

International Rett Syndrome Foundation (dba Rettsyndrome.org)

**Financial Statements
December 31, 2015 and 2014, and
Independent Auditors' Report**

**INTERNATIONAL RETT SYNDROME FOUNDATION
(DBA RETTSYNDROME.ORG)
December 31, 2015 and 2014**

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Independent Auditors' Report

To the Board of Trustees
International Rett Syndrome Foundation
Cincinnati, Ohio

We have audited the accompanying financial statements of International Rett Syndrome Foundation (dba Rettsyndrome.org) (a nonprofit organization), which comprise of the statements of financial position as of December 31, 2015 and 2014, and the related statements of activities, functional expenses, and cash flows 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 of 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 of 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 International Rett Syndrome Foundation (dba Rettsyndrome.org) as of December 31, 2015 and 2014, 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.



April 29, 2016
Cincinnati, Ohio

**INTERNATIONAL RETT SYNDROME FOUNDATION
(DBA RETTSYNDROME.ORG)**

**Statements of Financial Position
December 31, 2015 and 2014**

	2015	2014
Assets		
Cash and cash equivalents	\$ 1,605,760	\$ 1,618,116
Investments	3,577,272	3,564,425
Pledges receivable, net	994,214	966,779
Other	59,664	99,624
Total assets	\$ 6,236,910	\$ 6,248,944
 Liabilities and Net Assets		
Liabilities		
Accounts payable and accrued liabilities	\$ 34,742	\$ 172,310
Grants payable to researchers, net	4,055,164	3,652,834
Total liabilities	4,089,906	3,825,144
 Net Assets		
Unrestricted	71,557	343,751
Temporarily restricted	1,056,810	1,059,841
Permanently restricted	1,018,637	1,020,208
Total net assets	2,147,004	2,423,800
Total liabilities and net assets	\$ 6,236,910	\$ 6,248,944

See accompanying notes to financial statements.

**INTERNATIONAL RETT SYNDROME FOUNDATION
(DBA RETTSYNDROME.ORG)**

**Statements of Activities
Years Ended December 31, 2015 and 2014**

	2015				2014			
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
Revenues:								
Special events	\$ 2,859,399	\$ 5,100	\$ -	\$ 2,864,499	\$ 2,280,019	\$ 64,501	\$ -	\$ 2,344,520
Contributions and grants	1,741,211	519,435	-	2,260,646	1,995,280	802,105	-	2,797,385
In-kind revenue	204,120	-	-	204,120	171,383	-	-	171,383
Conference registrations	3,000	-	-	3,000	139,002	-	-	139,002
Investment return (loss)	45,891	627	(1,571)	44,947	40,055	23,176	(527)	62,704
Released from restriction	528,193	(528,193)	-	-	615,922	(615,922)	-	-
Total revenues	5,381,814	(3,031)	(1,571)	5,377,212	5,241,661	273,860	(527)	5,514,994
Operating expenses	5,654,008	-	-	5,654,008	5,249,319	-	-	5,249,319
Change in net assets	(272,194)	(3,031)	(1,571)	(276,796)	(7,658)	273,860	(527)	265,675
Net assets, beginning of year	343,751	1,059,841	1,020,208	2,423,800	351,409	785,981	1,020,735	2,158,125
Net assets, end of year	\$ 71,557	\$ 1,056,810	\$ 1,018,637	\$ 2,147,004	\$ 343,751	\$ 1,059,841	\$ 1,020,208	\$ 2,423,800

See accompanying notes to financial statements.

**INTERNATIONAL RETT SYNDROME FOUNDATION
(DBA RETTSYNDROME.ORG)**

**Statement of Functional Expenses
Year Ended December 31, 2015**

	Program				Administration	Fundraising			Total
	Research	Family Empowerment	Education	Total		Appeals and General	Direct Special Events	Total	
Direct program costs	\$ 3,278,467	\$ -	\$ -	\$ 3,278,467	\$ -	\$ -	\$ -	\$ -	\$ 3,278,467
Special events costs	-	-	-	-	-	62	823,429	823,491	823,491
Personnel related costs	369,752	271,907	-	641,659	109,067	50,617	-	50,617	801,343
Professional fees	-	98,757	8,643	107,400	58,382	73,385	-	73,385	239,167
Outside services	22,051	6,068	20,153	48,272	66,462	60,613	-	60,613	175,347
Miscellaneous costs	5,496	5,354	-	10,850	73,019	55,780	-	55,780	139,649
Travel and entertainment	37,610	4,136	-	41,746	10,676	17,780	-	17,780	70,202
Office costs	1,466	17,951	6,560	25,977	8,922	34,343	-	34,343	69,242
Conferences	200	-	44,000	44,200	-	-	-	-	44,200
Occupancy costs	-	-	-	-	12,900	-	-	-	12,900
Total expenses	<u>\$ 3,715,042</u>	<u>\$ 404,173</u>	<u>\$ 79,356</u>	<u>\$ 4,198,571</u>	<u>\$ 339,428</u>	<u>\$ 292,580</u>	<u>\$ 823,429</u>	<u>\$ 1,116,009</u>	<u>\$ 5,654,008</u>

See accompanying notes to financial statements.

**INTERNATIONAL RETT SYNDROME FOUNDATION
(DBA RETTSYNDROME.ORG)**

**Statement of Functional Expenses
Year Ended December 31, 2014**

	<u>Program</u>				<u>Administration</u>	<u>Fundraising</u>			<u>Total</u>
	<u>Research</u>	<u>Family Empowerment</u>	<u>Education</u>	<u>Total</u>		<u>Appeals and General</u>	<u>Direct Special Events</u>	<u>Total</u>	
Direct program costs	\$ 2,743,423	\$ -	\$ -	\$ 2,743,423	\$ -	\$ -	\$ -	\$ -	\$ 2,743,423
Special events costs	-	-	-	-	-	7	633,722	633,729	633,729
Personnel related costs	381,817	177,018	-	558,835	130,609	124,536	-	124,536	813,980
Professional fees	-	114,998	9,199	124,197	82,909	69,260	-	69,260	276,366
Outside services	21,760	47,310	48,937	118,007	8,892	72,577	-	72,577	199,476
Miscellaneous costs	3,398	1,790	882	6,070	46,274	46,804	-	46,804	99,148
Travel and entertainment	104,737	4,355	-	109,092	13,119	30,735	-	30,735	152,946
Office costs	4,307	14,772	12,889	31,968	10,980	38,699	-	38,699	81,647
Conferences	72,033	-	96,804	168,837	-	-	-	-	168,837
Occupancy costs	44,189	4,381	-	48,570	12,900	18,297	-	18,297	79,767
Total expenses	<u>\$ 3,375,664</u>	<u>\$ 364,624</u>	<u>\$ 168,711</u>	<u>\$ 3,908,999</u>	<u>\$ 305,683</u>	<u>\$ 400,915</u>	<u>\$ 633,722</u>	<u>\$ 1,034,637</u>	<u>\$ 5,249,319</u>

See accompanying notes to financial statements.

**INTERNATIONAL RETT SYNDROME FOUNDATION
(DBA RETTSYNDROME.ORG)**

**Statements of Cash Flows
Years Ended December 31, 2015 and 2014**

	2015	2014
Cash flows from operating activities		
Change in net assets	\$ (276,796)	\$ 265,675
Adjustments to reconcile change in net assets to net cash from operating activities:		
Realized and unrealized (gains) losses on investments	56,833	(18,998)
Change in:		
Pledges receivable	(27,435)	(214,316)
Other	38,389	12,728
Accounts payable and accrued liabilities	(137,568)	96,538
Grants payable to researchers	402,330	291,282
	55,753	432,909
Net cash provided by operating activities	55,753	432,909
Cash flows from investing activities		
Purchases of investments	(1,735,276)	(3,630,404)
Sales of investments	1,667,167	3,605,889
	(68,109)	(24,515)
Net cash used in investing activities	(68,109)	(24,515)
Change in cash and cash equivalents	(12,356)	408,394
Cash and cash equivalents, beginning of year	1,618,116	1,209,722
Cash and cash equivalents, end of year	\$ 1,605,760	\$ 1,618,116

See accompanying notes to financial statements.

**INTERNATIONAL RETT SYNDROME FOUNDATION
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Notes to Financial Statements

NOTE 1 NATURE OF ACTIVITIES AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Nature of Activities

International Rett Syndrome Foundation (dba Rettsyndrome.org) (IRSF) was founded as a not-for-profit organization in 1999 as The Rett Syndrome Research Foundation under the laws of the State of Ohio. The name was changed to International Rett Syndrome Foundation on July 1, 2007 when the organization was merged with International Rett Syndrome Association (IRSA) and commenced operations as IRSF. IRSF's mission is to fund research for treatments and a cure for Rett syndrome while enhancing the overall quality of life for those living with Rett syndrome by providing information, programs, and services. IRSF's revenue consists primarily of private donations in order to fund research grants and provide education.

International Rett Syndrome Foundation operates the following programs:

- **Research programs** include activities focused on finding a treatment and cure for Rett Syndrome and include items such as research grants, new studies/transitional research, medical symposiums and support of Natural History Study Clinics.
- **Family empowerment program** includes activities focused on enhancing the overall lives of those afflicted with Rett Syndrome and their families and includes items such as an 800 phone number, regional representatives and family advisory boards.
- **Education** activities focused on providing information about and raising awareness of Rett Syndrome and includes activities such as the website, newsletters, and an annual family conference.
- **Administrative and general** include operating activities such as corporate, executive, finance and human resource activities.
- **Appeals and General** includes activities of fundraising such as general contributions and appeals, fundraising office costs and personnel.
- **Direct Special Events** include activities of specific fundraising events such as dinners, parties, golf outings and strollathons.

Financial Statement Presentation

The financial statements have been prepared on the accrual basis of accounting in accordance with generally accepted accounting principles (GAAP). IRSF is required to report information regarding its financial position and activities according to three classes of net assets: unrestricted net assets which have no donor-imposed restriction; temporarily restricted net assets which have donor-imposed restrictions that will expire in the future; and permanently restricted net assets which have donor-imposed restriction which do not expire.

Fair Value Measurements

Under applicable GAAP for fair value measurements and disclosures, a three-level hierarchy is established for fair value measurements based on transparency of valuation inputs as of the measurement date. The hierarchy is based on the lowest level of input that is significant to the fair value measurement. The three levels are defined as follows: Level 1 – Inputs are unadjusted quoted prices for identical assets in active markets; Level 2 – Inputs are observable quoted prices for similar assets in active markets; Level 3 – Inputs are unobservable and reflect management's best estimates of what market participants would use as fair value.

**INTERNATIONAL RETT SYNDROME FOUNDATION
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**Notes to Financial Statements
(Continued)**

**NOTE 1 NATURE OF ACTIVITIES AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES
(Continued)**

Cash and Cash Equivalents

IRSF considers all liquid investments with original maturities of three months or less to be cash equivalents. At December 31, 2015 and 2014, cash equivalents consisted primarily of a money market account. IRSF maintains its cash in bank deposit accounts which, at times, exceed federally insured limits. IRSF has not experienced any losses in such accounts and management believes it is not exposed to any significant credit risk.

Investments and Investment Return

Investments in money market funds and debt securities are carried at fair value. Investments in certificates of deposit are carried at amortized cost. Investment return includes dividends, interest and realized and unrealized gains and losses on investments.

Investment return that is initially restricted by donor stipulation and for which the restriction will be satisfied in the same year is included in unrestricted net assets. Other investment return is reflected in the statements of activities as unrestricted, temporarily restricted or permanently restricted based upon the existence and nature of any donor or legally imposed restrictions. IRSF's investments do not have a significant concentration of credit or market risk within any industry, specific institution or group of investments.

Grants Payable to Researchers

Grants payable to researchers is comprised of research and post-doctoral grants approved by the Board of Trustees but not yet distributed. Grants payable extended over a year as of December 31, 2015 and 2014 were recorded at their fair value and reported as liabilities in accordance with applicable GAAP for not-for-profit entities which is estimated by discounting using rates less than two percent.

Contributions

IRSF records gifts of cash and other assets at their fair value as of the date of contribution. Such donations are recorded as unrestricted support unless explicit donor stipulations specify how the donated assets must be used. Gifts received with a donor stipulation that limits their use are reported as temporarily or permanently restricted revenue and net assets. When a donor 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. Gifts that are originally restricted by the donor and for which the restriction is met in the same time period are recorded as temporarily restricted and then released from restriction.

Gifts of long-lived assets with explicit restrictions that specify how the assets are to be used and gifts of cash or other assets that must be used to acquire long-lived assets are reported as restricted support. Absent explicit donor stipulations about how long-lived assets must be maintained, IRSF reports expirations of donor restrictions when the donated or acquired long-lived assets are placed in service.

**INTERNATIONAL RETT SYNDROME FOUNDATION
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**Notes to Financial Statements
(Continued)**

**NOTE 1 NATURE OF ACTIVITIES AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES
(Continued)**

Contributions (Continued)

Unconditional promises to give expected to be collected within one year are reported at their net realizable value. Unconditional gifts expected to be collected in future years are reported at the present value of estimated future cash flows. The resulting discount is amortized and reported as contribution revenue. Conditional promises to give are recognized as revenues when the conditions on which they depend are substantially met.

Donated Services

IRSF records donated services as revenues in the period received only if the services received create or enhance non-financial assets or required specialized skills, are provided by individuals possessing those skills, and would typically need to be purchased if not provided by donation.

In-kind Donations

IRSF receives certain in-kind donations during the year, which are recorded at fair value as contribution revenue and an expense in the financial statements.

Income Taxes

IRSF is exempt from income taxes under Section 501 of the Internal Revenue Code and a similar provision of Ohio law. However, the IRSF is subject to federal income tax on any unrelated business taxable income.

IRSF's IRS Form 990 is subject to review and examination by federal and state authorities. IRSF believes it has appropriate support for any tax positions taken, and therefore, does not have any uncertain income tax positions that are material to the financial statements.

Functional Allocation of Expenses

The costs of supporting the various programs and other activities have been reported on a functional basis in the accompanying statement of functional expenses. Expenses have been classified based upon the actual direct expenditures and cost allocations based upon estimates of time spent by IRSF personnel.

Use of Estimates

The preparation of financial statements requires management to make estimates and assumptions that affect the reported amounts of assets, liabilities, revenues and expenses and the disclosure of contingent assets and liabilities in the financial statements and accompanying notes. Actual results could differ from those estimates.

Subsequent Event Evaluation

In preparing its financial statements, IRSF has evaluated events subsequent to the statement of financial position date through April 29, 2016, which is the date the financial statements were available to be issued.

**INTERNATIONAL RETT SYNDROME FOUNDATION
(DBA RETTSYNDROME.ORG)**

**Notes to Financial Statements
(Continued)**

NOTE 2 INVESTMENTS AT FAIR VALUE

Investments consisted of the following:

	<u>2015</u>	<u>2014</u>
Level 1:		
Fixed income mutual funds	\$ 808,459	\$ 849,906
Equity securities	306,598	304,413
Level 2:		
Money market funds	491,076	121,735
Fixed income securities	1,971,139	2,288,371
	<u>\$ 3,577,272</u>	<u>\$ 3,564,425</u>

There were no valuations using Level 3 inputs.

Fixed income mutual funds and equity securities: Fair values are determined by reference to quoted market prices and other relevant information generated by market transactions. Mutual funds and equity securities are categorized using Level 1 inputs.

Fixed income securities and money market funds: Fair values for fixed income securities and money market funds are estimated by using pricing models or quoted prices of securities with similar characteristics, and are categorized using Level 2 inputs.

Investment return is comprised of the following:

	<u>2015</u>	<u>2014</u>
Interest and dividend income	\$ 101,780	\$ 43,706
Net realized and unrealized gains (losses)	(56,833)	18,998
	<u>\$ 44,947</u>	<u>\$ 62,704</u>

NOTE 3 PLEDGES RECEIVABLE

Pledges receivable consisted of the following:

	<u>2015</u>	<u>2014</u>
Due in one year	\$ 307,823	\$ 271,319
Due in future years	725,000	750,000
Gross pledges receivable	1,032,823	1,021,319
Less allowance for uncollectible pledges	(10,000)	(10,000)
Less discount on pledges receivable	(28,609)	(44,540)
	<u>\$ 994,214</u>	<u>\$ 966,779</u>

Discount rates ranging from 1.37% to 1.42% were applied to long-term pledges receivable at December 31, 2015 and 2014.

**INTERNATIONAL RETT SYNDROME FOUNDATION
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**Notes to Financial Statements
(Continued)**

NOTE 4 GRANTS PAYABLE TO RESEARCHERS

Grants payable to researchers consisted of the following:

	2015	2014
Due in one year	\$ 2,818,624	\$ 2,471,660
Due in future years	1,257,566	1,193,611
Gross grants payable to researchers	4,076,190	3,665,271
Less discounts on long-term grants	(21,026)	(12,437)
Grants payable to researchers, net	\$ 4,055,164	\$ 3,652,834

Discount rates of 1.06% and 0.67% were applied to long-term grants payable at December 31, 2015 and 2014, respectively.

NOTE 5 IN-KIND DONATIONS AND DONATED SERVICES

IRSF obtains in-kind donations for special event costs as well as administrative expenses. Generally, the in-kind special event costs represent donated items to be used as auction items for events.

In-kind donations and donated services have been recorded as the following expenses:

	2015	2014
Special event costs	\$ 131,220	\$ 83,483
Office space	12,900	12,900
Professional services	60,000	75,000
	\$ 204,120	\$ 171,383

NOTE 6 OPERATING LEASES

IRSF leased office space in New York, New York and Bethesda, Maryland under non-cancelable operating leases that expired at various times through January 31, 2015. These leases were not renewed upon expiration. Rent expense for these leases was \$-0- in 2015 and \$66,867 in 2014.

NOTE 7 TEMPORARILY RESTRICTED NET ASSETS AND RELEASED FROM RESTRICTIONS

Temporarily restricted net assets consisted of the following:

	2015	2014
For periods after December 31	\$ 505,411	\$ 421,319
Research	525,250	613,000
Helen M. McLoraine Endowment Fund Earnings	26,149	25,522
	\$ 1,056,810	\$ 1,059,841

**INTERNATIONAL RETT SYNDROME FOUNDATION
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**Notes to Financial Statements
(Continued)**

**NOTE 7 TEMPORARILY RESTRICTED NET ASSETS AND RELEASED FROM RESTRICTIONS
(Continued)**

Net assets were released from donor restrictions by incurring expenses satisfying the restricted purpose or by occurrence of other events specified by donors.

	2015	2014
Research	\$ 342,738	\$ 328,411
Time restrictions expired	185,455	287,511
	\$ 528,193	\$ 615,922

NOTE 8 HELEN M. MCLORAIN ENDOWMENT FUND

The Helen M. McLoraine Endowment Fund is a donor-restricted endowment fund established to provide general operating support. The beneficial interest in perpetual trust (\$18,637 and \$20,208 as of December 31, 2015 and 2014, respectively) included in other assets and permanently restricted net assets, is not considered a component of the endowment. As required by generally accepted accounting principles, net assets associated with endowment funds, including any funds designated by the Board of Trustees to function as endowments, are classified and reported based on the existence or absence of donor-imposed restrictions.

Interpretation of Relevant Law

The IRSF Board of Trustees follows the Uniform Prudent Management of Institutional Funds Act (UPMIFA). UPMIFA provides guidance on matters concerning the governance and management of donor-restricted endowment funds. Under UPMIFA, the original value of donated gifts to the permanent endowment, the original value of subsequent gifts to the permanent endowment, and accumulations to the permanent endowment made in accordance with the direction of the applicable donor gift instrument are classified as permanently restricted net assets. The remaining portion of the donor-restricted endowment fund that is not classified as permanently restricted net assets is classified as temporarily restricted net assets until those amounts are appropriated for expenditure by the Board of Trustees.

Endowment Net Asset Composition and Changes in Endowment Net Assets

The endowment net assets consist of donor contributors that are permanently restricted. The changes in these endowment net assets were as follows:

	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
Endowment net assets, December 31, 2013	\$ -	\$ 2,346	\$ 1,000,000	\$ 1,002,346
Investment return	-	23,176	-	23,176
Endowment net assets, December 31, 2014	-	25,522	1,000,000	1,025,522
Investment return	-	627	-	627
Endowment net assets, December 31, 2015	\$ -	\$ 26,149	\$ 1,000,000	\$ 1,026,149

**INTERNATIONAL RETT SYNDROME FOUNDATION
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**Notes to Financial Statements
(Continued)**

NOTE 8 HELEN M. MCLORAIN ENDOWMENT FUND (Continued)

Investment Policy

Endowment assets include those assets of donor-restricted funds that IRSF must hold in perpetuity. Under this policy, as approved by the Board of Trustees, the endowment assets are invested in a manner that is intended to produce results that exceed the price and yield results of the S&P 500 index while assuming a moderate level of investment risk.

Spending Policy

In accordance with the endowment agreement, IRSF may withdraw for general operating purposes up to 5% of the endowment each calendar year. An additional withdrawal of 5% may be authorized if a specific extraordinary opportunity arises that merits such additional distribution. However, the additional distribution may not cause the endowment value to fall below the original contribution amount. The value of the endowment shall be based on the average monthly value of the endowment as of the preceding 12 months of the prior calendar year, or otherwise calculated in accordance with Ohio law.

NOTE 9 SIGNIFICANT CONCENTRATIONS

Accounting principles generally accepted in the United States of America require disclosure of current vulnerabilities due to certain concentrations. One donor represented approximately 38% and 41% of pledges receivable at December 31, 2015 and 2014, respectively. No other individual donors represented more than 10% of contributions and grants in 2015 and 2014.