

Rett Syndrome Research Trust, Inc.

Financial Statements

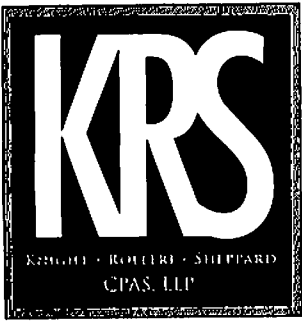
December 31, 2018



Rett Syndrome Research Trust, Inc.
December 31, 2018

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Knight • Rolleri • Sheppard, CPAS, LLP
Michael J. Knight, CPA, CVA, CFE, ABV
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Report of Independent Auditor

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

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, 2018 and 2017 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.

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, 2018 and 2017, 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.

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.

Knight Rolleri Sheppard CPAS, LLP

Knight Rolleri Sheppard CPAS, LLP
Fairfield, Connecticut
April 16, 2019

Rett Syndrome Research Trust, Inc.
Statements of Financial Position
December 31, 2018 and 2017

	<u>2018</u>	<u>2017</u>
<u>ASSETS</u>		
Current assets		
Cash and cash equivalents	\$ 8,694,126	\$ 7,311,717
Promises to give	2,253,575	2,441,508
Investments	-	71
Total current assets	10,947,701	9,753,296
Other assets		
Promises to give	369,932	2,090,867
Equipment, net of accumulated depreciation of \$4,318 and \$3,257 in 2018 and 2017, respectively	2,122	-
Total other assets	372,054	2,090,867
Total assets	\$ 11,319,755	\$ 11,844,163
<u>LIABILITIES AND NET ASSETS</u>		
Current liabilities		
Accounts payable	\$ 12,379	\$ 8,108
Grants payable	8,457,410	9,310,889
Accrued expenses	7,500	7,000
Total current liabilities	8,477,289	9,325,997
Other liabilities		
Grants payable	7,214,736	5,177,424
Total other liabilities	15,692,025	14,503,421
Net assets without donor restrictions		
Undesignated (deficit)	(4,372,270)	(2,659,258)
Total net assets (deficit)	(4,372,270)	(2,659,258)
Total liabilities and net assets	\$ 11,319,755	\$ 11,844,163

See report of independent auditor and notes to financial statements.

Rett Syndrome Research Trust, Inc.
Statements of Activities
For the Years Ended December 31, 2018 and 2017

	<u>2018</u>	<u>2017</u>
Public support and revenues		
Contributions	\$ 9,158,768	\$ 11,658,139
The Eva Fini Fund	2,780	230,000
The MECP2 Duplication Syndrome Fund	469,569	630,000
Donated services and rent	8,000	9,000
Interest income	23,178	11,583
Realized gains (losses) from sales of donated securities	1,885	(850)
Total public support and revenues	<u>9,664,180</u>	<u>12,537,872</u>
Expenses		
Program services	10,792,926	6,865,036
Supporting services:		
Management and general	166,080	167,739
Fundraising	418,186	419,669
Total expenses	<u>11,377,192</u>	<u>7,452,444</u>
Increase (decrease) in net assets from operations	<u>(1,713,012)</u>	<u>5,085,428</u>
Net assets (deficit) - beginning of year	<u>(2,659,258)</u>	<u>(7,744,686)</u>
Net assets (deficit) - end of year	<u><u>\$ (4,372,270)</u></u>	<u><u>\$ (2,659,258)</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, 2018 and 2017

	<u>2018</u>	<u>2017</u>
Cash flows from (used in) operating activities		
Increase (decrease) in net assets	\$ (1,713,012)	\$ 5,085,428
Adjustments to reconcile increase (decrease) in net assets to cash from (used in) operating activities		
Depreciation	1,061	-
(Increase) decrease in promises to give	1,908,868	(3,731,440)
Decrease in investments from donor donations held for sale	71	62,827
Increase (decrease) in accounts payable	4,271	(10,056)
Increase in accrued expenses	500	1,000
Increase in grants payable	<u>1,183,833</u>	<u>464,696</u>
Net cash provided from operating activities	1,385,592	1,872,455
 Cash flows from investing activities		
Investment in equipment	<u>(3,183)</u>	-
Net cash used in investing activities	(3,183)	-
 Increase in cash	<u>1,382,409</u>	<u>1,872,455</u>
 Cash and cash equivalents - beginning of year	<u>7,311,717</u>	<u>5,439,262</u>
 Cash and cash equivalents - end of year	<u><u>\$ 8,694,126</u></u>	<u><u>\$ 7,311,717</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, 2018

	<u>Program</u>	<u>Supporting Services</u>		<u>Total Expenses</u>
		<u>Management and General</u>	<u>Fundraising</u>	
Awards and grants	\$ 9,619,077	\$ -	\$ -	\$ 9,619,077
Bank and credit card fees	5,367	856	1,152	7,375
Bookkeeping	-	772	-	772
Depreciation	1,036	2	23	1,061
Employee benefits	32,986	5,259	7,080	45,325
Fundraising	-	-	219,926	219,926
Insurance	2,276	2,275	2,275	6,826
Miscellaneous	34,153	1,851	2,778	38,782
Office and supplies	1,285	2,984	276	4,545
Payroll taxes	49,359	7,870	10,595	67,824
Postage and shipping	4,081	651	876	5,608
Printing and publication	13,392	26	299	13,717
Professional fees (*)	-	15,240	-	15,240
Rent (**)	4,869	776	1,045	6,690
Rental and maintenance of equipment	300	1	7	308
Salaries	796,901	127,055	171,050	1,095,006
Scientific meetings	140,611	-	-	140,611
Telephone	2,791	445	599	3,835
Travel - scientific meetings	75,277	-	-	75,277
Website and hosting	9,165	17	205	9,387
	<u>\$ 10,792,926</u>	<u>\$ 166,080</u>	<u>\$ 418,186</u>	<u>\$ 11,377,192</u>

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

(**) Includes \$3,000 donated 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, 2017

	<u>Program</u>	<u>Supporting Services</u>		<u>Total Expenses</u>
		<u>Management and General</u>	<u>Fundraising</u>	
Awards and grants	\$ 6,069,512	\$ -	\$ -	\$ 6,069,512
Bank and credit card fees	13,834	3,190	4,326	21,350
Bookkeeping (**)	-	1,671	-	1,671
Employee benefits	22,397	5,164	7,005	34,566
Fundraising	-	-	220,202	220,202
Insurance	1,875	1,874	1,874	5,623
Miscellaneous	27,617	509	746	28,872
Office and supplies	3,492	3,928	1,092	8,512
Payroll taxes	30,913	7,128	9,668	47,709
Postage and shipping	3,154	727	986	4,867
Printing and publication	9,173	30	325	9,528
Professional fees (*)	-	15,842	-	15,842
Rent (**)	4,098	945	1,282	6,325
Salaries	547,146	126,156	171,117	844,419
Scientific meetings	50,911	-	-	50,911
Telephone	2,368	546	740	3,654
Travel - scientific meetings	69,902	-	-	69,902
Website and hosting	8,644	29	306	8,979
	<u>\$ 6,865,036</u>	<u>\$ 167,739</u>	<u>\$ 419,669</u>	<u>\$ 7,452,444</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, 2018
(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

Basis of Accounting and Presentation

The financial statements of the Organization have been prepared in accordance with generally accepted accounting principles in the United States of America (GAAP). Accordingly, the accounts of the Organization are reported by net asset category. Net assets, revenues, gains, and losses are classified based on the existence or absence of donor or grantor-imposed restrictions. Accordingly, net assets and changes therein are classified and reported as follows:

Net Assets Without Donor Restrictions – Net assets available for use in general operations and not subject to donor (or certain grantor) restrictions.

Net Assets With Donor Restrictions – Net assets subject to donor (or certain grantor) imposed restrictions. Some donor-imposed restrictions are temporary in nature, such as those that will be met by the passage of time or other events specified by the donor. Other donor-imposed restrictions are perpetual in nature, where the donor stipulates that resources be maintained in perpetuity. The Organization reports contributions restricted by donors as increase in net assets without donor restriction if the restrictions expire (that is, when stipulated time restriction ends or purpose restriction is accomplished) in the reporting period in which the revenue is recognized. All other donor-restricted contributions are reported as increases in net assets with donor restrictions, depending on the nature of the restrictions. When a restriction expires, net assets with donor restrictions are reclassified to net asset without donor restrictions and reported in the statements of activities as net assets released from restrictions.

Use of Estimates

The preparation of financial statements in conformity with GAAP 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

Rett Syndrome Research Trust, Inc.
Notes to Financial Statements
December 31, 2018
(See Report of Independent Auditor)

of December 31, 2018, the Organization is insured up to \$500,000 of recorded bank balances. The balance in excess of FDIC limitations is \$9,523,423 at December 31, 2018. 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 promises to give. As of December 31, 2018, management believes that all promises are fully collectable as there has been no history of any bad debts.

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 years ended December 31, 2018 and 2017. 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. The value of contributed services reflected as professional services is \$5,000 each for the years ended December 31, 2018 and 2017, respectively.

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 – LIQUIDITY AND AVAILABILITY

Financial assets available for general expenditure, that is, without donor and other restrictions limiting their use, within one year of the statement of financial position date, comprise the following:

Cash and cash equivalents	<u>\$ 8,694,126</u>
	<u>\$ 8,694,126</u>

The Organization has committed significant resources to research grants within one year of the statement of financial position date. Meeting those commitments require collection of promises to give due within one year along with ongoing fundraising efforts for additional funds.

As part of the organization's liquidity management plan, RSRT invest cash in excess of daily requirements in short-term investments and money market funds.

Rett Syndrome Research Trust, Inc.
Notes to Financial Statements
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NOTE 4 – FAIR VALUE MEASUREMENT

The Organization follows the guidance under Statement of Financial Accounting Standards Codification 820, Fair Value Measurements. This standard establishes a fair value hierarchy that prioritizes inputs to valuation techniques used to measure fair value. The hierarchy gives the highest priority to unadjusted quoted prices in active markets for identical assets or liabilities (Level 1 measurements) and the lowest priority to unobservable inputs (Level 3 measurements). The three levels of the fair value hierarchy are described below:

Level 1 Inputs

Unadjusted quoted prices in active markets that are accessible at the measurement date for identical, unrestricted instruments;

Level 2 Inputs

Quoted prices for similar instruments in active markets or quoted prices for similar instruments in markets that are not active whose inputs are observable, either directly or indirectly;

Level 3 Inputs

Prices or valuations that require inputs that are both significant to the fair value and unobservable.

In certain cases, the inputs used to measure fair value may fall into different levels of the fair value hierarchy. In such cases, an investment's level within the fair value hierarchy is based on the lowest level of input that is significant to the fair value measurement. The input or methodology used for valuation of securities is not necessarily an indication of the risk associated with investing in those securities.

The following is a description of the valuation methodologies used for assets measured at fair value:

Promises to Give – promises to give are values based on discounted cash flows reduced by an allowance of collectability.

There have been no changes in methodologies used at December 31, 2018.

NOTE 5 – 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, 2016.

Rett Syndrome Research Trust, Inc.
Notes to Financial Statements
December 31, 2018
(See Report of Independent Auditor)

NOTE 6 – PROMISES TO GIVE

At December 31, 2018 and 2017, contributors to the Organization have unconditionally promised to give \$2,631,057 and \$4,575,491, 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>2018</u>	<u>2017</u>
Within one year	\$ 2,253,575	\$ 2,441,508
One to five years	377,482	2,133,983
More than five years	-	-
Subtotal	<u>2,631,057</u>	<u>4,575,491</u>
Less: present value component	(7,550)	(43,116)
Less: allowance for doubtful accounts	-	-
Promises to give, net	<u>\$ 2,623,507</u>	<u>\$ 4,532,375</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.

All promises to give have valued using level 3 criteria as described in Note 3 to the financial statements.

NOTE 7 – GRANTS PAYABLE

The Organization has committed to unconditional promises to give of \$15,860,900 and \$14,494,992 as of December 31, 2018 and 2017, 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>2018</u>	<u>2017</u>
Within one year	\$ 8,457,410	\$ 9,310,889
One to five years	7,403,490	5,284,103
More than five years	-	-
Subtotal	<u>15,860,900</u>	<u>14,594,992</u>
Less: present value component	(188,754)	(106,679)
Grants payable, net	<u>\$ 15,672,146</u>	<u>\$ 14,488,313</u>

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

Rett Syndrome Research Trust, Inc.
Notes to Financial Statements
December 31, 2018
(See Report of Independent Auditor)

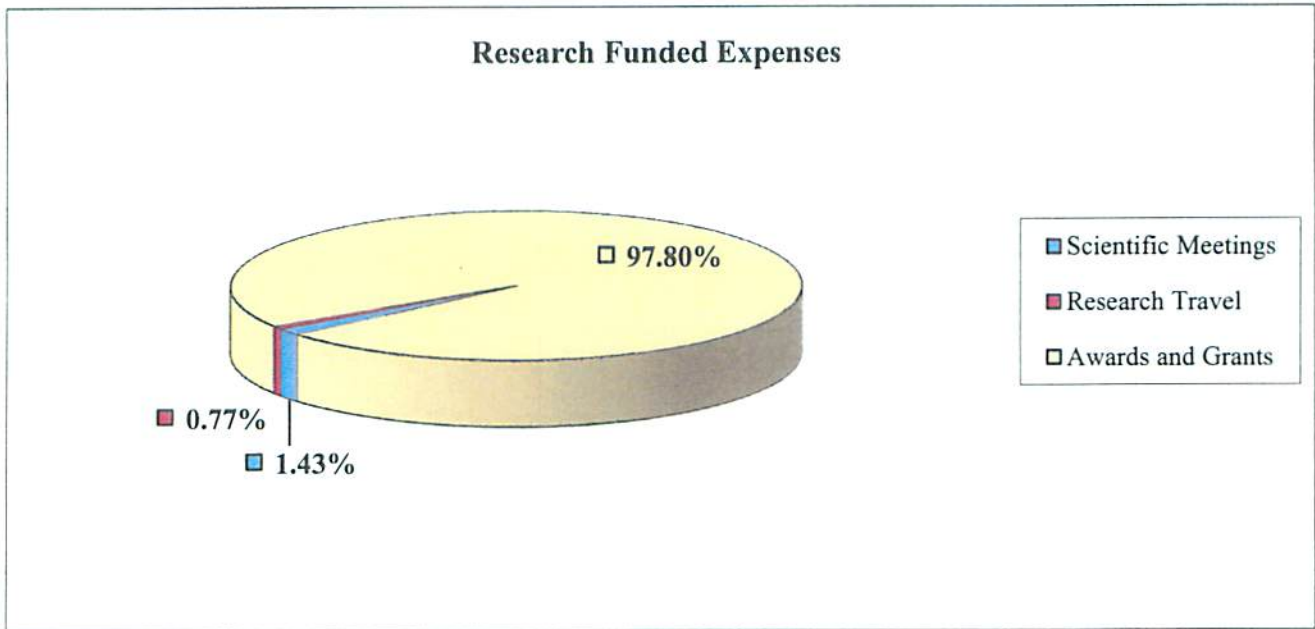
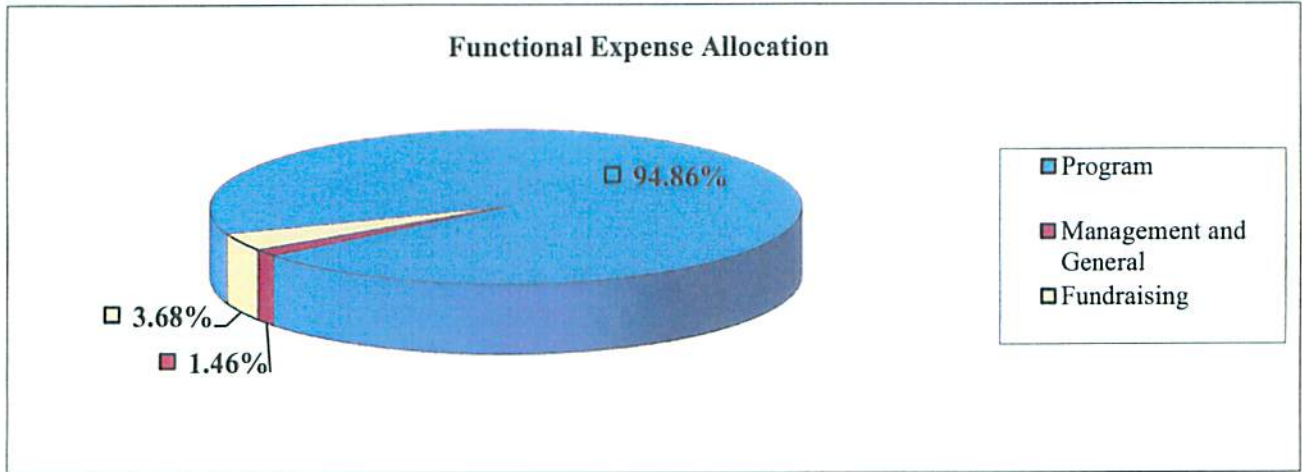
NOTE 8– CONCENTRATIONS

The Organization has several donors that have provided at least 10% of aggregate contributions for the year ended December 31, 2018.

NOTE 9 – 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, 2018 through April 16, 2019, 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, 2018



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, 2018

	<u>Commitment at December 31, 2017</u>	<u>Additional Commitments</u>	<u>Payments Against Commitments</u>	<u>Commitment at December 31, 2018</u>
Fred Hutchinson Cancer Research Antonio Bedalov	\$ 285,465	\$ 38,000	\$ (285,465)	\$ 38,000
MECP2 Consortium Harvard University of Edinburgh OHSU	2,396,215	-	(1,228,492)	1,167,723
Gene Therapy Consortium UNC - Chapel Hill University of Glasgow/Edinburgh UCSD University of Pennsylvania	2,631,531	540,284	(2,030,209)	1,141,606
Baylor College of Medicine MECP2 Duplication ASO Screen	188,623 -	- 752,660	(150,740) (91,962)	37,883 660,698
UCSD Alyson Muotri - MECP2 Duplication	330,000	-	(264,000)	66,000
Children's Hospital at Montefiore	-	75,000	(75,000)	-
Case Western/Cleveland Clinic (Ketamine Trial) David Katz/Daniel Sessler	977,769	-	(84,146)	893,623
University of Rochester John Foxe	181,404	-	(181,404)	-
Erasmus MC Joost Gribnau	68,100	-	(68,100)	-
Harvard University Jeannie Lee	255,618	-	(255,618)	-
University of Glasgow Stuart Cobb - supplement Stuart Cobb - optimizing RNA Stuart Cobb - RNA supplement Stuart Cobb - qPCR machine	157,500 246,640 290,000 -	- - 1,351 13,945	(87,500) (136,372) (194,683) (13,945)	70,000 110,268 96,668 -
USCD Alyson Muotri - Rett	87,085	-	(69,668)	17,417
Whitehead Institute Rudolph Jaenisch Rudolph Jaenisch - editing	75,000 449,888	- -	(60,000) (199,950)	15,000 249,938
Armagen	41,000	(41,000) *	-	-
Q State Michael Greenberg	553,967	-	(553,967)	-

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, 2018

	<u>Commitment at December 31, 2017</u>	<u>Additional Commitments</u>	<u>Payments Against Commitments</u>	<u>Commitment at December 31, 2018</u>
Washington State University Hassan Ghasemzadeh	-	10,000	(10,000)	-
Queen Mary University of London Andrea Cerase	-	351,022	(58,502)	292,520
Autism Science Foundation Laurel Joy Gabard-Durnam	-	17,500	(17,500)	-
OHSU John Sinnamon	-	345,000	(28,750)	316,250
University of California Davis Peter Beal	-	563,870	-	563,870
Beam Therapeutics	-	1,870,660	-	1,870,660
MIT Guoping Feng	-	2,332,000	-	2,332,000
University of Massachusetts Medical School Jonathan Watts	-	2,403,735	-	2,403,735
University of Massachusetts Medical School Allan Jacobson/ Jonathan Watts	-	323,000	-	323,000
UNC Benjamin Philpot	74,487	-	(74,487)	-
Nationwide Children's Hospital Kathrine Meyer	152,489	-	(101,659)	50,830
Clinical Trial Consortium	2,235,586	74,792	(755,195)	1,555,183
OMBD Consortium University of Alabama/Birmingham CRND University of Colorado	2,916,625	-	(1,328,615)	1,588,010
	<u>\$ 14,594,992</u>	<u>\$ 9,671,819</u>	<u>\$ (8,405,929)</u>	<u>\$ 15,860,882</u>

* Reduction in commitment from cancelled grant

See report of independent auditor.