850.    |
| b | Prior year adjustments                                                           | 2b |            |
| c | Other losses                                                                     | 2c |            |
| d | Other (Describe in Part XIV.)                                                    | 2d | 802,115.   |
| e | Add lines 2a through 2d                                                          | 2e | 822,965.   |
| 3 | Subtract line 2e from line 1                                                     | 3  | 3,489,796. |
| 4 | Amounts included on Form 990, Part IX, line 25, but not on line 1:               |    |            |
| a | Investment expenses not included on Form 990, Part VIII, line 7b                 | 4a |            |
| b | Other (Describe in Part XIV.)                                                    | 4b |            |
| c | Add lines 4a and 4b                                                              | 4c | 0.         |
| 5 | Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.) | 5  | 3,489,796. |

**Part XIV Supplemental Information**

Complete this part to provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, line 8; Part XII, lines 2d and 4b, and Part XIII, lines 2d and 4b. Also complete this part to provide any additional information.

**Part V, line 4: Distributions from charitable remainder trust are used**

**for general operating expenses.**

**Part XI, Line 8 - Other Adjustments:**

**Change in Beneficial Interest in Trust: 2641.**

**Part XII, Line 2d - Other Adjustments:**

**Change in Beneficial Interest in Trust: 2641.**

**Part XIV** Supplemental Information (continued)

Part XII, Line 4b - Other Adjustments:

Special Event Expense: -802115.

Part XIII, Line 2d - Other Adjustments:

Special Event Expense: 802115.

Department of the Treasury  
Internal Revenue Service

▶ **Complete if the organization answered "Yes" to Form 990, Part IV, line 14b, 15, or 16.**  
▶ **Attach to Form 990. ▶ See separate instructions.**

OMB No. 1545-0047

# 2009

**Open to Public Inspection**

**Name of the organization**

Employer identification number

International Rett Syndrome Foundation

31-1682518

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

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

**3 Activities per Region. (Use Schedule F-1 (Form 990) if additional space is needed )**

| (a) Region | (b) Number of offices in the region | (c) Number of employees or agents in region | (d) Activities conducted in region (by type) (i.e., fundraising, program services, grants to recipients located in the region) | (e) If activity listed in (d) is a program service, describe specific type of service(s) in region | (f) Total expenditures for region |
|------------|-------------------------------------|---------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------|-----------------------------------|
|            |                                     |                                             |                                                                                                                                |                                                                                                    |                                   |
|            |                                     |                                             |                                                                                                                                |                                                                                                    |                                   |
|            |                                     |                                             |                                                                                                                                |                                                                                                    |                                   |
|            |                                     |                                             |                                                                                                                                |                                                                                                    |                                   |
|            |                                     |                                             |                                                                                                                                |                                                                                                    |                                   |
|            |                                     |                                             |                                                                                                                                |                                                                                                    |                                   |
|            |                                     |                                             |                                                                                                                                |                                                                                                    |                                   |
|            |                                     |                                             |                                                                                                                                |                                                                                                    |                                   |
|            |                                     |                                             |                                                                                                                                |                                                                                                    |                                   |
|            |                                     |                                             |                                                                                                                                |                                                                                                    |                                   |
| Totals     | 0                                   | 0                                           |                                                                                                                                |                                                                                                    | 0                                 |

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

Schedule F (Form 990) 2009



**Use Schedule F-1 (Form 990) if additional space is needed.**

[illegible]

**Part IV** Supplemental Information

Complete this part to provide the information required in Part I, line 2, and any additional information.

Schedule F, Part I, Line 2: The Foundation makes quarterly payments to researchers outside of the United States. They are required to file progress reports on their research two times a year. The Chief Scientific Officer reviews the reports and corresponds with the researcher to ensure proper use of funds.

Department of the Treasury  
Internal Revenue Service

▶ **Complete if the organization answered "Yes" to Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.**  
▶ **Attach to Form 990 or Form 990-EZ.** ▶ **See separate instructions.**

OMB No. 1545-0047

# 2009

**Open To Public Inspection**

Name of the organization

International Rett Syndrome Foundation

Employer identification number

31-1682518

## Part I

**Fundraising Activities.** Complete if the organization answered "Yes" to Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.

- 1** Indicate whether the organization raised funds through any of the following activities. Check all that apply.

- a ☐ Mail solicitations  
b ☐ Internet and email solicitations  
c ☐ Phone solicitations  
d ☐ In-person solicitations  
e ☐ Solicitation of non-government grants  
f ☐ Solicitation of government grants  
g ☐ Special fundraising events

- 2 a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?

☐ Yes☐ No

- b** If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

| (i) Name of individual or entity (fundraiser) | (ii) Activity | (iii) Did fundraiser have custody or control of contributions? |    | (iv) Gross receipts from activity | (v) Amount paid to (or retained by) fundraiser listed in col. (i) | (vi) Amount paid to (or retained by) organization |
|-----------------------------------------------|---------------|----------------------------------------------------------------|----|-----------------------------------|-------------------------------------------------------------------|---------------------------------------------------|
|                                               |               | Yes                                                            | No |                                   |                                                                   |                                                   |
|                                               |               |                                                                |    |                                   |                                                                   |                                                   |
|                                               |               |                                                                |    |                                   |                                                                   |                                                   |
|                                               |               |                                                                |    |                                   |                                                                   |                                                   |
|                                               |               |                                                                |    |                                   |                                                                   |                                                   |
|                                               |               |                                                                |    |                                   |                                                                   |                                                   |
|                                               |               |                                                                |    |                                   |                                                                   |                                                   |
|                                               |               |                                                                |    |                                   |                                                                   |                                                   |
|                                               |               |                                                                |    |                                   |                                                                   |                                                   |
|                                               |               |                                                                |    |                                   |                                                                   |                                                   |
|                                               |               |                                                                |    |                                   |                                                                   |                                                   |
| <b>Total</b>                                  |               |                                                                |    |                                   |                                                                   |                                                   |

**Total**

- 3 List all states in which the organization is registered or licensed to solicit funds or has been notified it is exempt from registration or licensing.

**Part II Fundraising Events.** Complete if the organization answered "Yes" to Form 990, Part IV, line 18, or reported more than \$15,000 on Form 990-EZ, line 6a. List events with gross receipts greater than \$5,000

|                 |                                                                | (a) Event #1<br>Boston<br>Festival | (b) Event #2<br>New York<br>Picture a Cu | (c) Other events<br>38 | (d) Total events<br>(add col. (a) through<br>col. (c)) |
|-----------------|----------------------------------------------------------------|------------------------------------|------------------------------------------|------------------------|--------------------------------------------------------|
|                 |                                                                | (event type)                       | (event type)                             | (total number)         |                                                        |
| Revenue         | 1 Gross receipts                                               | 709,921.                           | 327,753.                                 | 1,749,448.             | 2,787,122.                                             |
|                 | 2 Less: Charitable contributions                               | 335,458.                           | 193,593.                                 | 1,441,578.             | 1,970,629.                                             |
|                 | 3 Gross income (line 1 minus line 2)                           | 374,463.                           | 134,160.                                 | 307,870.               | 816,493.                                               |
| Direct Expenses | 4 Cash prizes                                                  |                                    |                                          |                        |                                                        |
|                 | 5 Noncash prizes                                               | 151,912.                           | 56,495.                                  |                        | 208,407.                                               |
|                 | 6 Rent/facility costs                                          | 30,000.                            | 6,000.                                   | 97,603.                | 133,603.                                               |
|                 | 7 Food and beverages                                           | 42,563.                            | 35,605.                                  | 57,726.                | 135,894.                                               |
|                 | 8 Entertainment                                                |                                    |                                          | 9,777.                 | 9,777.                                                 |
|                 | 9 Other direct expenses                                        | 15,765.                            | 19,124.                                  | 208,073.               | 242,962.                                               |
|                 | 10 Direct expense summary. Add lines 4 through 9 in column (d) |                                    |                                          |                        | ( 730,643 )                                            |
|                 | 11 Net income summary. Combine line 3, column (d), and line 10 |                                    |                                          |                        | 85,850.                                                |

**Part III Gaming.** Complete if the organization answered "Yes" to Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

|                 |                                                                     | (a) Bingo                                                           | (b) Pull tabs/instant<br>bingo/progressive bingo                    | (c) Other gaming                                                    | (d) Total gaming (add<br>col. (a) through col. (c)) |
|-----------------|---------------------------------------------------------------------|---------------------------------------------------------------------|---------------------------------------------------------------------|---------------------------------------------------------------------|-----------------------------------------------------|
|                 |                                                                     |                                                                     |                                                                     |                                                                     |                                                     |
| Revenue         | 1 Gross revenue                                                     |                                                                     |                                                                     |                                                                     |                                                     |
|                 | 2 Cash prizes                                                       |                                                                     |                                                                     |                                                                     |                                                     |
| Direct Expenses | 3 Noncash prizes                                                    |                                                                     |                                                                     |                                                                     |                                                     |
|                 | 4 Rent/facility costs                                               |                                                                     |                                                                     |                                                                     |                                                     |
|                 | 5 Other direct expenses                                             |                                                                     |                                                                     |                                                                     |                                                     |
|                 | 6 Volunteer labor                                                   | <input type="checkbox"/> Yes _____ %<br><input type="checkbox"/> No | <input type="checkbox"/> Yes _____ %<br><input type="checkbox"/> No | <input type="checkbox"/> Yes _____ %<br><input type="checkbox"/> No |                                                     |
|                 | 7 Direct expense summary. Add lines 2 through 5 in column (d)       |                                                                     |                                                                     |                                                                     | ( )                                                 |
|                 | 8 Net gaming income summary. Combine line 1, column (d), and line 7 |                                                                     |                                                                     |                                                                     |                                                     |

9 Enter the state(s) in which the organization operates gaming activities \_\_\_\_\_

a Is the organization licensed to operate gaming activities in each of these states?

b If "No," explain:

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year?

b If "Yes," explain:

11 Does the organization operate gaming activities with nonmembers?

12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming?

|     | Yes | No |
|-----|-----|----|
| 9a  |     |    |
| 10a |     |    |
| 11  |     |    |
| 12  |     |    |

**13** Indicate the percentage of gaming activity operated in:

- a The organization's facility 13a %
- b An outside facility 13b %

**14** Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name ► \_\_\_\_\_

Address ► \_\_\_\_\_

**15a** Does the organization have a contract with a third party from whom the organization receives gaming revenue? 15a

- b If "Yes," enter the amount of gaming revenue received by the organization ► \$ \_\_\_\_\_ and the amount of gaming revenue retained by the third party ► \$ \_\_\_\_\_

## c If "Yes," enter name and address of the third party:

Name ► \_\_\_\_\_

Address ► \_\_\_\_\_

**16** Gaming manager information

Name ► \_\_\_\_\_

Gaming manager compensation ► \$ \_\_\_\_\_

Description of services provided ► \_\_\_\_\_

☐ Director/officer
                    
 ☐ Employee
                    
 ☐ Independent contractor
**17** Mandatory distributions:

- a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? 17a
- b Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ► \$ \_\_\_\_\_

Schedule G (Form 990 or 990-EZ) 2009

**SCHEDULE I**  
**(Form 990)**

Department of the Treasury  
Internal Revenue Service

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

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

OMB No 1545-0047

**2009**

Open to Public  
Inspection

Name of the organization

**International Rett Syndrome Foundation**

Employer identification number  
**31-1682518**

**1** Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?

☒ Yes ☐ No

**2** Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States

**Part II** **Grants and Other Assistance to Governments and Organizations in the United States.** Complete if the organization answered "Yes" to Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Check this box if no one recipient received more than \$5,000. Use Part IV and Schedule I-1 (Form 990) if additional space is needed. ▶ ☐

| 1 (a) Name and address of organization or government                             | (b) EIN    | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|----------------------------------------------------------------------------------|------------|-------------------------------|--------------------------|-----------------------------------|-------------------------------------------------------|----------------------------------------|------------------------------------|
| A.I. duPont Children's<br>1600 Rockland Rd.<br>Wilmington, DE 19803              | 59-0634433 | 501(c)(3)                     | 150,000.                 | 0.                                |                                                       |                                        | Rett Syndrome Research             |
| Baylor College of Medicine<br>1 Baylor Plz # 672E<br>Houston, TX 77030           | 74-1613878 | 501(c)(3)                     | 100,000.                 | 0.                                |                                                       |                                        | Rett Syndrome Research             |
| Oregon Health & Science University<br>611 SW Campus Dr.<br>Portland, OR 97239    | 93-1176109 | 501(c)(3)                     | 99,000.                  | 0.                                |                                                       |                                        | Rett Syndrome Research             |
| UCLA Medical Center<br>10920 Wilshire Boulevard<br>Los Angeles, CA 90095         | 95-6006143 | 501(c)(3)                     | 100,000.                 | 0.                                |                                                       |                                        | Rett Syndrome Research             |
| Cold Spring Harbor Laboratory<br>1 Bungtown Road<br>Cold Spring Harbor, NY 11724 | 11-2013303 | 501(c)(3)                     | 100,000.                 | 0.                                |                                                       |                                        | Rett Syndrome Research             |
| Boston Children's Hospital<br>300 Longwood, Fegan 11<br>Boston, MA 02115         | 01-2774441 | 501(c)(3)                     | 200,000.                 | 0.                                |                                                       |                                        | Rett Syndrome Research             |

**2** Enter total number of section 501(c)(3) and government organizations

14.

**3** Enter total number of other organizations

0.

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

Schedule I (Form 990) 2009

**Part III**

Grants and Other Assistance to Individuals in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 22.  
Use Part IV and Schedule I-1 (Form 990) if additional space is needed.

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

**Part IV** Supplemental Information. Complete this part to provide the information required in Part I, line 2, and any other additional information.

Schedule I, Part I, Line 2: Grantees are required to submit an interim report on their research every 6 months. They are required to attend a yearly symposium sponsored by the Foundation and (in the second year of their grant) they must submit a poster at the symposium. Also, the Chief Scientific Officer keeps in touch by phone with researchers.

**SCHEDULE I-1**

(Form 990)

Department of the Treasury  
Internal Revenue Service

Continuation Sheet for Schedule I (Form 990)  
▶ Attach to Form 990 to list additional information for  
Schedule I (Form 990), Part II or Part III.

OMB No. 1545-0047

2009

Open to Public  
Inspection

Name of the organization

**International Rett Syndrome Foundation**

Employer identification number

31-1682518

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

| (a) Name and address of organization or government                                         | (b) EIN    | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|--------------------------------------------------------------------------------------------|------------|-------------------------------|--------------------------|-----------------------------------|-------------------------------------------------------|----------------------------------------|------------------------------------|
| New York University at Sunny Brook<br>Department of Neurology<br>Stony Brook, NY 11794     | 11-2587430 | 501(c)(3)                     | 100,000.                 | 0.                                |                                                       |                                        | Rett Syndrome Research             |
| California Institute of Technology<br>1200 East California Boulevard<br>Pasadena, CA 91125 | 95-1643307 | 501(c)(3)                     | 100,000.                 | 0.                                |                                                       |                                        | Rett Syndrome Research             |
| University of New Mexico<br>1 University of New Mexico<br>Albuquerque, NM 87131            | 85-6000542 | 501(c)(3)                     | 100,000.                 | 0.                                |                                                       |                                        | Rett Syndrome Research             |
| Northwestern University<br>633 Clark Street<br>Evanston, IL 60208                          | 36-2167817 | 501(c)(3)                     | 100,000.                 | 0.                                |                                                       |                                        | Rett Syndrome Research             |
| University of N. Carolina, Chapel Hill - P.O. Box 309 - Chapel Hill, NC 27514              | 56-6001393 | 501(c)(3)                     | 100,000.                 | 0.                                |                                                       |                                        | Rett Syndrome Research             |
| University of Massachusetts<br>225 Franklin St., 33rd Fl<br>Boston, MA 02110               | 04-6013152 | 501(c)(3)                     | 99,998.                  | 0.                                |                                                       |                                        | Rett Syndrome Research             |
| UC, San Diego<br>9500 Gillman Street<br>LaJolla, CA 92093                                  | 95-6006144 | 501(c)(3)                     | 200,000.                 | 0.                                |                                                       |                                        | Rett Syndrome Research             |
| University of Illinois at Chicago<br>833 South Wood Street<br>Chicago, IL 60612            | 37-6000511 | 501(c)(3)                     | 129,866.                 | 0.                                |                                                       |                                        | Rett Syndrome Research             |

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

Schedule I-1 (Form 990) 2009

**SCHEDULE J  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Compensation Information**

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

► Complete if the organization answered "Yes" to Form 990,  
Part IV, line 23.

► Attach to Form 990. ► See separate instructions.

OMB No 1545-0047

**2009**

Open to Public  
Inspection

Name of the organization

**International Rett Syndrome Foundation**

Employer identification number

**31-1682518**

**Part I Questions Regarding Compensation**

**1a** Check the appropriate box(es) if the organization provided any of the following to or for a person listed in Form 990,  
Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.

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

**b** If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or  
reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain

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

**3** Indicate which, if any, of the following the organization uses to establish the compensation of the organization's  
CEO/Executive Director. Check all that apply

- |                                                                         |                                                                                     |
|-------------------------------------------------------------------------|-------------------------------------------------------------------------------------|
| <input checked="" type="checkbox"/> Compensation committee              | <input checked="" type="checkbox"/> Written employment contract                     |
| <input checked="" type="checkbox"/> Independent compensation consultant | <input type="checkbox"/> Compensation survey or study                               |
| <input type="checkbox"/> Form 990 of other organizations                | <input checked="" type="checkbox"/> Approval by the board or compensation committee |

**4** During the year, did any person listed in Form 990, Part VII, Section A, line 1a, with respect to the filing  
organization or a related organization:

**a** Receive a severance payment or change-of-control payment?

**b** Participate in, or receive payment from, a supplemental nonqualified retirement plan?

**c** Participate in, or receive payment from, an equity-based compensation arrangement?

If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.

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

**5** For persons listed in Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation  
contingent on the revenues of:

**a** The organization?

**b** Any related organization?

If "Yes" to line 5a or 5b, describe in Part III.

**6** For persons listed in Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation  
contingent on the net earnings of:

**a** The organization?

**b** Any related organization?

If "Yes" to line 6a or 6b, describe in Part III.

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

**8** Were any amounts reported in Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the  
initial contract exception described in Regs. section 53.4958-4(a)(3)? If "Yes," describe in Part III

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

Yes No

1b

2

4a

4b

4c

5a

5b

6a

6b

7

8

9

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

Schedule J (Form 990) 2009



**SCHEDULE L**  
(Form 990 or 990-EZ)

Department of the Treasury  
Internal Revenue Service

**Transactions With Interested Persons**

▶ Complete if the organization answered  
"Yes" on Form 990, Part IV, line 25a, 25b, 26, 27, 28a, 28b, or 28c,  
or Form 990-EZ, Part V, line 38a or 40b.  
▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

OMB No. 1545-0047

**2009**

Open To Public  
Inspection

Name of the organization

**International Rett Syndrome Foundation**

Employer identification number

**31-1682518**

**Part I Excess Benefit Transactions** (section 501(c)(3) and section 501(c)(4) organizations only).

Complete if the organization answered "Yes" on Form 990, Part IV, line 25a or 25b, or Form 990-EZ, Part V, line 40b.

| 1 | (a) Name of disqualified person | (b) Description of transaction | (c) Corrected? |    |
|---|---------------------------------|--------------------------------|----------------|----|
|   |                                 |                                | Yes            | No |
|   |                                 |                                |                |    |
|   |                                 |                                |                |    |
|   |                                 |                                |                |    |
|   |                                 |                                |                |    |
|   |                                 |                                |                |    |
|   |                                 |                                |                |    |

2 Enter the amount of tax imposed on the organization managers or disqualified persons during the year under section 4958 .....

▶ \$

3 Enter the amount of tax, if any, on line 2, above, reimbursed by the organization .....

▶ \$

**Part II Loans to and/or From Interested Persons.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 26, or Form 990-EZ, Part V, line 38a.

| (a) Name of interested person and purpose | (b) Loan to or from the organization? |      | (c) Original principal amount | (d) Balance due | (e) In default? |    | (f) Approved by board or committee? |    | (g) Written agreement? |    |
|-------------------------------------------|---------------------------------------|------|-------------------------------|-----------------|-----------------|----|-------------------------------------|----|------------------------|----|
|                                           | To                                    | From |                               |                 | Yes             | No | Yes                                 | No | Yes                    | No |
|                                           |                                       |      |                               |                 |                 |    |                                     |    |                        |    |
|                                           |                                       |      |                               |                 |                 |    |                                     |    |                        |    |
|                                           |                                       |      |                               |                 |                 |    |                                     |    |                        |    |
|                                           |                                       |      |                               |                 |                 |    |                                     |    |                        |    |
|                                           |                                       |      |                               |                 |                 |    |                                     |    |                        |    |
|                                           |                                       |      |                               |                 |                 |    |                                     |    |                        |    |
|                                           |                                       |      |                               |                 |                 |    |                                     |    |                        |    |

Total ..... ▶ \$

**Part III Grants or Assistance Benefiting Interested Persons.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 27.

| (a) Name of interested person | (b) Relationship between interested person and the organization | (c) Amount and type of assistance |
|-------------------------------|-----------------------------------------------------------------|-----------------------------------|
| <b>Carolyn Schanen</b>        | <b>Sister of IRSF Board Chair, Ka</b>                           | <b>\$25,000 Research g</b>        |
|                               |                                                                 |                                   |
|                               |                                                                 |                                   |
|                               |                                                                 |                                   |
|                               |                                                                 |                                   |
|                               |                                                                 |                                   |

**Part IV Business Transactions Involving Interested Persons.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 28a, 28b, or 28c.

| (a) Name of interested person | (b) Relationship between interested person and the organization | (c) Amount of transaction | (d) Description of transaction | (e) Sharing of organization's revenues? |    |
|-------------------------------|-----------------------------------------------------------------|---------------------------|--------------------------------|-----------------------------------------|----|
|                               |                                                                 |                           |                                | Yes                                     | No |
|                               |                                                                 |                           |                                |                                         |    |
|                               |                                                                 |                           |                                |                                         |    |
|                               |                                                                 |                           |                                |                                         |    |
|                               |                                                                 |                           |                                |                                         |    |
|                               |                                                                 |                           |                                |                                         |    |

LHA For Privacy Act and Paperwork Reduction Act Notice, see the  
Instructions for Form 990 or 990-EZ.

Schedule L (Form 990 or 990-EZ) 2009

See Schedule O for Schedule L Continuations

**SCHEDULE M**  
**(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Noncash Contributions**

► Complete if the organizations answered "Yes" on Form  
990, Part IV, lines 29 or 30.  
► Attach to Form 990.

OMB No 1545-0047

**2009**

Open to Public  
Inspection

Name of the organization

**International Rett Syndrome Foundation**

Employer identification number

**31-1682518**

**Part I** **Types of Property**

|                                                                 | (a)<br>Check if<br>applicable | (b)<br>Number of<br>contributions | (c)<br>Revenues reported on<br>Form 990, Part VIII, line 1g | (d)<br>Method of determining<br>revenues |
|-----------------------------------------------------------------|-------------------------------|-----------------------------------|-------------------------------------------------------------|------------------------------------------|
| 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                                  | X                             | 2                                 | 19,540.                                                     | Fair Market Value                        |
| 10 Securities - Closely held stock                              |                               |                                   |                                                             |                                          |
| 11 Securities - Partnership, LLC, or<br>trust interests         |                               |                                   |                                                             |                                          |
| 12 Securities - Miscellaneous                                   |                               |                                   |                                                             |                                          |
| 13 Qualified conservation contribution -<br>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 Items )                                    | X                             | 250                               | 256,774.                                                    | Retail                                   |
| 26 Other ► ( Research Equi )                                    | X                             | 1                                 | 50,000.                                                     | Retail                                   |
| 27 Other ► ( Postage )                                          | X                             | 2                                 | 1,456.                                                      | Cost                                     |
| 28 Other ► ( )                                                  |                               |                                   |                                                             |                                          |

29 Number of Forms 8283 received by the organization during the tax year for contributions  
for which the organization completed Form 8283, Part IV, Donee Acknowledgment

29

0

30a During the year, did the organization receive by contribution any property reported in Part I, lines 1-28 that it must hold for  
at least three years from the date of the initial contribution, and which is not required to be used for exempt purposes for  
the entire holding period?

Yes No

30a

X

b If "Yes," describe the arrangement in Part II

31 Does the organization have a gift acceptance policy that requires the review of any non-standard contributions?

31

X

32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash  
contributions?

32a

X

b If "Yes," describe in Part II

33 If the organization did not report revenues in column (c) for a type of property for which column (a) is checked,  
describe in Part II.

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

Schedule M (Form 990) 2009

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

Department of the Treasury  
Internal Revenue Service

**Supplemental Information to Form 990**

Complete to provide information for responses to specific questions on  
Form 990 or to provide any additional information.  
▶ Attach to Form 990.

OMB No. 1545-0047

**2009**

Open to Public  
Inspection

Name of the organization

International Rett Syndrome Foundation

Employer identification number

31-1682518

Form 990, Part I, Line 1, Description of Organization Mission:

life for those living with Rett Syndrome by providing information,  
programs and services.

Form 990, Part VI, Section B, line 11: The organization emails the 990 to  
board members, asking for comments or questions before it is filed.

Form 990, Part VI, Section B, Line 12c: Annually the entire board reviews  
the policy and a vote is taken. Additionally, when new members are elected  
they receive the policy and acknowledge their agreement.

Form 990, Part VI, Section B, Line 15: Used a recruiting firm to hire  
Chief Scientific Officer. They investigated compensation. We also  
benchmarked against other nonprofits on their websites. Compensation is  
approved by the board.

Form 990, Part VI, Line 17, List of States receiving copy of Form 990:

OH,AL,CT,IL,MA,NJ,NY,PA,WA,CO,FL,GA,MD,MI,MS,MO,OR,VA,AK,AZ,CA,DC,KS,KY,LA  
ME,NH,NM,NC,ND,OK,RI,UT,WI,IN,AR,SC,TN,TX,WV

Form 990, Part VI, Section C, Line 19: The governing documents of the  
organization are available on the Ohio Secretary of State's website. The  
financial statements are available within the annual report which is  
available upon request. The conflict of interest policy is available upon  
request.

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

Department of the Treasury  
Internal Revenue Service

**Supplemental Information to Form 990**

Complete to provide information for responses to specific questions on  
Form 990 or to provide any additional information.  
▶ Attach to Form 990.

OMB No 1545-0047

**2009**

Open to Public  
Inspection

Name of the organization

International Rett Syndrome Foundation

Employer identification number

31-1682518

Form 990, Part XI, line 2c:

There were no changes to the process in the current year.

Sch L, Part III, Grants or Assistance Benefitting Interested Persons:

(a) Name of Person: Carolyn Schanen

(b) Relationship Between Interested Person and Organization:

Sister of IRSF Board Chair, Kathryn Kissam

(c) Type of Assistance: \$25,000 Research grant