Rett Syndrome Research Trust, Inc.

**Financial Statements** 

December 31, 2019



Making Rett History

#### Rett Syndrome Research Trust, Inc. December 31, 2019

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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, 2019 and 2018 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, 2019 and 2018, 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 Skeppard CPAS, LLP

Knight Rolleri Sheppard CPAS, LLP Fairfield, Connecticut May 8, 2020

#### Rett Syndrome Research Trust, Inc. Statements of Financial Position December 31, 2019 and 2018

	2019	<u>2018</u>
<u>ASSETS</u>		
Current assets		
Cash and cash equivalents	\$ 8,232,008	\$ 8,767,464
Promises to give	1,464,982	2,253,575
Investments	1,100	
Total current assets	9,698,090	11,021,039
Other assets		
Promises to give	102,165	369,932
Equipment, net of accumulated depreciation of \$5,379 and \$4,318		
in 2019 and 2018, respectively	1,060	2,122
Total other assets	103,225	372,054
Total assets	\$ 9,801,315	\$11,393,093
LIABILITIES AND NET ASSETS		
Curent liabilities		
Accounts payable	\$ 6,227	\$ 12,379
Grants payable	7,320,828	8,457,410
Accrued expenses	25,681	7,500
Total current liabilities	7,352,736	8,477,289
Other liabilities		
Grants payable	8,897,504	7,214,736
Total other liabilities	16,250,240	15,692,025
Net assets without donor restrictions		
Undesignated (deficit)	(6,448,925)	(4,298,932)
Total net assets (deficit)	(6,448,925)	(4,298,932)
Total liabilities and net assets	\$ 9,801,315	\$11,393,093

## Rett Syndrome Research Trust, Inc. Statements of Activities For the Years Ended December 31, 2019 and 2018

	<u>2019</u>	<u>2018</u>
Public support and revenues		
Contributions	\$ 7,505,400	\$ 9,232,106
The Eva Fini Fund	299,634	2,780
The MECP2 Duplication Syndrome Fund	535,069	469,569
Licensing	128,333	-
Donated services and rent	8,000	8,000
Interest income	36,443	23,178
Realized gains from sales of donated securities	2,235	1,885
Total public support and revenues	8,515,114	9,737,518
Expenses		
Program services	9,865,527	10,792,926
Supporting services:		
Management and general	208,243	166,080
Fundraising	591,337	418,186
Total expenses	10,665,107	11,377,192
Decrease in net assets from operations	(2,149,993)	(1,639,674)
Net assets (deficit) - beginning of year	(4,298,932)	(2,659,258)
Net assets (deficit) - end of year	\$ (6,448,925)	\$ (4,298,932)

## Rett Syndrome Research Trust, Inc. Statements of Cash Flows For the Years Ended December 31, 2019 and 2018

	<u>2019</u>	<u>2018</u>
Cash flows from (used in) operating activities		
Decrease in net assets	\$ (2,149,993)	\$ (1,639,674)
Adjustments to reconcile decrease in net assets		
to cash from (used in) operating activities		
Depreciation	1,061	1,061
Decrease in promises to give	1,056,361	1,908,868
(Increase) decrease in investments from donor donations held for sale	(1,100)	71
Increase (decrease) in accounts payable	(6,152)	4,271
Increase in accrued expenses	18,181	500
Increase in grants payable	546,186	1,183,833
Net cash provided (used in) from operating activities	(535,456)	1,458,930
Cash flows from investing activities		
Investment in equipment		(3,183)
Net cash used in investing activities	-	(3,183)
Decrease in cash	(535,456)	1,455,747
Cash and cash equivalents - beginning of year	8,767,464	7,311,717
Cash and cash equivalents - end of year	\$ 8,232,008	\$ 8,767,464

#### Rett Syndrome Research Trust, Inc. Statement of Functional Expenses For the Year Ended December 31, 2019

	Supporting Services			
		Management		Total
	<b>Program</b>	and General	<b>Fundraising</b>	Expenses
Awards and grants	\$ 8,530,142	\$ -	\$ -	\$ 8,530,142
Bank and credit card fees	3,149	446	593	4,188
Bookkeeping	-	784	-	784
Depreciation	1,013	5	43	1,061
Employee benefits	38,589	5,471	7,265	51,325
Fundraising	· -	-	371,936	371,936
Insurance	1,973	1,971	1,971	5,915
Miscellaneous	34,627	1,822	2,858	39,307
Office and supplies	1,052	7,567	198	8,817
Payroll taxes	67,595	9,584	12,727	89,906
Postage and shipping	3,772	535	710	5,017
Printing and publication	6,007	30	257	6,294
Professional fees (*)	16,818	34,933	-	51,751
Rent (**)	3,812	540	718	5,070
Salaries	1,016,420	144,115	191,367	1,351,902
Scientific meetings	84,045	-	-	84,045
Telephone	2,999	425	565	3,989
Travel - scientific meetings	50,498	-	_	50,498
Website and hosting	3,016	15	129	3,160
	\$ 9,865,527	\$ 208,243	\$ 591,337	\$ 10,665,107

<sup>(\*)</sup> Includes \$5,000 of donated services.

<sup>(\*\*)</sup> Includes \$3,000 donated rent.

#### Rett Syndrome Research Trust, Inc. Statement of Functional Expenses For the Year Ended December 31, 2018

		Management		Total
	Program	and General	<b>Fundraising</b>	Expenses
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
	\$ 10,792,926	\$ 166,080	\$ 418,186	\$ 11,377,192

<sup>(\*)</sup> Includes \$5,000 of donated services.

<sup>(\*\*)</sup> Includes \$3,000 donated rent.

#### **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 – CORRECTION OF AN ERROR**

Management discovered an error in the prior year's financial statements which increased assets by \$77,340 and correspondingly increased revenues. The prior year's financial statements have been restated to reflect the corrected accounts.

#### NOTE 3 – 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 of December 31, 2019, the Organization is insured up to \$500,000 of recorded bank balances. The balance in excess of FDIC limitations is \$9,899,057 at December 31, 2019. 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, 2019, 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.

#### Revenue and Revenue Recognition

The Organization recognize contributions when cash, securities or other assets, an unconditional promise to give, or notification of a beneficial interest is received. Conditional promises to give, that is, those with a measurable performance or other barrier, and a right of return, are not recognized until the conditions on which they depend have been substantially met.

#### **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, 2019 and 2018. 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, 2019 and 2018, 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 4 – 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	\$ 8,232,008
Promises to give	1,464,982
	\$ 9,696,990

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.

#### NOTE 5 – 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, 2019.

#### **NOTE 6 – 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, 2017.

#### NOTE 7 – PROMISES TO GIVE

At December 31, 2019 and 2018, contributors to the Organization have unconditionally promised to give \$1,569,232 and \$2,631,057, 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>2019</u>	<u>2018</u>
Within one year	\$ 1,464,982	\$ 2,253,575
One to five years	104,250	377,482
More than five years		
Subtotal	1,569,232	2,631,057
Less: present value component	(2,085)	(7,550)
Less: allowance for doubtful accounts	<u>-</u>	
Promises to give, net	\$ 1,567,147	\$ 2,623,507

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 5 to the financial statements.

#### NOTE 8 – GRANTS PAYABLE

The Organization has committed to unconditional promises to give of \$16,463,644 and \$15,860,900 as of December 31, 2019 and 2018, 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> 2019</u>	<u>2018</u>
Within one year	\$ 7,320,828	\$ 8,457,410
One to five years	9,143,087	7,403,490
More than five years	-	
Subtotal	16,463,915	15,860,900
Less: present value component	(245,583)	(188,754)
Grants payable, net	\$ 16,218,332	\$ 15,672,146

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

#### **NOTE 9- CONCENTRATIONS**

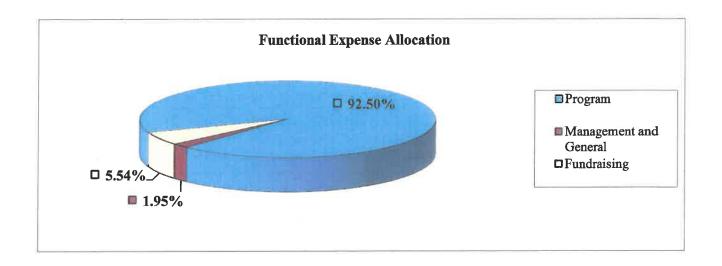
The Organization has several donors that have provided at least 10% of aggregate contributions for the year ended December 31, 2019.

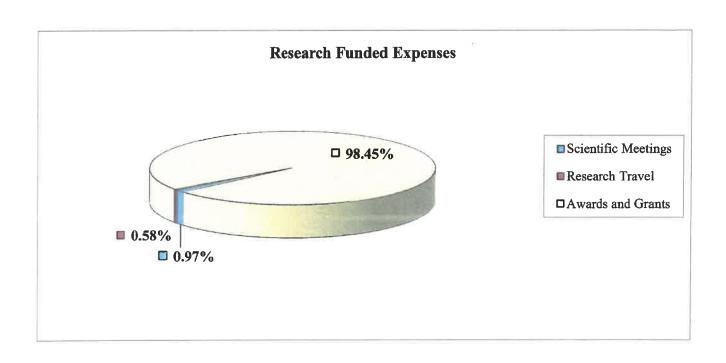
#### *NOTE 10 – SUBSEQUENT EVENTS*

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, 2019 through May 8, 2020, which is the date the financial statements were available to be issued. On January 30, 2020, the World Health Organization ("WHO") announced a global health emergency because of a new strain of coronavirus originating in Wuhan, China (the "COVID-19 outbreak") and the risks to the international community as the virus spreads globally beyond its point of origin. In March 2020, the WHO classified the COVID-19 outbreak as a pandemic, based on the rapid increase in exposure globally.

The full impact of the COVID-19 outbreak continues to evolve as of the date of this report. As such, it is uncertain as to the full magnitude that the pandemic will have on the Organization's financial condition, liquidity, and future results of operations. Management is actively monitoring the global situation on its financial condition, liquidity, operations, and workforce. Given the daily evolution of the COVID-19 outbreak and the global responses to curb its spread, the Organization is not able to estimate the effects of the COVID-19 outbreak on its results of operations, financial condition, or liquidity for fiscal year 2020.

# Rett Syndrome Research Trust, Inc. Supplemental Statement - Functional Expense Allocation and Research Funded Expense Graphs For the Year Ended December 31, 2019





#### Rett Syndrome Research Trust, Inc.

#### Supplemental Statement - Research Awards and Grant Commitments and Payments Schedule For the Year Ended December 31, 2019

	Commitment at December 31, 2018	Additional Commitments	Payments Against Commitments	Commitment at December 31, 2019
Fred Hutchinson Cancer Research				
Antonio Bedalov	\$ 38,000	\$ 20,000	\$ (58,000)	\$ -
MECP2 Consortium Harvard University of Edinburgh OHSU	1,167,723	3,359,054	(1,167,723)	3,359,054
Gene Therapy Consortium . University of Glasgow/Edinburgh UCSD University of Pennsylvania	1,141,606	803,606	(889,002)	1,056,210
Children's Hospital at Montefiore		75,000	(75,000)	-
Case Western/Cleveland Clinic (Ketamine Trial) David Katz/Daniel Sessler	893,623	-	(279,978)	613,645
University of Glasgow				
Stuart Cobb - supplement	70,000	-	(70,000)	•
Stuart Cobb - optimizing RNA	110,268	-	(110,268)	-
Stuart Cobb - RNA supplement	96,668	-	(96,668)	-
Stuart Cobb - qPCR machine	· =			-
USCD				
Alyson Muotri - Rett	17,417	-	(17,417)	-
Whitehead Institute Rudolph Jaenisch	15,000	-	(15,000)	-
Rudolph Jaenisch - editing	249,938	-	(199,950)	49,988
Queen Mary University of London Andrea Cerase	292,520	-	(58,504)	234,016
OHSU				
John Sinnamon	316,250	-	(115,000)	201,250
University of California Davis Peter Beal	563,870	-	(215,471)	348,399
Beam Therapeutics	1,870,660		(805,160)	1,065,500
MIT				
MIT Guoping Feng	2,332,000	-	(777,332)	1,554,668
University of MassachusettsMedical School Jonathan Watts	2,403,735	-	(594,709)	1,809,026
University of MassachusettsMedical School Allan Jacobson/ Jonathan Watts	323,000	-	(242,250)	80,750
Nationwide Children's Hospital Kathrine Meyer	50,830	-	(50,830)	~
Clinical Trial Consortium	1,555,183	-	(306,634)	1,248,549
OMBD Consortium	1,588,010	-	(619,186)	968,824

### Rett Syndrome Research Trust, Inc. Supplemental Statement - Research Awards and Grant Commitments and Payments Schedule For the Year Ended December 31, 2019

	Commitment at December 31, 2018	Additional Commitments	Payments Against Commitments	Commitment at December 31, 2019
California Institute of Technology Michael Elowitz	-	212,374	(104,577)	107,797
Yale University Peter Glazer/Mark Salttzman	-	275,000	(103,125)	171,875
University of California Berkley Alanna Schepartz	-	297,716	(111,642)	186,074
Milliman	(#C	27,522	(27,522)	-
Cellular Engineering Technology	-	20,000	(20,000)	-
University of Nottingham James Dixon	-	20,000	(20,000)	-
Ophidion	-	68,000	(39,000)	29,000
University of Massachsetts Medical School Beth McCormick	-	520,316	-	520,316
University of Tubingen Thorsten Stafforst		359,856	-	359,856
University of Edinburgh Stuart Cobb/Chris Sibley	-	235,949	(39,323)	196,626
MIT Joseph Jacobson	-	50,000	3.	50,000
Erasnus	-	401,000	-	401,000
Harvard Stem Cell Institute	-	101,912	(101,912)	-
Emerald	-	164,670	(28,336)	136,334
Jackson Laboraties	3	417,690	(216,625)	201,065
Coriell Institute for Medical Research	=	135,000	-	135,000

### Rett Syndrome Research Trust, Inc. Supplemental Statement - Research Awards and Grant Commitments and Payments Schedule For the Year Ended December 31, 2019

	Commitment at December 31, 2018	Additional <u>Commitments</u>	Payments Against Commitments	Commitment at December 31, 2019
MECP2 Duplication Syndrome				
Baylor College of Medicine	37.033		(27,022)	
ASO -Huda Zoghbi	37,933	-	(37,933)	
Screen - Huda Zoghbi	660,698	-	(185,458)	475,240
UCSD Alyson Muotri - MECP2 Duplication	66,000	_	(66,000)	
Alyson Whoth - WEST 2 Duplication	00,000	•	(00,000)	-
University of Massachusetts Medical School Annastasia Khvorova	-	435,515	(54,162)	381,353
Hospital for Sick Kids Ronald Cohn	-	570,000	(47,500)	522,500
	\$ 15,860,932	\$ 8,570,180	\$ (7,967,197)	\$ 16,463,915