

**Rett Syndrome Research Trust, Inc.**

**Financial Statements**

**December 31, 2016**



**Rett Syndrome Research Trust, Inc.**  
**December 31, 2016**

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Knight • Rolleri • Sheppard, CPAS, LLP  
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Ryan C. Sheppard, CPA, CFF

### **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, 2016 and 2015 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, 2016 and 2015, 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 10, 2017

**Rett Syndrome Research Trust, Inc.**  
**Statements of Financial Position**  
**December 31, 2016 and 2015**

	<u>2016</u>	<u>2015</u>
<b><u>ASSETS</u></b>		
<b>Current assets</b>		
Cash and cash equivalents	\$ 5,439,262	\$ 4,330,089
Promises to give	800,935	725,738
Investments	62,898	14,002
Total current assets	<u>6,303,095</u>	<u>5,069,829</u>
<b>Property and equipment, net of accumulated depreciation of \$3,258 and \$2,172 in 2016 and 2015, respectively</b>	-	1,086
Total assets	<u><u>\$ 6,303,095</u></u>	<u><u>\$ 5,070,915</u></u>
<b><u>LIABILITIES AND NET ASSETS</u></b>		
<b>Current liabilities</b>		
Accounts payable	\$ 18,164	\$ 14,821
Grants payable	6,633,266	6,639,332
Accrued expenses	6,000	8,059
Total current liabilities	<u>6,657,430</u>	<u>6,662,212</u>
<b>Other liabilities</b>		
Grants payable	<u>7,390,351</u>	<u>5,465,104</u>
Total liabilities	14,047,781	12,127,316
<b>Net assets</b>		
For mission purposes	(7,744,686)	(7,057,487)
Property and equipment	-	1,086
Total net assets (deficit)	<u>(7,744,686)</u>	<u>(7,056,401)</u>
Total liabilities and net assets	<u><u>\$ 6,303,095</u></u>	<u><u>\$ 5,070,915</u></u>

See report of independent auditor and notes to financial statements.

**Rett Syndrome Research Trust, Inc.**  
**Statements of Activities**  
**For the Years Ended December 31, 2016 and 2015**

	<u>2016</u>	<u>2015</u>
<b>Public support and revenues</b>		
Contributions	\$ 7,825,957	\$ 5,816,392
The Eva Fini Fund	23,695	172,200
Donated services and rent	10,500	9,500
Interest income	10,864	13,509
Realized gain (loss) from sales of donated securities	(398)	(59)
Total support and revenue	<u>7,870,618</u>	<u>6,011,542</u>
<b>Expenses</b>		
Program services	7,962,675	9,259,014
Supporting services:		
Management and general	164,426	150,292
Fundraising	431,802	464,131
Total expenses	<u>8,558,903</u>	<u>9,873,437</u>
Decrease in net assets from operations	(688,285)	(3,861,895)
<b>Net assets (deficit) - beginning of year</b>	<u>(7,056,401)</u>	<u>(3,194,506)</u>
<b>Net assets (deficit) - end of year</b>	<u><u>\$ (7,744,686)</u></u>	<u><u>\$ (7,056,401)</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, 2016 and 2015**

	<u>2016</u>	<u>2015</u>
<b>Cash flows from (used in) operating activities</b>		
Decrease in net assets	\$ (688,285)	\$ (3,861,895)
Adjustments to reconcile decrease in net assets to cash from (used in) operating activities		
Amortization	1,086	1,086
(Increase) decrease in promises to give	(75,197)	519,691
Increase in investments from donor donations held for sale	(48,896)	(13,982)
Increase in accounts payable	3,343	12,321
Decrease in accrued expenses	(2,059)	(7,489)
Increase in grants payable	<u>1,919,181</u>	<u>2,677,859</u>
Net cash provided from (used by) operating activities	<u>1,109,173</u>	<u>(672,409)</u>
 Increase (decrease) in cash	 <u>1,109,173</u>	 <u>(672,409)</u>
 <b>Cash and cash equivalents - beginning of year</b>	 <u>4,330,089</u>	 <u>5,002,498</u>
 <b>Cash and cash equivalents - end of year</b>	 <u><u>\$ 5,439,262</u></u>	 <u><u>\$ 4,330,089</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, 2016**

	<u>Program</u>	<u>Supporting Services</u>		<u>Total Expenses</u>
		<u>Management and General</u>	<u>Fundraising</u>	
Awards and grants	\$ 7,284,447	\$ -	\$ -	\$ 7,284,447
Bank and credit card fees	17,772	4,874	8,621	31,267
Bookkeeping (**)	-	3,381	-	3,381
Depreciation	1,055	4	27	1,086
Employee benefits	15,611	4,281	7,573	27,465
Fundraising	-	-	184,548	184,548
Insurance	2,249	2,248	2,248	6,745
Miscellaneous	2,363	488	6,262	9,113
Office and supplies	1,825	3,075	885	5,785
Payroll taxes	26,096	7,157	12,659	45,912
Postage and shipping	4,995	1,370	2,423	8,788
Printing and publication	12,353	45	315	12,713
Professional fees (*)	-	20,978	-	20,978
Professional fees - patent research	47,066	-	-	47,066
Rent (**)	1,705	468	827	3,000
Salaries	420,990	115,457	204,213	740,660
Scientific meetings	46,798	-	-	46,798
Telephone	2,094	574	1,016	3,684
Travel - scientific meetings	67,999	-	-	67,999
Website and hosting	7,257	26	185	7,468
	<u>\$ 7,962,675</u>	<u>\$ 164,426</u>	<u>\$ 431,802</u>	<u>\$ 8,558,903</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, 2015**

	<u>Program</u>	<u>Supporting Services</u>		<u>Total Expenses</u>
		<u>Management and General</u>	<u>Fundraising</u>	
Awards and grants	\$ 8,782,977	\$ -	\$ -	\$ 8,782,977
Bank and credit card fees	9,597	5,932	12,155	27,684
Bookkeeping (**)	1,119	1,119	1,119	3,357
Depreciation	1,056	4	26	1,086
Employee benefits	9,186	5,677	11,632	26,495
Fundraising	-	-	214,304	214,304
Graphic design	2,163	8	54	2,225
Insurance	1,456	1,455	1,455	4,366
Miscellaneous	1,280	791	13,676	15,747
Office and supplies	1,081	1,025	1,369	3,475
Payroll taxes	9,879	6,106	12,511	28,496
Postage and shipping	3,068	1,896	3,886	8,850
Printing and publication	7,484	27	187	7,698
Professional fees (*)	106,025	32,667	-	138,692
Professional fees - patent research	11,197	-	-	11,197
Rent (**)	3,000	-	-	3,000
Salaries	150,107	92,773	190,093	432,973
Scientific meetings	88,417	-	-	88,417
Telephone	1,314	812	1,664	3,790
Travel - scientific meetings	58,113	-	-	58,113
Website and hosting	10,495	-	-	10,495
	<u>\$ 9,259,014</u>	<u>\$ 150,292</u>	<u>\$ 464,131</u>	<u>\$ 9,873,437</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, 2016**  
**(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.

**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, 2016**  
**(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, 2016, the Organization is insured up to \$500,000 of recorded bank balances. The balance in excess of FDIC limitations is \$6,018,260 at December 31, 2016. 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, 2016, management believes that all promises are fully collectable.

**Property and Equipment**

Property and equipment is recorded at cost and is being depreciated over three years.

**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, 2016. 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, 2013.

**Rett Syndrome Research Trust, Inc.**  
**Notes to Financial Statements**  
**December 31, 2016**  
(See Report of Independent Auditor)

**NOTE 4 – Promises to Give**

At December 31, 2016 and 2015, contributors to the Organization have unconditionally promised to give \$804,398 and \$725,738, 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>2016</u>	<u>2015</u>
Within one year	\$ 631,299	\$ 725,738
One to five years	173,099	-
More than five years	-	-
Subtotal	<u>804,398</u>	<u>725,738</u>
Less: present value component	(3,463)	-
Less: allowance for doubtful accounts	-	-
Promises to give, net	<u><u>\$ 800,935</u></u>	<u><u>\$ 725,738</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 \$14,211,772 and \$12,262,715 as of December 31, 2016 and 2015, 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>2016</u>	<u>2015</u>
Within one year	\$ 6,633,266	\$ 6,639,332
One to five years	7,578,506	5,623,383
More than five years	-	-
Subtotal	<u>14,211,772</u>	<u>12,262,715</u>
Less: present value component	(188,155)	(158,279)
Grants payable, net	<u><u>\$ 14,023,617</u></u>	<u><u>\$ 12,104,436</u></u>

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

**NOTE 6 – Concentrations**

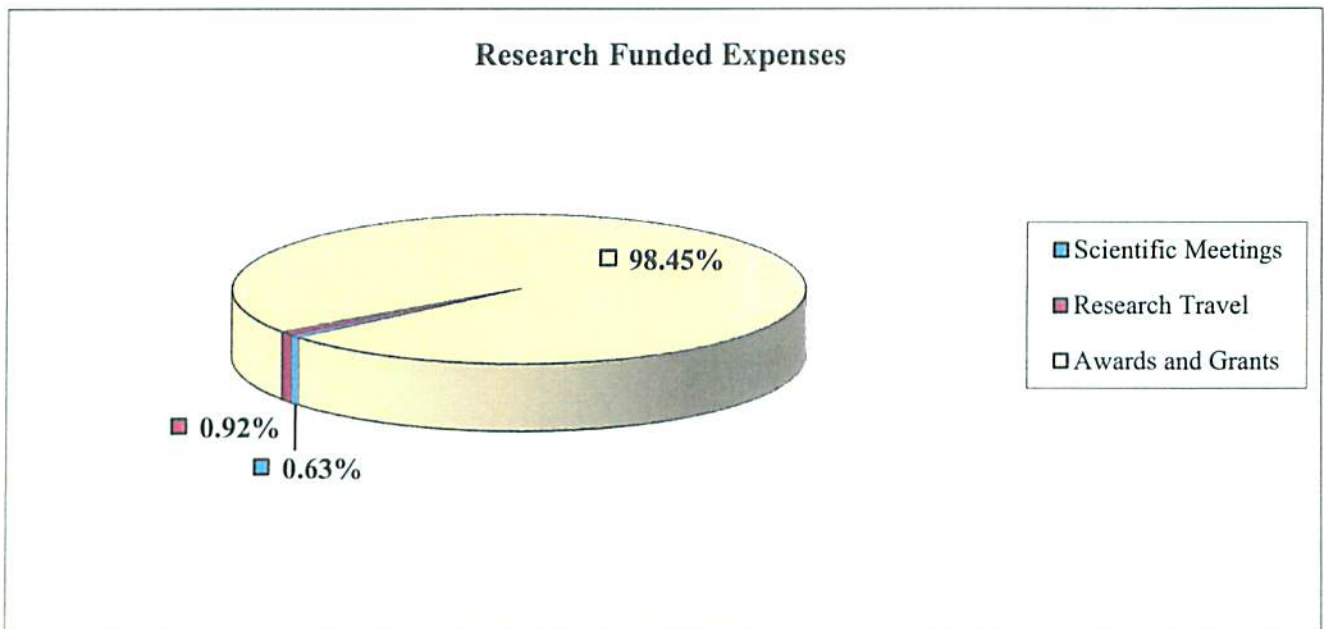
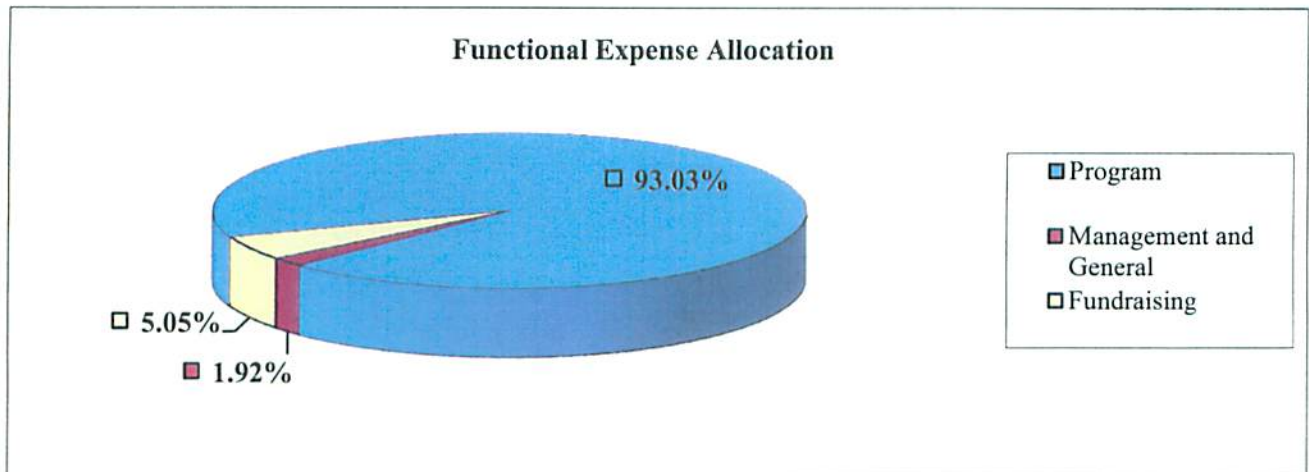
The Organization has several donors that have provided at least 10% of aggregate contributions for the year ended December 31, 2016.

**Rett Syndrome Research Trust, Inc.**  
**Notes to Financial Statements**  
**December 31, 2016**  
**(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, 2016 through April 26, 2017, 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, 2016**



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, 2016**

	<u>Commitment at December 31, 2015</u>	<u>Additional Commitments</u>	<u>Payments Against Commitments</u>	<u>Commitment at December 31, 2016</u>
Hospital for Sick Kids Monica Justice	\$ 361,384	\$ -	\$ (361,384)	\$ -
Fred Hutchinson Cancer Research Antonio Bedalov	824,575	-	(262,430)	562,145
Harvard University/MGH Jeannie Lee	310,000	-	(155,000)	155,000
UMASS Medical School Michael Green	62,500	-	(62,500)	-
Children's Hospital at Montefiore Aleksandra Djukic	134,332	-	(134,332)	-
MECP2 Consortium Harvard University of Edinburgh OHSU	1,149,141	3,454,021	(1,149,141)	3,454,021
Gene Therapy Consortium UNC - Chapel Hill Nationwide Children's Hospital University of Glasgow OHSU	565,051	1,450,275	(565,051)	1,450,275
Baylor College of Medicine - Huda Zoghbi - duplication ASO Screen	86,250 414,065	- -	(86,250) (217,117)	- 196,948
UCSD Allyson Muotri - duplication	-	792,000	(198,000)	594,000
Children's Hospital at Montefiore	-	84,000	(84,000)	-
LSRF Sung Yon Kim	91,500	(91,500) (*)		-
California Institute of Technology Ali Khoshnan	50,000	-	(50,000)	-
Lurie Children's Hospital Debra Weese Mayer/Michael Carroll	58,990	-	(58,990)	-
Case Western David Katz	77,733	250,000	(77,733)	250,000
Case Western/Cleveland Clinic David Katz/Daniel Sessler	1,136,450	-	(158,681)	977,769
Jackson Labs	6,844	838	(7,682)	-
Boston Children's Hospital				

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, 2016**

	<u>Commitment at December 31, 2015</u>	<u>Additional Commitments</u>	<u>Payments Against Commitments</u>	<u>Commitment at December 31, 2016</u>
Michela Fagiolini	212,095	-	(169,509)	42,586
University of Rochester John Foxe	533,607	-	(172,108)	361,499
Erasmus MC Joost Gribnau	177,900	-	(43,400)	134,500
Harvard University Jeannie Lee	766,854	-	(255,618)	511,236
UNC - Chapel Hill Mark Zylka	250,000	-	(200,000)	50,000
Nemours/ AI duPont Andrew Napper	230,101	(114,386) (*)	(115,715)	-
Neurolix	60,000	-	(60,000)	-
University of Glasgow Stuart Cobb	86,208	-	(86,208)	-
Stuart Cobb - supplement	-	210,000	-	210,000
Stuart Cobb - RNA	-	330,804	-	330,804
Washington University Daniel Ory	-	3,000	(3,000)	-
UTSW Stephen Turley	117,135	-	(117,135)	-
USCD Allyson Muotri - ASF	-	12,500	(12,500)	-
Allyson Muotri - Rett	-	209,000	(52,248)	156,752
Whitehead Institute Rudolph Jaenisch	-	180,000	(45,000)	135,000
Armagen	-	125,000	(42,000)	83,000
Genetics Network	-	20,000	(20,000)	-
Harvard University Michael Greenburg	-	110,000	(110,000)	-
Q State	-	330,000	(82,500)	247,500
Washington University Hassan Ghasemzadeh	-	10,000	(10,000)	-
OMBD Consortium University of Alabama/Birmingham Emory University Children's Hospita; at Montefiore	4,500,000	-	(191,263)	4,308,737

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, 2016**

	<u>Commitment at December 31, 2015</u>	<u>Additional Commitments</u>	<u>Payments Against Commitments</u>	<u>Commitment at December 31, 2016</u>
University of Colorado	<u>\$ 12,262,715</u>	<u>\$ 7,365,552</u> (**)	<u>\$ (5,416,495)</u>	<u>\$ 14,211,772</u>

(\*) After scientific evaluation the study was terminated and no further payments were made.

(\*\*) Additional commitments are new commitments and have not been adjusted for discounts on long-term funding, voids for uncashed checks, etc...