International Rett Syndrome Foundation (dba Rettsyndrome.org)

Financial Statements
December 31, 2016 and 2015, and
Independent Auditors' Report

INTERNATIONAL RETT SYNDROME FOUNDATION (DBA RETTSYNDROME.ORG) December 31, 2016 and 2015

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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, 2016 and 2015, 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, 2016 and 2015, 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 17, 2017 Cincinnati, Ohio

Statements of Financial Position December 31, 2016 and 2015

	 2016	 2015
Assets		
Cash and cash equivalents	\$ 1,054,250	\$ 1,605,760
Investments	2,710,446	3,577,272
Pledges receivable, net	1,340,280	994,214
Prepaids and other assets	 114,401	 59,664
Total assets	\$ 5,219,377	\$ 6,236,910
Liabilities and Net Assets		
Liabilities		
Accounts payable and accrued liabilities	\$ 94,502	\$ 34,742
Grants payable to researchers, net	 1,870,433	4,055,164
Total liabilities	1,964,935	 4,089,906
Net Assets		
Unrestricted	732,042	71,557
Temporarily restricted	1,503,813	1,056,810
Permanently restricted	 1,018,587	 1,018,637
Total net assets	 3,254,442	 2,147,004
Total liabilities and net assets	\$ 5,219,377	\$ 6,236,910

Statements of Activities Years Ended December 31, 2016 and 2015

2016 2015 **Temporarily Permanently Temporarily** Permanently Restricted Restricted Unrestricted Restricted Total Unrestricted Restricted Total Revenues: Special events \$ \$ 2,406,936 \$ 2,406,936 \$ \$ 2,859,399 5,100 \$ \$ 2,864,499 Contributions and grants 1,586,231 2,691,027 519,435 2,260,646 1,104,796 1,741,211 In-kind revenue 173,332 173,332 204,120 204,120 117,807 3,000 Conference registrations 117,807 3,000 Investment return (loss) 88,580 68,582 (50)157,112 45,891 627 44,947 (1,571)(726, 375)528,193 Released from restriction 726,375 (528, 193)5,546,214 Total revenues 5,099,261 447,003 (50)5,381,814 (3,031)(1,571)5,377,212 Operating expenses 4,438,776 4,438,776 5,654,008 5,654,008 Change in net assets 447,003 (272, 194)(3,031)(1,571)(276,796)660,485 (50)1,107,438 Net assets, beginning of year 1,018,637 71,557 1,056,810 2,147,004 343,751 1,059,841 1,020,208 2,423,800 \$ 1,503,813 \$ 1,018,587 \$ 3,254,442 \$ 1,056,810 \$ 1,018,637 Net assets, end of year 732,042 71,557 \$ 2,147,004

Statement of Functional Expenses Year Ended December 31, 2016

		Program							Fundraising						
	Research		Family powerment	E	ducation	Total	Adn	ninistration		Appeals and General		Direct Special Events		Total	Total
Direct program costs	\$ 2,107,765	\$	-	\$	-	\$ 2,107,765	\$	_	\$	-	\$	-	\$	_	\$ 2,107,765
Personnel related costs	383,311		349,259		8,810	741,380		120,558		89,047		-		89,047	950,985
Special events costs	-		-		-	-		-		172		685,765		685,937	685,937
Outside services	25,127		42,996		65,309	133,432		15,079		24,501		-		24,501	173,012
Conferences	78,077		-		65,267	143,344		-		-		-		-	143,344
Miscellaneous costs	900		7,874		58	8,832		72,772		49,108		-		49,108	130,712
Professional fees	17,000		44,119		-	61,119		31,895		7,817		-		7,817	100,831
Office costs	4,284		21,672		24,356	50,312		6,400		19,983		-		19,983	76,695
Travel and entertainment	25,522		24,564		-	50,086		1,724		4,785		-		4,785	56,595
Occupancy costs			-					12,900							12,900
Total expenses	\$ 2,641,986	\$	490,484	\$	163,800	\$ 3,296,270	\$	261,328	\$	195,413	\$	685,765	\$	881,178	\$ 4,438,776

Statement of Functional Expenses Year Ended December 31, 2015

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

Statements of Cash Flows Years Ended December 31, 2016 and 2015

	2016	2015
Cash flows from operating activities		
Change in net assets	\$ 1,107,438	\$ (276,796)
Adjustments to reconcile change in net assets to		
net cash from operating activities:		
Realized and unrealized (gains) losses on investments	(53,442)	56,833
Bad debt expense	15,083	-
Change in:		
Pledges receivable	(361,149)	(27,435)
Preoaids and other assets	(54,787)	38,389
Accounts payable and accrued liabilities	59,760	(137,568)
Grants payable to researchers	(2,184,731)	402,330
Net cash provided (used) by operating activities	(1,471,828)	55,753
Cash flows from investing activities		
Purchases of investments	(1,234,301)	(1,735,276)
Sales of investments	2,154,619	1,667,167
Net cash provided (used) by investing activities	920,318	(68,109)
Change in cash and cash equivalents	(551,510)	(12,356)
Cash and cash equivalents, beginning of year	1,605,760	1,618,116
Cash and cash equivalents, end of year	\$ 1,054,250	\$ 1,605,760

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.

Notes to Financial Statements (Continued)

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

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.

Cash and Cash Equivalents

IRSF considers all liquid investments with original maturities of three months or less to be cash equivalents. At December 31, 2016 and 2015, cash equivalents consisted primarily of a money market deposit 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 recorded as temporarily restricted and then released from restriction. 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, 2016 and 2015 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.

Notes to Financial Statements (Continued)

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

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.

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 for special events costs as well as administrative expenses, which are recorded at fair value as contribution revenue and an expense in the financial statements. Generally, the in-kind special event costs represent donated items to be used as auction items for events.

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.

Notes to Financial Statements (Continued)

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

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 17, 2017, which is the date the financial statements were available to be issued.

NOTE 2 INVESTMENTS AT FAIR VALUE

Investments at December 31 consisted of the following:

	2016	 2015	
Level 1:		 _	
Mutual funds	\$ 903,031	\$ 808,459	
Equity securities	371,355	306,598	
Level 2:			
Money market funds	174,957	491,076	
Municipal bonds	1,261,103	 1,971,139	
	\$ 2,710,446	\$ 3,577,272	

There were no valuations using Level 3 inputs.

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.

Money market funds and municipal bonds: Fair values are estimated by using pricing models or quoted prices of securities with similar characteristics. Money market funds and municipal bounds categorized using Level 2 inputs.

Notes to Financial Statements (Continued)

NOTE 2 INVESTMENTS AT FAIR VALUE (CONTINUED)

Investment return is comprised of the following:

			2015	
Interest and dividend income Net realized and unrealized gains (losses)	\$	103,670 53,442	\$	101,780 (56,833)
	\$	157,112	\$	44,947

NOTE 3 PLEDGES RECEIVABLE

Pledges receivable at December 31 consisted of the following:

	2016	2015
Due within one year	\$ 535,568	\$ 307,823
Due in one to five years	673,514	475,000
Due in more than five years	200,000	250,000
	1,409,082	1,032,823
Less allowance for uncollectible pledges	(10,000)	(10,000)
Less discount on pledges receivable	(58,802)	(28,609)
	\$ 1,340,280	\$ 994,214

Discount rates ranging from 1.370% to 1.725% were applied to long-term pledges receivable at December 31, 2016 and 2015.

NOTE 4 GRANTS PAYABLE TO RESEARCHERS

Grants payable at December 31 to researchers consisted of the following:

	2016	2015
Due in one year Due in one to five years	\$ 1,432,539 445,051	\$ 2,818,624 1,257,566
Less discounts on long-term grants	1,877,590 (7,157)	4,076,190 (21,026)
	\$ 1,870,433	\$ 4,055,164

Discount rates of 1.025% and 1.06% were applied to long-term grants payable at December 31, 2016 and 2015, respectively.

Notes to Financial Statements (Continued)

NOTE 5 IN-KIND DONATIONS AND DONATED SERVICES

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

	 2016			2015
Special event costs	\$ 60,432		\$	131,220
Office space	12,900			12,900
Professional services	 100,000			60,000
	\$ 173,332		\$	204,120

NOTE 6 TEMPORARILY RESTRICTED NET ASSETS AND RELEASED FROM RESTRICTIONS

Temporarily restricted net assets at December 31 consisted of the following:

		2015		
For periods after December 31	\$	246,210	\$	505,411
Research		1,162,872		525,250
Helen M. McLoraine Endowment Fund Earnings		94,731		26,149
	\$	1,503,813	\$	1,056,810

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

	2016		2015
Research Time restrictions expired	\$ 271,634 454,741	\$	342,738 185,455
	\$ 726,375	\$	528,193

NOTE 7 HELEN M. MCLORAINE ENDOWMENT FUND AND PERMANENTLY RESTRICTED NET ASSETS

The Helen M. McLoraine Endowment Fund is a donor-restricted endowment fund established to provide general operating support. 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.

Included in permanently restricted net assets is a beneficial interest in a perpetual trust (\$18,587 and \$18,637 as of December 31, 2016 and 2015, respectively), which is not considered a component of the endowment.

Notes to Financial Statements (Continued)

NOTE 7 HELEN M. MCLORAINE ENDOWMENT FUND AND PERMANENTLY RESTRICTED NET ASSETS (CONTINUED)

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, 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
Investment return		-		68,582		-		68,582
Endowment net assets,								
December 31, 2016	\$	_	\$	94,731	\$	1,000,000	\$	1,094,731

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 withdrawal 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.

Notes to Financial Statements (Continued)

NOTE 8 SIGNIFICANT CONCENTRATIONS

Accounting principles generally accepted in the United States of America require disclosure of current vulnerabilities due to certain concentrations. At December 31, 2016 and 2015, five and three donors, respectfully, represented substantially all of pledges receivable. Approximately 30% of contribution and grants was received from two of these donors in 2016.

NOTE 9 RECENTLY ADOPTED ACCOUNTING STANDARDS UPDATE

On August 18, 2016, the FASB issued ASU 2016-14, *Presentation of Financial Statements of Not-for-Profit Entities*. The standard aims to improve nonprofit financial statements in an effort to provide more useful information to donors, grantors, creditors and other users. Major components of this standard include: net asset classifications, liquidity and availability of cash and consistency in reporting expenses. Net asset classifications will be reduced from three classes (unrestricted, temporarily restricted and permanently restricted) to two: net assets with donor restrictions and net assets without donor restrictions. Updated disclosure requirements will be presented regarding risk exposure and availability of cash for short term use. Expenses will be reported by both their natural and functional classification to aid in the usefulness of financial statements. This standard will be effective for calendar year ending December 31, 2018.

On May 28 2014, the FASB issued ASU 2014-09, *Revenue from Contracts with Customers*. The standard's core principle is that a company will recognize revenue when it transfers promised goods or services to customers in an amount that reflects the consideration to which the company expects to be entitled in exchange for those goods or services. This standard also includes expanded disclosure requirements that result in an entity providing users of financial statements with comprehensive information about the nature, amount, timing, and uncertainty of revenue and cash flows arising from the entity's contracts with customers. This standard will be effective for the calendar year ending December 31, 2019.

In February 2016, the FASB issued ASU 2016-02, *Leases*. The standard requires all leases with lease terms over 12 months to be capitalized as a right-of-use asset and lease liability on the balance sheet at the date of lease commencement. Leases will be classified as either finance or operating. This distinction will be relevant for the pattern of expense recognition in the income statement. This standard will be effective for the calendar year ending December 31, 2020.

IRSF is currently in the process of evaluating the impact of adoption of these ASUs on the financial statements.