

Rett Syndrome Research Trust, Inc.

Financial Statements

December 31, 2013



**Rett Syndrome Research Trust, Inc.
December 31, 2013**

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Report of Independent Auditor

To the Board of Trustees
Rett Syndrome Research Trust, Inc.

We have audited the accompanying financial statements of Rett Syndrome Research Trust, Inc. (a nonprofit organization) which comprise the statements of financial position as of December 31, 2013 and 2012 and the related statements of activities, cash flows and functional expenses for the years then ended, and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditor's Responsibility

Our responsibility is to express an opinion on these financial statements based on our audits. We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Other Matter

Our audits were conducted for the purpose of forming an opinion on the financial statements as a whole. The Supplemental Statements of Functional Expense Allocation and Research Funded Expense Graphs, and the Research Awards and Grant Commitments and Payments Schedule are presented for purposes of additional analysis and are not a required part of the basic financial statements. Such information is the responsibility of management and was derived from and relates directly to the underlying accounting and other records used to prepare the financial statements. The information has been subjected to the auditing procedures applied in the audit of the financial statements and certain additional procedures, including comparing and reconciling such information directly to the underlying accounting and other records used to prepare the financial statements or to the financial statements themselves, and other additional procedures in accordance with auditing standards generally accepted in the United States of America. In our opinion, the information is fairly stated in all material respects in relation to the financial statements as a whole.

Opinion

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Rett Syndrome Research Trust, Inc. as of December 31, 2013 and 2012, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

Knight Rolleri Sheppard CPAS, LLP

Knight Rolleri Sheppard CPAS, LLP
Fairfield, Connecticut
April 16, 2014

Rett Syndrome Research Trust, Inc.
Statements of Financial Position
December 31, 2013 and 2012

	<u>2013</u>	<u>2012</u>
<u>ASSETS</u>		
Current assets		
Cash and cash equivalents	\$ 4,694,376	\$ 4,386,224
Promises to give	1,079,668	191,400
Investment income receivable	-	426
Investments	20	16
Total current assets	5,774,064	4,578,066
Other assets		
Website, net of accumulated amortization of \$10,442 and \$6,773 in 2013 and 2012 respectively	-	3,669
Total other assets	-	3,669
Total assets	\$ 5,774,064	\$ 4,581,735
<u>LIABILITIES AND NET ASSETS</u>		
Current liabilities		
Accounts payable	\$ 6,684	\$ 996
Grants payable	3,719,507	2,906,830
Accrued expenses	15,554	5,886
Total current liabilities	3,741,745	2,913,712
Other liabilities		
Grants payable	4,446,697	2,040,667
Total liabilities	8,188,442	4,954,379
Net assets		
Unrestricted (deficit)	(2,414,378)	(372,644)
Total net assets	(2,414,378)	(372,644)
Total liabilities and net assets	\$ 5,774,064	\$ 4,581,735

See report of independent auditor and notes to financial statements.

Rett Syndrome Research Trust, Inc.
Statements of Activities
For the Years Ended December 31, 2013 and 2012

	<u>December 31, 2013</u>			<u>December 31, 2012</u>		
	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>
Public support and revenues						
Contributions	\$ 5,498,185	\$ -	\$ 5,498,185	3,266,089	\$ 400,697	\$ 3,666,786
The Eva Fini Fund	147,251	-	147,251	144,000	-	144,000
Donated services and rent	10,500	-	10,500	8,500	-	8,500
Interest income	15,004	-	15,004	20,348	-	20,348
Realized gain from sales of donated securities	411	-	411	572	-	572
Net assets released from restriction	-	-	-	406,543	(406,543)	-
Total support and revenue	<u>5,671,351</u>	<u>-</u>	<u>5,671,351</u>	<u>3,846,052</u>	<u>(5,846)</u>	<u>3,840,206</u>
Expenses						
Program services	7,389,001	-	7,389,001	4,432,798	-	4,432,798
Supporting services:						
Management and general	65,644	-	65,644	18,541	-	18,541
Fundraising	258,440	-	258,440	141,100	-	141,100
Total expenses	<u>7,713,085</u>	<u>-</u>	<u>7,713,085</u>	<u>4,592,439</u>	<u>-</u>	<u>4,592,439</u>
Decrease in net assets from operations	(2,041,734)	-	(2,041,734)	(746,387)	(5,846)	(752,233)
Net assets (deficit) - beginning of year	<u>(372,644)</u>	<u>-</u>	<u>(372,644)</u>	<u>373,743</u>	<u>5,846</u>	<u>379,589</u>
Net assets (deficit) - end of year	<u><u>\$ (2,414,378)</u></u>	<u><u>\$ -</u></u>	<u><u>\$ (2,414,378)</u></u>	<u><u>\$ (372,644)</u></u>	<u><u>\$ -</u></u>	<u><u>\$ (372,644)</u></u>

See report of independent auditor and notes to financial statements.

Rett Syndrome Research Trust, Inc.
Statements of Cash Flows
For the Years Ended December 31, 2013 and 2012

	<u>2013</u>	<u>2012</u>
Cash flows from (used in) operating activities		
Decrease in net assets	\$ (2,041,734)	\$ (752,233)
Adjustments to reconcile increase (decrease) in net assets to cash from (used in) operating activities		
Amortization	3,669	6,039
(Increase) decrease in promises to give	(888,268)	69,820
Decrease in investment income receivable	426	57
Increase in investments	(4)	(16)
Increase (decrease) in accounts payable	5,688	(3,528)
Increase in accrued expenses	9,668	874
Increase in grants payable	3,218,707	1,479,260
Net cash provided from operating activities	<u>308,152</u>	<u>800,273</u>
 Cash flows from investing activities		
Investment in website	-	(1,636)
Net cash used in investing activities	<u>-</u>	<u>(1,636)</u>
 Increase in cash	<u>308,152</u>	<u>798,637</u>
 Cash and cash equivalents - beginning of year	<u>4,386,224</u>	<u>3,587,587</u>
 Cash and cash equivalents - end of year	<u><u>\$ 4,694,376</u></u>	<u><u>\$ 4,386,224</u></u>

See report of independent auditor and notes to financial statements.

Rett Syndrome Research Trust, Inc.
Statement of Functional Expenses
For the Year Ended December 31, 2013

	<u>Program</u>	<u>Supporting Services</u>		<u>Total Expenses</u>
		<u>Management and General</u>	<u>Fundraising</u>	
Amortization	\$ 3,669	\$ -	\$ -	\$ 3,669
Awards and grants	7,152,602	-	-	7,152,602
Bank and credit card fees	3,159	1,598	3,231	7,988
Bookkeeping (**)	979	978	978	2,935
Employee benefits	7,292	3,689	7,457	18,438
Fundraising	-	-	133,126	133,126
Graphic design	2,333	1	43	2,377
Insurance	1,208	1,208	1,208	3,624
Miscellaneous	39	20	1,908	1,967
Office and supplies	1,854	2,791	1,896	6,541
Payroll taxes	7,849	3,971	8,027	19,847
Postage and shipping	2,692	1,362	2,753	6,807
Printing and publication	6,948	2	130	7,080
Professional fees (*)	3,367	3,366	3,366	10,099
Professional fees - patent research	15,630	-	-	15,630
Rent (**)	3,000	-	-	3,000
Salaries	90,790	45,929	92,844	229,563
Scientific communications	2,700	-	-	2,700
Scientific meetings	12,333	-	-	12,333
Telephone	1,441	729	1,473	3,643
Travel - scientific meetings	68,199	-	-	68,199
Website and hosting	917	-	-	917
	<u>\$ 7,389,001</u>	<u>\$ 65,644</u>	<u>\$ 258,440</u>	<u>\$ 7,713,085</u>

(*) Includes \$5,000 of donated services.

(**) Includes donated services and rent.

See report of independent auditor and notes to financial statements.

Rett Syndrome Research Trust, Inc.
Statement of Functional Expenses
For the Year Ended December 31, 2012

	<u>Program</u>	<u>Supporting Services</u>		<u>Total Expenses</u>
		<u>Management and General</u>	<u>Fundraising</u>	
Amortization	\$ 6,039	\$ -	\$ -	\$ 6,039
Awards and grants	4,256,358	-	-	4,256,358
Bank and credit card fees	6,019	752	752	7,523
Bookkeeping (**)	984	984	984	2,952
Fundraising	-	-	110,646	110,646
Insurance	1,027	1,027	1,027	3,081
Miscellaneous	281	35	12,622	12,938
Office and supplies	1,623	983	203	2,809
Payroll taxes	7,103	888	888	8,879
Postage and shipping	2,806	351	351	3,508
Printing and publication	3,741	1	107	3,849
Professional fees (*)	2,701	2,700	2,700	8,101
Rent (**)	3,000	-	-	3,000
Research	4,250	-	-	4,250
Salaries	83,966	10,496	10,496	104,958
Scientific meetings	11,175	-	-	11,175
Telephone	2,594	324	324	3,242
Travel - scientific meetings	38,415	-	-	38,415
Website and hosting	716	-	-	716
	<u>\$ 4,432,798</u>	<u>\$ 18,541</u>	<u>\$ 141,100</u>	<u>\$ 4,592,439</u>

(*) Includes \$5,000 of donated services.

(**) Includes donated services and rent.

See report of independent auditor and notes to financial statements.

Rett Syndrome Research Trust, Inc.
Notes to Financial Statements
December 31, 2013
(See Report of Independent Auditor)

NOTE 1 – Organization

Rett Syndrome Research Trust, Inc. (the “Organization” and “RSRT”) is a not-for-profit organization formed under Internal Revenue Code 501(c)(3). The organization is focused on the development of treatments and cures for Rett Syndrome and related *MECP2* disorders. The Organization funds research projects and organizes and sponsors scientific workshops. Equally important, RSRT brings to the scientific community a deep knowledge of the disease and access to intellectual capital. It provides a comprehensive view of the field and a focus on translational efforts.

NOTE 2 – Significant Accounting Policies

Financial Statement Presentation

The Organization prepares its financial statements using guidelines established under Statement on Financial Accounting Standard Codification 958. This Standard requires that a non-profit organization provide information regarding the net assets of the organization based on the existence or absence of donor-imposed restrictions. The types of restrictions are described as follows:

Temporarily restricted net assets -The part of net assets of a not-for-profit organization resulting from contributions and other inflows of assets whose use by the organization is limited by donor – imposed stipulations that either expire by passage of time or can be fulfilled by actions of the organization pursuant to those stipulations.

Permanently restricted net assets - The part of net assets of a not-for-profit organization resulting from contributions and other inflows of assets whose use by the organization is limited by donor – imposed stipulations that neither expire by passage of time nor can be fulfilled or otherwise removed by actions of the organization pursuant to those stipulations.

Unrestricted net assets- The part of net assets of a not-for-profit organization that is neither permanently restricted nor temporarily restricted by donor- imposed stipulations.

The Organization does not maintain any permanently restricted net assets as of December 31, 2013. All restrictions on temporarily restricted net assets have been met as of December 31, 2012.

Contributions

The Organization reports gifts of cash and other assets as restricted support if they are received with donor stipulations that limit the use of the donated assets. When a donor restriction expires, that is, when a stipulated time restriction ends or purpose restriction is accomplished, temporarily restricted net assets are reclassified to unrestricted net assets and reported in the statement of activities as net assets released from restrictions.

Rett Syndrome Research Trust, Inc.
Notes to Financial Statements
December 31, 2013
(See Report of Independent Auditor)

Use of Estimates

The preparation of financial statements in conformity with generally accepted accounting principles requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosures of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenues and expenses during the reported period. These assumptions can include depreciable lives of long-lived assets, allocation of functional expenses and discount factors used to record long term grants payable to name a few. Actual results could differ from those estimates.

Cash Equivalents

For purposes of the statement of cash flows, the Organization considers all highly liquid debt instruments purchased with maturity of three months or less to be cash equivalents. The Organization maintains its cash accounts at various financial institutions across the State of Connecticut. Accounts are guaranteed by the FDIC up to \$250,000 per financial institution. As of December 31, 2013, the Organization is insured up to \$500,000 of recorded cash balances. The Organization has not experienced any losses in such accounts and believes it is not exposed to any significant risk in maintaining accounts with the financial institutions.

Promise to Give and Allowance for Uncollectable Accounts

Promises to give are stated net of an allowance for doubtful accounts and valuation discount. The Organization estimates the allowance based on its historical experience of the relationship between actual bad debts and receivables. As of December 31, 2013, management believes that all promises are fully collectable.

Website Costs

Web-site costs are capitalized and amortized on the straight-line basis over the asset useful life, which is 2 years. As of December 31, 2013 the costs are fully depreciated.

Donated Facilities and Services

The Organization records the value of donated facilities as revenue with an equivalent amount recorded as expense. The value of this donation is \$3,000 for the year ended December 31, 2013. Contributed services that create or enhance non-financial assets and require a specialized skill are reported as contributions at their fair value with a corresponding amount recorded as an expense.

Functional Expenses

The Organization allocates its expenses on a functional basis among its program and support services. Expenses that can be specifically identified with a program or support service are allocated directly according to their natural classifications. Other expenses that are common to several functions are allocated based upon estimates made by management.

NOTE 3 – Income Taxes

The Organization has been granted tax-exempt status by the Internal Revenue Service under Internal Revenue Code Section 501(c)(3). Accordingly, no provision for federal or state income taxes has been recorded in the accompanying financial statements. Management of the Organization does not believe it has any uncertain tax positions. The Organization's tax returns remain open to examination by regulatory authorities from December 31, 2010.

Rett Syndrome Research Trust, Inc.
Notes to Financial Statements
December 31, 2013
(See Report of Independent Auditor)

NOTE 4 – Promises to Give

At December 31, 2013 and 2012, contributors to the Organization have unconditionally promised to give \$1,079,668 and \$191,400, respectively. Long-term promises have been discounted at 2% per annum which the Organization believes to be its risk free rate of return. The promised contributions are due as follows:

	<u>2013</u>	<u>2012</u>
Within one year	\$ 398,788	\$ 191,400
One to five years	700,000	-
More than five years	-	-
Subtotal	<u>1,098,788</u>	<u>191,400</u>
Less: present value component	(19,120)	-
Less: allowance for doubtful accounts	-	-
Promises to give, net	<u><u>\$ 1,079,668</u></u>	<u><u>\$ 191,400</u></u>

Management has evaluated all promises to give and believes that a reserve for uncollectable accounts is not warranted as there has never been any history of write-offs.

NOTE 5 – Grants Payable

The Organization has committed to unconditional promises to give of \$8,292,695 and \$5,002,075 as of December 31, 2013 and 2012, respectively to various research organizations over the next several years. Long-term commitments have been discounted at 2% per annum which the Organization believes to be its risk free rate of return. The timing of future grants payable is as follows:

	<u>2013</u>	<u>2012</u>
Within one year	\$ 3,719,507	\$ 2,906,830
One to five years	4,573,188	2,095,245
More than five years	-	-
Subtotal	<u>8,292,695</u>	<u>5,002,075</u>
Less: present value component	(126,491)	(54,578)
Grants payable, net	<u><u>\$ 8,166,204</u></u>	<u><u>\$ 4,947,497</u></u>

Future funding of committed grants is predicated upon anticipated fundraising activities.

NOTE 6 – Concentrations

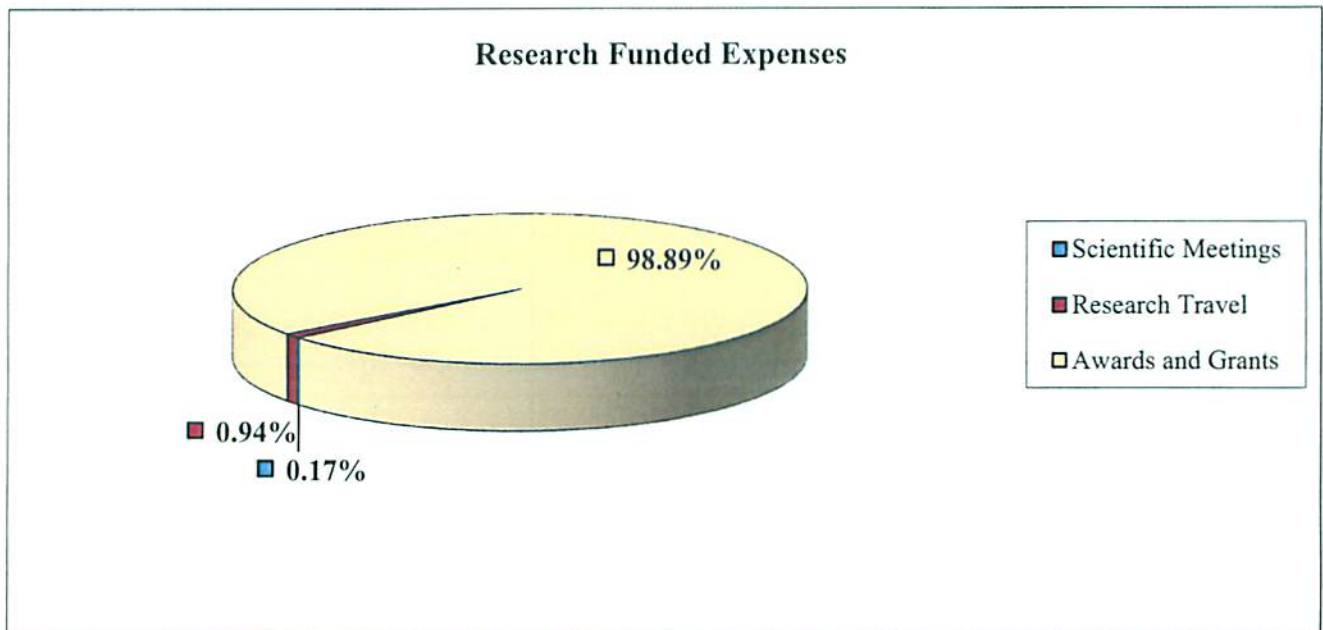
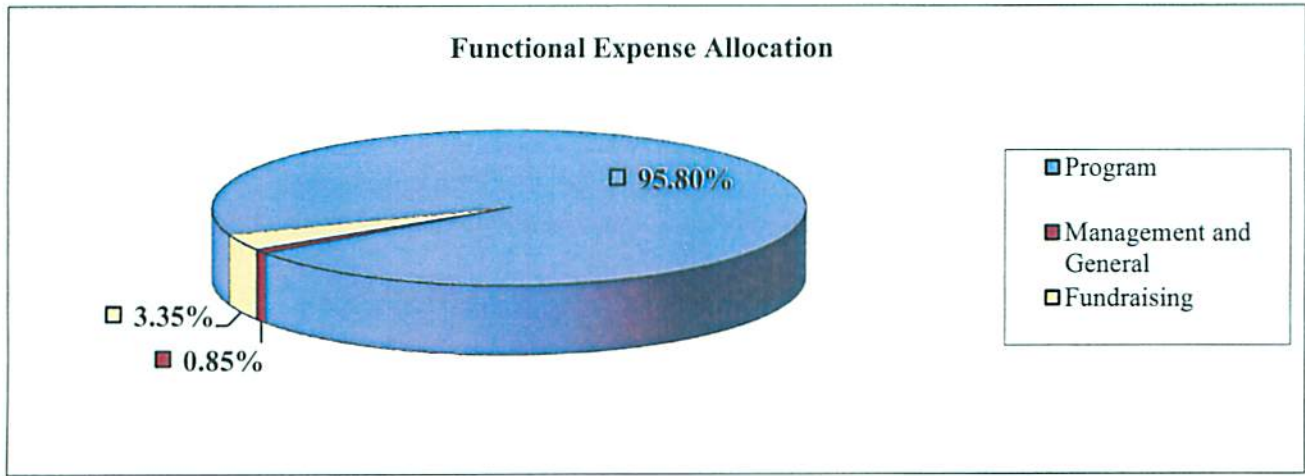
The Organization has several donors that have provided at least 10% of aggregate contributions for the year ended December 31, 2013.

Rett Syndrome Research Trust, Inc.
Notes to Financial Statements
December 31, 2013
(See Report of Independent Auditor)

NOTE 7 – Subsequent Events

In accordance with FASB Accounting Standards Codification 855, Subsequent Events, the Association has evaluated subsequent events to the Statement of Financial Position date of December 31, 2013 through April 21, 2014, which is the date the financial statements were available to be issued. Management has determined that there are no subsequent events that require disclosure.

Rett Syndrome Research Trust, Inc.
Supplemental Statement - Functional Expense Allocation and
Research Funded Expense Graphs
For the Year Ended December 31, 2013



See report of independent auditor.

Rett Syndrome Research Trust, Inc.
Supplemental Statement - Research Awards and Grant Commitments and Payments Schedule
For the Year Ended December 31, 2013

	<u>Commitment at December 31, 2012</u>	<u>Additional Commitments</u>	<u>Payments Against Commitments</u>	<u>Commitment at December 31, 2013</u>
Baylor College of Medicine - Monica Justice	\$ 668,478	\$ -	\$ (366,663)	\$ 301,815
Baylor College of Medicine - Huda Zoghbi	257,588	-	(182,972)	74,616
Fred Hutchinson Cancer Research Antonio Bedalov	13,922	-	(13,922)	-
University of Texas Southwest Medical Center Andrew Pieper	-	10,123	(10,123)	-
University of Edinburgh Adrian Bird	218,088	-	(218,088)	(0)
University of Virginia Jonathan Kipnis	660,000	-	(275,000)	385,000
Weill Cornell Medical Center Ronald Crystal	100,854	-	(100,854)	-
OHSU John Bissonnette	14,911	-	(14,911)	-
MIT Mark Bear	10,989	45,943	(45,447)	11,485
University of North Carolina Benjamin Philpot	1,966,066	-	(789,935)	1,176,131
Harvard University Jeannie Lee	175,000	100,000	(125,000)	150,000
Case Western David Katz	-	150,000	(100,000)	50,000
UMASS Michael Green	-	750,000	(187,500)	562,500
Sheba Medical Center Bruria Ben Zeev	-	197,962	(98,980)	98,982
Harvard University Michela Fagiolini	-	126,741	-	126,741

See report of independent auditor.

Rett Syndrome Research Trust, Inc.
Supplemental Statement - Research Awards and Grant Commitments and Payments Schedule
For the Year Ended December 31, 2013

	<u>Commitment at December 31, 2012</u>	<u>Additional Commitments</u>	<u>Payments Against Commitments</u>	<u>Commitment at December 31, 2013</u>
Children's Hospital at Montefiore Aleksandra Djukic	-	474,247	(474,247)	-
MECP2 Consortium	761,379	3,417,575	(761,379)	3,417,575
Gene Therapy Consortium	-	1,535,942	-	1,535,942
Baylor College of Medicine - Huda Zoghbi - duplication	154,800	319,224	(72,116)	401,908
Ohio State Kevin Foust	-	39,340	(39,340)	-
	<u>\$ 5,002,075</u>	<u>\$ 7,167,097</u>	<u>\$ (3,876,477)</u>	<u>\$ 8,292,695</u>

See report of independent auditor.