Rett Syndrome Research Trust, Inc.

**Financial Statements** 

December 31, 2024



# Rett Syndrome Research Trust, Inc. December 31, 2024

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### REPORT OF INDEPENDENT AUDITOR

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

### Opinion

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, 2024 and 2023, and the related statements of activities, functional expenses and cash flows for the years then ended, and the related notes to the financial statements.

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, 2024 and 2023, 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.

#### **Basis for Opinion**

We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of Rett Syndrome Research Trust, Inc. and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audits. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

#### **Responsibilities of Management for the Financial Statements**

Management is responsible for the preparation and fair presentation of the financial statements in accordance with accounting principles generally accepted in the United States of America, and for 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.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about Rett Syndrome Research Trust, Inc.'s ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

### Auditor's Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with generally accepted auditing standards will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements, including omissions, are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with generally accepted auditing standards, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or
  error, and design and perform audit procedures responsive to those risks. Such procedures include
  examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit 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
  Rett Syndrome Research Trust, Inc.'s internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting
  estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise
  substantial doubt about Rett Syndrome Research Trust, Inc.'s ability to continue as a going concern for a
  reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control related matters that we identified during the audit.

#### Supplementary Information

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 is presented for purposes of additional analysis and is not a required part of the 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 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.

# Rolleri & Sheppard CPAS. LLP

Rolleri & Sheppard CPAS, LLP Fairfield, Connecticut May 7, 2025

## Rett Syndrome Research Trust, Inc. Statements of Financial Position December 31, 2024 and 2023

	2024	2023
ASS	ETS	
Current assets		
Cash and cash equivalents	\$ 17,999,520	\$ 17,266,396
Promises to give	1,218,539	1,039,389
Other receivable	98,281	98,281
Prepaid assets	34,552	31,064
Other current assets	7,274	
Investments		1,078
Total current assets	19,358,166	18,436,208
Other assets		
Promises to give	998,414	20,876
Total other assets	998,414	20,876
Total assets	\$ 20,356,580	\$ 18,457,084

# LIABILITIES AND NET ASSETS

Curent liabilities		
Accounts payable	\$ 86,750	\$ 20,625
Grants payable	9,891,231	6,137,004
Accrued expenses	16,500	14,500
Total current liabilities	9,994,481	6,172,129
Other liabilities		
Grants payable	5,642,021	5,149,143
Total other liabilities	15,636,502	11,321,272
Net assets without donor restrictions		
Undesignated	4,720,078	7,135,812
Total net assets	4,720,078	7,135,812
Total liabilities and net assets	\$ 20,356,580	\$ 18,457,084

## Rett Syndrome Research Trust, Inc. Statements of Activities For the Years Ended December 31, 2024 and 2023

	2024	2023
Public support and revenues		
Contributions	\$ 8,204,650	\$ 7,406,934
The MECP2 Duplication Syndrome Fund	225,807	196,159
Licensing	156,372	84,450
Biorepository	22,164	22,500
Donated materials	248,716	299,570
Donated services and rent	9,500	8,000
Interest income	446,592	333,088
Realized gains from sales of donated securities	3,008	3,093
Unrealized losses	(1,078	) -
Refundable payroll tax government grant	-	178,021
Total public support and revenues	9,315,731	8,531,815
Expenses		
Program services	10,822,119	11,398,647
Supporting services:		
Management and general	197,028	197,503
Fundraising	712,318	750,154
Total expenses	11,731,465	12,346,304
Decrease in net assets from operations	(2,415,734	(3,814,489)
Net assets - beginning of year	7,135,812	10,950,301
Net assets - end of year	\$ 4,720,078	\$ 7,135,812

### Rett Syndrome Research Trust, Inc. Statement of Functional Expenses For the Year Ended December 31, 2024

	Supporting Services			
	Program	Management and General	Fundraising	Total <u>Expenses</u>
Awards and grants	\$ 9,350,537	s -	s .	\$ 9,350,537
Bad debt	31,440	8	1,692	33,140
Bank and credit card fees	6,579	1,086	1,625	9,290
Bookkeeping	-	660		660
Employee benefits	42,927	7,084	10,601	60,612
Fundraising	· ·		447,893	447,893
Insurance	2,489	2,488	2,488	7,465
Miscellaneous	83,954	400	4,138	88,492
Office and supplies	6,642	1,097	1,640	9,379
Payroll taxes	51,144	8,440	12,630	72,214
Postage and shipping	4,714	778	1,164	6,656
Printing and publication	920	5	45	970
Professional fees (*)	375,983	46,164	35,611	457,758
Rent (**)	3,187	526	787	4,500
Research costs	46,602		-	46,602
Salaries	775,529	127,977	191,520	1,095,026
Scientific meetings	30,655		-	30,655
Telephone	1,895	313	468	2,676
Travel - scientific meetings	6,596			6,596
Website and hosting	326	2	16	344
	\$ 10,822,119	\$ 197,028	\$ 712,318	\$ 11,731,465

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

(\*\*) Includes \$4,500 donated rent.

### Rett Syndrome Research Trust, Inc. Statement of Functional Expenses For the Year Ended December 31, 2023

		Supporting Services		
		Management		Total
	<b>Program</b>	and General	Fundraising	Expenses
Awards and grants	\$ 9,938,988	s -	s -	\$ 9,938,988
Bad debt	5,000		-	5,000
Bank and credit card fees	9,384	1,577	2,400	13,361
Bookkeeping		374		374
Employee benefits	41,526	6,978	10,622	59,126
Fundraising		-	491,819	491,819
Insurance	2,268	2,268	2,268	6,804
Miscellaneous	51,633	6,623	10,183	68,439
Office and supplies	845	6,388	216	7,449
Payroll taxes	56,777	9,541	14,523	80,841
Printing and publication	586	2	28	616
Professional fees (*)	142,727	26,780	9,557	179,064
Rent (**)	2,107	354	539	3,000
Research costs	80,625		-	80,625
Salaries	806,159	135,466	206,211	1,147,836
Scientific meetings	247,510	-	-	247,510
Telephone	1,908	321	488	2,717
Travel - scientific meetings	4,859	-	-	4,859
Website and hosting	816	3	39	858
	\$ 11,398,647	\$ 197,503	\$ 750,154	\$ 12,346,304

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

(\*\*) Includes \$3,000 donated rent.

# Rett Syndrome Research Trust, Inc. Statements of Cash Flows For the Years Ended December 31, 2024 and 2023

	2024	2023
Cash flows from (used in) operating activities		
Decrease in net assets	\$ (2,415,734)	\$ (3,814,489)
Adjustments to reconcile increase (decrease) in net assets to cash from (used in) operating activities		
Increase in promises to give	(1,156,688)	(20,413)
Increase in other receivable		(98,281)
Increase in prepaid assets	(3,488)	(24,785)
Increase in other current assets	(7,274)	-
Decrease in investments	1,078	3,910
Increase in accounts payable	66,125	20,625
Increase in accrued expenses	2,000	1,500
Increase in grants payable	4,247,105	7,366,368
Net cash provided from operating activities	733,124	3,434,435
Increase in cash	733,124	3,434,435
Cash and cash equivalents - beginning of year	17,266,396	13,831,961
Cash and cash equivalents - end of year	\$ 17,999,520	\$ 17,266,396

### NOTE 1 - ORGANIZATION

Rett Syndrome Research Trust, Inc. (the "Organization") 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, the Organization 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, the disclosure of contingent assets and liabilities as of the date of the financial statements, and the reported amounts of revenues and expenses during the reporting period. Significant estimates include, but are not limited to, the useful lives of long-lived assets, the allocation of functional expenses, and the discount rates applied to long-term promises to give and long-term grants payable. Actual results may differ from those estimates.

### Cash and Cash Equivalents

For purposes of the statement of cash flows, the Organization considers all highly liquid debt instruments with original maturities of three months or less to be cash equivalents. The Organization maintains cash balances at multiple financial institutions in the State of Connecticut. These balances are insured by the Federal Deposit Insurance Corporation (FDIC) up to \$250,000 per institution. As of December 31, 2024, the Organization's cash balances exceeded FDIC insurance limits by \$3,491,387.

#### Promise to Give and Allowance for Uncollectable Accounts

Promises to give are recorded as contributions when pledged and are stated at their estimated net realizable value. Promises to give are presented net of an allowance for doubtful accounts and, if expected to be collected in more than one year, are also discounted to present value using a risk-free adjusted discount rate. The allowance is based on historical collection experience, as well as management's evaluation of other relevant factors.

## Revenue Recognition and Contributions (ASC 606 and ASC 958);

The Organization recognizes revenue from exchange transactions in accordance with FASB ASC Topic 606, *Revenue from Contracts with Customers*, which outlines a five-step framework to reflect the transfer of goods or services in exchange for consideration. Revenues from non-contribution sources are insignificant in the aggregate. Additional information regarding significant revenue concentrations is disclosed in *Note 9 – Revenue Concentrations*.

The Organization applies the guidance under FASB ASC Topic 958, Not-for-Profit Entities, to determine whether a transaction qualifies as a contribution (nonreciprocal) or an exchange transaction (reciprocal), and whether a contribution is conditional. Contributions, including unconditional promises to give, are recognized when cash, securities, other assets, or notification of a beneficial interest is received. These contributions are recorded as revenue in the period received and are presented at net realizable value. Conditional contributions — those that include a measurable performance or other barrier and a right of return — are not recognized until the conditions are substantially met.

### In-Kind Contributions

The Organization receives significant in-kind contributions, including volunteer time and pro bono services, primarily in connection with special events and fundraising activities. Donated services are recognized as contributions if they either create or enhance nonfinancial assets or require specialized skills, are provided by individuals possessing those skills, and would otherwise need to be purchased by the Organization.

In-kind contributions are recorded as both revenue and expense at estimated fair value at the time of donation. Donated auction items received for fundraising events are recorded at their gross selling price when sold.

### Donated Securities

Donated publicly traded securities are recorded at their fair market value on the date of donation. Fair market value is determined using the closing market price of the security on the date the Organization gains control, which is typically the date the securities are received. These contributions are recognized as revenue in the period received. For the year ended December 31, 2024, all donated securities were unrestricted and available for general use.

### Property and Equipment

Property and equipment are recorded at cost and depreciated over a useful life of three years using the straight-line method. All assets were fully depreciated as of December 31, 2024 and 2023.

#### Functional Expenses

The Organization allocates expenses on a functional basis among program and supporting services. Expenses that are directly attributable to a specific function are charged accordingly based on their natural classification. Shared expenses are allocated among functions based on management's estimates of usage or benefit received.

Direct fundraising expenses totaled \$447,893 and \$491,819 for the years ended December 31, 2024 and 2023, respectively.

### NOTE 3 - LIQUIDITY AND AVAILABILITY

Financial assets available for general expenditure, meaning those without donor or other restrictions limiting their use within one year of the statement of financial position date, are as follows:

Cash and cash equivalents	\$ 17,999,520
Promises to give	1,218,539
	\$ 19,218,059

The Organization has committed significant resources to research grants due within one year of the statement of financial position date. To meet these commitments, the Organization relies on the collection of promises to give due within one year, along with ongoing fundraising efforts to secure additional funds.

As part of its liquidity management plan, the Organization invests cash in excess of daily requirements in short-term investments and money market funds.

### NOTE 4 - FAIR VALUE MEASUREMENTS

The Organization follows the fair value measurement guidance under ASC 820, which prioritizes the inputs used in valuation techniques to measure fair value. The fair value hierarchy consists of three levels:

- Level 1: Unadjusted quoted prices in active markets for identical assets or liabilities
  accessible to the Organization.
- Level 2: Observable inputs other than quoted prices included in Level 1, such as quoted prices for similar assets in active or inactive markets, or inputs corroborated by observable market data.
- Level 3: Unobservable inputs significant to the fair value measurement, requiring significant judgment.

The Organization determines fair value based on assumptions that market participants would use in pricing an asset or liability in the most advantageous market. The fair value measurement approach is influenced by factors such as the investment type, market liquidity, and whether observable market data is available. Level 3 measurements, which rely on unobservable inputs, involve greater judgment due to the inherent uncertainty of valuation.

Valuation Methodologies

 Promises to Give: Valued based on discounted cash flows, adjusted by an allowance for collectability.

There have been no changes in valuation methodologies as of December 31, 2024.

The following table summarizes changes in the fair value of the Organization's Level 3 assets for the years ended December 31, 2024 and 2023:

	Promises to Give	
	2024	2023
Balance - beginning of year	\$ 1,066,119	\$ 1,046,179
New promises to give	2,294,648	625,909
Collections and adjustments	(1,084,752)	(605,969)
Balance - end of year	\$ 2,276,015	\$ 1,066,119

### NOTE 5 - INCOME TAXES

The Organization is exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code and is generally exempt from state income taxes as well. Accordingly, no provision for federal or state income taxes has been recorded in the accompanying financial statements.

Management has evaluated the Organization's tax positions and concluded that there are no uncertain tax positions requiring recognition or disclosure. The Organization's informational returns (Forms 990) remain subject to examination by federal and state taxing authorities for three years from the date of filing.

### NOTE 6 - PROMISES TO GIVE

At December 31, 2024 and 2023, the Organization had unconditional promises to give totaling \$2,276,015 and \$1,066,119, respectively. Promises expected to be collected in more than one year are discounted at an annual rate of 4%, which management considers to be a reasonable estimate of the risk-free rate of return.

The expected timing of collections is as follows:

	2024	2023
Within one year	\$ 1,229,679	\$ 1,044,389
One to five years	1,046,336	21,730
More than five years	-	
Subtotal	2,276,015	1,066,119
Less: present value component	(47,922)	(854)
Less: allowance for doubtful accounts	(11,140)	(5,000)
Promises to give, net	\$ 2,216,953	\$ 1,060,265
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All promises to give are valued using Level 3 inputs, as described in Note 4, due to the use of unobservable inputs and management's judgment in assessing collectability and timing.

## NOTE 7 - GRANTS PAYABLE

As of December 31, 2024 and 2023, the Organization had committed to unconditional promises to give totaling \$15,768,336 and \$11,557,155, respectively, to various research organizations over the next several years. Commitments expected to be paid in more than one year are discounted at an annual rate of 4%, which management considers to be a reasonable estimate of the risk-free rate of return.

Future funding of these committed grants is predicated upon anticipated fundraising activities and the continued availability of financial resources.

The expected timing of grant payments is as follows:

	2024	2023
Within one year	\$ 9,891,231	\$ 6,137,004
One to five years	5,877,105	5,420,151
More than five years	1	· · · · · ·
Subtotal	15,768,336	11,557,155
Less: present value component	(235,084)	(271,008)
Grants payable, net	\$15,533,252	\$11,286,147

### NOTE 8 - DONATED SERVICES AND IN-KIND CONTRIBUTIONS

The Organization received the following contributions of nonfinancial assets for the years ending December 31, 2024 and 2023:

	-	2024		2023
Auction and raffle items	\$	248,716	s	299,570
In-kind services	~~~	9,500		8,000
	\$	258,216	S	307,570

## NOTE 9- REVENUE CONCENTRATIONS

For the year ended 2024, the Organization received a significant portion of its total revenue from one individual donor. Contributions from this donor accounted for approximately 11% of total revenue. While the Organization is actively working to diversify its funding sources, it remains reliant on this donor to support a meaningful portion of its activities. A reduction or loss of this support could have a noticeable impact on operations and financial results.

Other sources of income — including revenue from biorepository storage fees, patient data license agreements, and donated materials and services — each accounted for less than 10% of total revenue and are not considered individually significant.

The Organization remains focused on monitoring revenue sources and is committed to strengthening long-term financial sustainability through continued fundraising and partnership development.

### NOTE 10 - SUBSEQUENT EVENTS

The Organization has evaluated events and transactions occurring subsequent to December 31, 2024 through May 7, 2025, the date the financial statements were available to be issued, in accordance with FASB ASC 855, *Subsequent Events*. Management has determined that there are no subsequent events requiring disclosure or adjustment to the financial statements.

Rett Syndrome Research Trust, Inc. Supplemental Statement - Functional Expense Allocation and Research Funded Expense Graphs For the Year Ended December 31, 2024





# Rett Syndrome Research Trust, Inc. Supplemental Statement - Research Awards and Grant Commitments and Payments Schedule For the Year Ended December 31, 2024

	Commitment at December 31, 2023		Additional <u>Commitments</u>		Payments Against <u>Commitments</u>		Commitment at December 31, 2024	
Fred Hutchinson Cancer Research								
Antonio Bedalov	s	46,754	s -	s	(46,754)	\$		
University of Edinburgh								
Adrian Bird		315,502			(105,168)		210,334	
Children's Hospital at Montefiore			25,000		(25,000)			
Ketamine Trial		265,798					265,798	
University of California Davis								
Peter Beal		246,742			(197,037)		49,705	
Kyle Fink		46,367	97,554		(46,365)		97,554	
MIT							-	
Guoping Feng		3,734,738			(1,244,914)		2,489,824	
University of Columbia								
Shawn Liu		96,578			(96,578)			
Boston Chidren's Hospital		69,088			(69,088)			
Emory University								
Faundez 2023		1,150,965			(424,881)		726,084	
Rett Syndrome Global Registry		15,059	103,596		(118,655)			
OMBD Consortium		568,048	1		(28,510)		539,538	
RSRT Biorepository								
Harvard Stem Cell Institute			45,077		(45,077)			
Sampled			16,898		(16,898)			
Coriell Institute for Medical Research		-	100,599		(100,599)			
Genetic Alliance IRB		-	300		(300)		82	
Emerald 2		535,725	<u>_</u>		(107,145)		428,580	
Jackson Laboratories		33,209			10		33,209	
Citizen		296,000					296,000	
Cal Tech								
Michael Elowitz		500,000	9		(250,000)		250,000	
ProQR		1,120,000	2,625,451		(1,095,451)		2,650,000	
UMass Medical School								
Sontheimer, Watts, Wolfe		2,343,090			(781,032)		1,562,059	

#### Rett Syndrome Research Trust, Inc. Supplemental Statement - Research Awards and Grant Commitments and Payments Schedule For the Year Ended December 31, 2024

	Commitment at December 31, 2023	Additional <u>Commitments</u>	Payments Against <u>Commitments</u>	Commitment at December 31, 2024
NYU				
Orrin Devinsky	50,000		(30,234)	19,766
Jackson Labs (Khvorova)	123,492		(108,623)	14,869
Jiangbing Zhou (Feng)	1.51	588,306	(97,328)	490,978
Jiangbing Zhou (Liu)	652	548,306	<b>t</b> 3	548,306
Shawn Liu (Zhou)	22	476,241		476,241
Apertura		2,000,000	2	2,000,000
Jef Boeke		161,753	2	161,753
Omar Abudayayyeh		643,004		643,004
Jonathan Gootenberg		214,997	5	214,997
Kai Chen (Jennifer Doudna lab)		1,158,523		1,158,523
Couragene		60,000	(15,000)	45,000
Han Zhang		194,732	2	194,732
Jackson Labs (Kumar)		258,979	(57,497)	201,482
	\$ 11,557,155	\$ 9,319,316	\$ (5,108,134)	\$ 15,768,336