

Rett Syndrome Research Trust, Inc.

Financial Statements

December 31, 2014



**Rett Syndrome Research Trust, Inc.
December 31, 2014**

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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, 2014 and 2013 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, 2014 and 2013, 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 3, 2015

Rett Syndrome Research Trust, Inc.
Statements of Financial Position
December 31, 2014 and 2013

	<u>2014</u>	<u>2013</u>
<u>ASSETS</u>		
Current assets		
Cash and cash equivalents	\$ 5,002,498	\$ 4,694,376
Promises to give	716,229	398,788
Investments	20	20
Total current assets	<u>5,718,747</u>	<u>5,093,184</u>
Property and equipment, net of accumulated depreciation of \$1,086	2,171	-
Other assets		
Promises to give	<u>529,200</u>	<u>680,880</u>
Total other assets	529,200	680,880
Total assets	<u><u>\$ 6,250,118</u></u>	<u><u>\$ 5,774,064</u></u>
<u>LIABILITIES AND NET ASSETS</u>		
Current liabilities		
Accounts payable	\$ 2,500	\$ 6,684
Grants payable	5,537,722	3,719,507
Accrued expenses	<u>15,548</u>	<u>15,554</u>
Total current liabilities	5,555,770	3,741,745
Other liabilities		
Grants payable	<u>3,888,854</u>	<u>4,446,697</u>
Total liabilities	9,444,624	8,188,442
Net assets		
For mission purposes	(3,196,677)	(2,414,378)
Property and equipment	<u>2,171</u>	<u>-</u>
Total net assets (deficit)	<u>(3,194,506)</u>	<u>(2,414,378)</u>
Total liabilities and net assets	<u><u>\$ 6,250,118</u></u>	<u><u>\$ 5,774,064</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, 2014 and 2013

	<u>2014</u>	<u>2013</u>
Public support and revenues		
Contributions	\$ 5,629,478	\$ 5,498,185
The Eva Fini Fund	140,406	147,251
Donated services and rent	8,990	10,500
Interest income	14,729	15,004
Realized gain from sales of donated securities	1	411
Total support and revenue	<u>5,793,604</u>	<u>5,671,351</u>
Expenses		
Program services	6,121,491	7,389,001
Supporting services:		
Management and general	93,634	65,644
Fundraising	358,607	258,440
Total expenses	<u>6,573,732</u>	<u>7,713,085</u>
Decrease in net assets from operations	(780,128)	(2,041,734)
Net assets (deficit) - beginning of year	<u>(2,414,378)</u>	<u>(372,644)</u>
Net assets (deficit) - end of year	<u><u>\$ (3,194,506)</u></u>	<u><u>\$ (2,414,378)</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, 2014 and 2013

	<u>2014</u>	<u>2013</u>
Cash flows from (used in) operating activities		
Decrease in net assets	\$ (780,128)	\$ (2,041,734)
Adjustments to reconcile increase (decrease) in net assets to cash from (used in) operating activities		
Amortization	1,086	3,669
Increase in promises to give	(165,761)	(888,268)
Decrease in investment income receivable	-	426
Increase in investments	-	(4)
Increase (decrease) in accounts payable	(4,184)	5,688
Increase (decrease) in accrued expenses	(6)	9,668
Increase in grants payable	1,260,372	3,218,707
Net cash provided from operating activities	<u>311,379</u>	<u>308,152</u>
Cash flows from investing activities		
Investment in office equipment	<u>(3,257)</u>	<u>-</u>
Net cash used in investing activities	(3,257)	-
Increase in cash	<u>308,122</u>	<u>308,152</u>
Cash and cash equivalents - beginning of year	<u>4,694,376</u>	<u>4,386,224</u>
Cash and cash equivalents - end of year	<u><u>\$ 5,002,498</u></u>	<u><u>\$ 4,694,376</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, 2014

	<u>Program</u>	<u>Supporting Services</u>		<u>Total Expenses</u>
		<u>Management and General</u>	<u>Fundraising</u>	
Amortization	\$ 147	\$ -	\$ -	\$ 147
Awards and grants	5,861,289	-	-	5,861,289
Bank and credit card fees	3,415	2,006	4,980	10,401
Bookkeeping (**)	1,083	1,083	1,083	3,249
Depreciation	1,055	2	29	1,086
Employee benefits	3,675	2,159	5,360	11,194
Fundraising	-	-	161,268	161,268
Insurance	1,541	1,541	1,541	4,623
Miscellaneous	16	10	2,787	2,813
Office and supplies	78	3,904	113	4,095
Payroll taxes	7,383	4,337	10,768	22,488
Postage and shipping	1,080	634	1,575	3,289
Printing and publication	2,564	6	71	2,641
Professional fees (*)	-	9,872	-	9,872
Professional fees - patent research	29,996	-	-	29,996
Rent (**)	3,000	-	-	3,000
Salaries	114,844	67,459	167,490	349,793
Scientific meetings	88,230	-	-	88,230
Telephone	1,058	621	1,542	3,221
Travel - scientific meetings	694	-	-	694
Website and hosting	343	-	-	343
	<u>\$ 6,121,491</u>	<u>\$ 93,634</u>	<u>\$ 358,607</u>	<u>\$ 6,573,732</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, 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.
Notes to Financial Statements
December 31, 2014
(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, 2014
(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, 2014, 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, 2014, 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, 2014. 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, 2011.

Rett Syndrome Research Trust, Inc.
Notes to Financial Statements
December 31, 2014
(See Report of Independent Auditor)

NOTE 4 – Promises to Give

At December 31, 2014 and 2013, contributors to the Organization have unconditionally promised to give \$1,234,629 and \$1,098,788, 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>2014</u>	<u>2013</u>
Within one year	\$ 716,229	\$ 398,788
One to five years	540,000	700,000
More than five years	-	-
Subtotal	<u>1,256,229</u>	<u>1,098,788</u>
Less: present value component	(10,800)	(19,120)
Less: allowance for doubtful accounts	-	-
Promises to give, net	<u><u>\$ 1,245,429</u></u>	<u><u>\$ 1,079,668</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 \$9,513,123 and \$8,292,695 as of December 31, 2014 and 2013, 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>2014</u>	<u>2013</u>
Within one year	\$ 5,537,722	\$ 3,719,507
One to five years	3,975,401	4,573,188
More than five years	-	-
Subtotal	<u>9,513,123</u>	<u>8,292,695</u>
Less: present value component	(86,547)	(126,491)
Grants payable, net	<u><u>\$ 9,426,576</u></u>	<u><u>\$ 8,166,204</u></u>

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

NOTE 6 – Concentrations

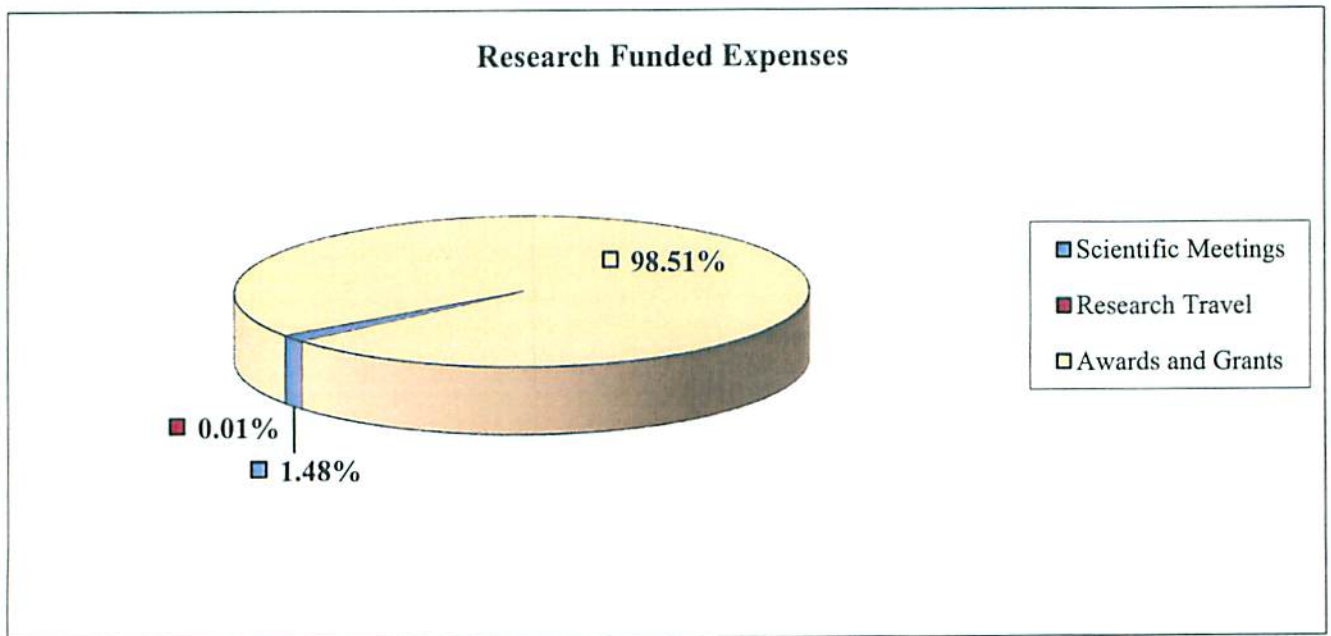
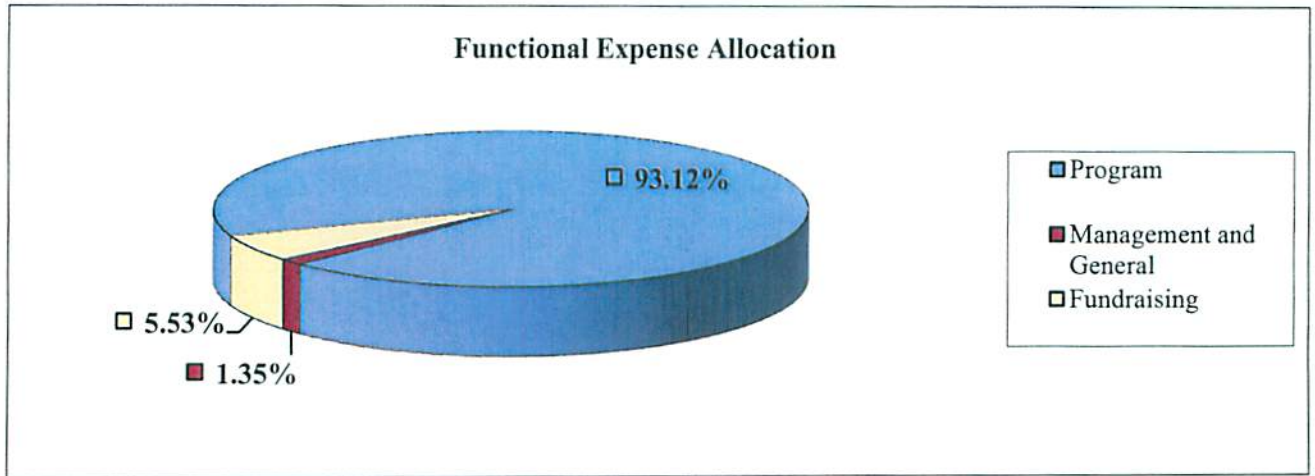
The Organization has several donors that have provided at least 10% of aggregate contributions for the year ended December 31, 2014.

Rett Syndrome Research Trust, Inc.
Notes to Financial Statements
December 31, 2014
(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, 2014 through April 5, 2015, 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, 2014



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, 2014

	<u>Commitment at December 31, 2013</u>	<u>Additional Commitments</u>	<u>Payments Against Commitments</u>	<u>Commitment at December 31, 2014</u>
Hospital for Sick Kids Monica Justice	\$ 301,815	\$ 715,680	\$ (301,815)	\$ 715,680
Baylor College of Medicine - Huda Zoghbi	74,616	-	(74,616)	-
Fred Hutchinson Cancer Research Antonio Bedalov	-	290,000	(72,500)	217,500
University of Virginia Jonathan Kipnis	385,000	-	(220,000)	165,000
MIT Mark Bear	11,485	-	(11,485)	-
UNC - Chapel Hill Benjamin Philpot	1,176,131	-	(707,432)	468,699
Harvard University/MGH Jeannie Lee	150,000	465,000	(125,000)	490,000
Case Western David Katz	50,000	-	(50,000)	-
UMASS Medical School Michael Green	562,500	-	(250,000)	312,500
Sheba Medical Center Bruria Ben Zeev	98,982	-	(98,982)	-
Harvard University Michela Fagiolini	126,741	-	(126,741)	-
Children's Hospital at Montefiore Aleksandra Djukic	-	403,000		403,000
MECP2 Consortium Harvard University of Edinburgh OHSU	3,417,575	250,000	(1,379,345)	2,288,230
Gene Therapy Consortium UNC - Chapel Hill Nationwide Children's Hospital University of Glasgow OHSU	1,535,942	67,401	(460,192)	1,143,151
Baylor College of Medicine - Huda Zoghbi - duplication Reversal	82,684	-	(82,684)	-
ASO	-	230,000	(28,750)	201,250
Screen	319,224	414,065	(89,590)	643,699
Children's Hospital at Montefiore		82,500	(82,500)	-

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, 2014

	<u>Commitment at December 31, 2013</u>	<u>Additional Commitments</u>	<u>Payments Against Commitments</u>	<u>Commitment at December 31, 2014</u>
UCSD				
Jeff Neul	-	314,456	(159,806)	154,650
LSRF				
Sung Yon Kim	-	91,500	-	91,500
UTSW				
Stephen Turley	-	20,000	(20,000)	-
Kennedy Krieger Institute				
Jay Shapiro	-	4,000	(4,000)	-
California Institute of Technology				
Ali Khoshnan	-	200,000	(50,000)	150,000
Trinity College				
Daniela Tropea	-	13,000	-	13,000
Washington University				
Daniel Ory	-	3,000	-	3,000
Lurie Children's Hospital				
Debra Weese Mayer/Michael Carroll	-	157,300	(19,662)	137,638
Stonybrook University				
Nurit Ballas	-	20,000	(20,000)	-
UNC - Chapel Hill				
Terry Magnuson	-	200,000	-	200,000
Case Western				
David Katz	-	271,700	-	271,700
Case Western/Cleveland Clinic				
David Katz/Daniel Sessler	-	1,295,131	-	1,295,131
University of Alabama/Birmingham				
Lucas Pozzo Miller	-	110,000	-	110,000
Children's Hospital at Montefiore				
Aleksandra Djukic - Copaxone Supplement	-	47,000	(47,000)	-
Children's Hospital at Montefiore				
Aleksandra Djukic - Copaxone additional	-	57,661	(19,866)	37,795
DaimiR	-	6,768	(6,768)	-
Neurolix	-	54,945	(54,945)	-
Recursion	-	25,000	(25,000)	-
	<u>\$ 8,292,695</u>	<u>\$ 5,809,107</u>	<u>\$ (4,588,679)</u>	<u>\$ 9,513,123</u>

See report of independent auditor.