International Rett Syndrome Foundation (dba Rettsyndrome.org)

Financial Statements
December 31, 2019 and 2018, and
Independent Auditors' Report

INTERNATIONAL RETT SYNDROME FOUNDATION (DBA RETTSYNDROME.ORG) December 31, 2019 and 2018

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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, 2019 and 2018, 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, 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.

April 10, 2020 Cincinnati, Ohio

Burner, Dunig & Co., Std.

Statements of Financial Position December 31, 2019 and 2018

	2019	2018
Assets		
Cash and cash equivalents	\$ 2,477,679	\$ 1,887,062
Investments	3,302,434	2,690,843
Pledges receivable, net	310,910	566,756
Prepaids and other assets	147,472	363,272
Total assets	\$ 6,238,495	\$ 5,507,933
Liabilities and Net Assets		
Liabilities		
Accounts payable and accrued liabilities	\$ 143,844	\$ 449,714
Grants payable to researchers, net	1,809,368	3,016,944
Total liabilities	1,953,212	3,466,658
Net Assets		
Without donor restrictions	2,741,682	418,835
With donor restrictions	1,543,601	1,622,440
Total net assets	4,285,283	2,041,275
Total liabilities and net assets	\$ 6,238,495	\$ 5,507,933

Statements of Activities Years Ended December 31, 2019 and 2018

2019 2018 Without Donor With Donor With Donor Without Donor Restrictions Restrictions Restrictions Total Restrictions Total Revenues: Special events \$ 1,724,826 \$ 1,724,826 2,085,943 2,085,943 Contributions and grants 3,280,486 58,069 3,338,555 2,109,087 220,638 2,329,725 In-kind revenue 12,900 12,900 43,275 43,275 4,697 7,360 (214,537)Other income 2.663 2.314 (216,851)491,278 (403,333)(63,949)(467, 282)Investment return, net 299,357 191,921 (331,492)Released from restriction 331,492 564,965 (564,965)Total revenues 5,653,758 (78,839)5,574,919 4,402,251 (625, 127)3,777,124 **Operating expenses** 3,330,911 3,330,911 4,291,496 4,291,496 Change in net assets (78,839)2,322,847 2,244,008 110,755 (625, 127)(514,372)Net assets, beginning of year 308,080 418,835 2,041,275 2,247,567 2,555,647 1,622,440 Net assets, end of year 1,543,601 4,285,283 1,622,440 2,041,275 2,741,682 \$ 418,835

Statement of Functional Expenses Year Ended December 31, 2019

		P	rogram		_		Fundraising					
		ı	Family				-	Appeals		Direct		
		Emp	owerment					and		Special		
	Research	_ & E	Education	Total	Adn	ninistration	(General		Events	 Total	Total
Direct program costs	\$ 1,413,091	\$	_	\$ 1,413,091	\$	-	\$	_	\$	-	\$ _	\$ 1,413,091
Personnel related costs	266,168		398,245	664,413		96,197		51,261		-	51,261	811,871
Special events costs	-		-	-		-		7,644		433,070	440,714	440,714
Outside services	31,453		50,174	81,627		30,340		106,141		-	106,141	218,108
Miscellaneous costs	2,542		14,346	16,888		40,708		57,941		-	57,941	115,537
Professional fees	70,614		10,233	80,847		33,973		13,660		-	13,660	128,480
Office costs	5,323		29,802	35,125		7,980		28,486		-	28,486	71,591
Travel and entertainment	72,093		39,990	112,083		5,895		641		-	641	118,619
Occupancy costs				_		12,900						12,900
	\$ 1,861,284	\$	542,790	\$ 2,404,074	\$	227,993	\$	265,774	\$	433,070	\$ 698,844	\$ 3,330,911

Statement of Functional Expenses Year Ended December 31, 2018

		P	Program		_		Fundraising									
	Research	Emp	Family powerment Education	Total	Administration		and Spe		and		and		Direct Special Events		Total	Total
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Direct program costs	\$ 2,107,367	\$	-	\$ 2,107,367	\$	-	\$	-	\$	-	\$	-	\$ 2,107,367			
Personnel related costs	397,638		378,088	775,726		95,250		43,188		-		43,188	914,164			
Special events costs	-		-	-		-		5,275		658,962		664,237	664,237			
Outside services	42,783		99,326	142,109		44,067		91,718		-		91,718	277,894			
Miscellaneous costs	1,900		13,584	15,484		31,897		36,848		-		36,848	84,229			
Professional fees	36,605		15,059	51,664		32,621		3,415		-		3,415	87,700			
Office costs	5,400		36,972	42,372		8,479		11,286		-		11,286	62,137			
Travel and entertainment	49,268		26,736	76,004		2,811		2,053		-		2,053	80,868			
Occupancy costs						12,900							12,900			
	\$ 2,640,961	\$	569,765	\$ 3,210,726	\$	228,025	\$	193,783	\$	658,962	\$	852,745	\$ 4,291,496			

Statements of Cash Flows Years Ended December 31, 2019 and 2018

	2019	2018
Cash flows from operating activities		
Change in net assets	\$ 2,244,008	\$ (514,372)
Adjustments to reconcile change in net assets to		
net cash from operating activities:		
Net realized and unrealized (gains) losses on investments	(421,441)	534,809
Bad debt expense (recoveries)	1,000	(7,875)
Change in:		
Pledges receivable	254,846	463,443
Prepaids and other assets	215,800	(226,737)
Accounts payable and accrued liabilities	(305,870)	319,454
Grants payable to researchers	(1,207,576)	(478,936)
Net cash provided by operating activities	780,767	89,786
Cash flows from investing activities		
Purchases of investments	(2,123,163)	(1,795,872)
Sales of investments	1,933,013	1,774,568
N . () () () () () () ()	(400, 450)	(04.004)
Net cash used in investing activities	(190,150)	(21,304)
Change in cash and cash equivalents	590,617	68,482
-		
Cash and cash equivalents, beginning of year	1,887,062	1,818,580
Cash and cash equivalents, end of year	\$ 2,477,679	\$ 1,887,062
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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 and education programs 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. Additionally, these programs include 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 two classes of net assets: net assets without donor restrictions, which are available for use in general operations and not subject to donor restrictions; and net asset with donor restrictions, which are either temporary in nature, such as those that will be met by the passage of time or other events specified by the donor, or are perpetual in nature, where the donor stipulates that resources be maintained in perpetuity.

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, 2019 and 2018, 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 revenues with donor restrictions and then released from restriction. Other investment return is reflected in the statements of activities as revenues with or without donor restrictions 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, 2019 and 2018 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 support without donor restrictions unless explicit donor stipulations specify how the donated assets must be used. A gift that is originally restricted by the donor and for which the restriction is met in the same year that the gift is received is recorded as revenue without donor restrictions.

Notes to Financial Statements (Continued)

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

Contributions (Continued)

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, the Organization 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.

Functional Allocation of Expenses

The cost of program and supporting services activities have been summarized on a functional classification basis in the statements of functional expenses. Accordingly, certain costs have been allocated among the programs and supporting services. Such allocations are determined by management on an equitable basis. The most significant allocations were salaries and related expenses, which were allocated based on time and effort.

Notes to Financial Statements (Continued)

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

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 10, 2020, which is the date the financial statements were available to be issued.

Effect of Adopting New Accounting Standards

During 2019, IRSF adopted FASB ASU 2018-08, *Not-For-Profit Entities (Topic 958): Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made.* The standard clarified and improved previous guidance about whether a transfer of assets is a contribution or an exchange transaction. The standard clarified how an entity determined whether a resource provider is participating in an exchange transaction by evaluating whether the resource provider is receiving commensurate value in return for the resources transferred. The standard also required than an entity determine whether a contribution is conditional on the basis of whether an agreement includes a barrier that must be overcome and either a right of return of assets transferred or a right of release of a promisor's obligation to transfer assets. The ASU has been applied using the modified prospective basis for all grants and contracts that were not completed as of January 1, 2019.

Recently Issued Accounting Standards

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, 2021.

IRSF is currently in the process of evaluating the impact of adoption of this ASU on the financial statements.

Reclassifications

Certain 2018 figures have been reclassified to conform to the 2019 presentation.

NOTE 2 LIQUIDITY AND AVAILABILITY

IRSF receives the majority of its funding through support without donor restrictions or support with donor restrictions spent in the same year; such support has historically represented approximately 90% of annual program funding needs, with the remainder funded by government grants, investment income without donor restrictions and appropriated earnings from gifts with donor restrictions.

Notes to Financial Statements (Continued)

NOTE 2 LIQUIDITY AND AVAILABILITY (CONTINUED)

IRSF considers investment income without donor restrictions, appropriated earnings from donor-restricted and board-designated (quasi) endowments, contributions without donor restrictions and contributions with donor restrictions for use in current programs which are ongoing, major, and central to its annual operations to be available to meet cash needs for general expenditures. General expenditures include administrative and general expenses, fundraising expenses and grant commitments expected to be paid in the subsequent year. Annual operations are defined as activities occurring during IRSF's fiscal year.

IRSF manages its cash available to meet general expenditures following three guiding principles:

- Operating within a prudent range of financial soundness and stability,
- Maintaining adequate liquid assets, and
- Maintaining sufficient reserves to provide reasonable assurance that long term grant commitments and obligations under the permanent that supports mission fulfillment will continue to be met, ensuring the sustainability of IRSF.

IRSF's Board of Directors meets regularly, and at least twice a year reviews and approves grant requests. Due to this timing, IRSF strives to maintain financial assets available to meet general expenditures at a level that represents 100% of annual expenses for administrative, general, and fundraising expenses plus an amount that represents the next year of expected payments for grant commitments approved by the Board, which typically represents approximately 50% of the expected annual cash needs.

The table below presents financial assets available for general expenditures within one year at December 31. 2019 and 2018:

	2019		2018
Financial assets at year end:			
Cash and cash equivalents	\$ 2,477,679	\$	1,887,062
Investments	3,302,434		2,690,843
Pledges receivable, net	310,910		566,756
	6,091,023		5,144,661
Less amounts not avaiable to be used within one year:			
Investments held in endowments	(1,203,115)		(1,011,194)
Pledges receivable due after one year, net	(180,706)		(258,743)
	\$ 4,707,202	\$	3,874,724

Notes to Financial Statements (Continued)

NOTE 3 INVESTMENTS AT FAIR VALUE

Investments at December 31 consisted of the following:

	 2019			2018
Level 1:				
Mutual funds	\$ 1,332,169		\$	860,326
Common stock	647,548			586,535
Level 2:				
Money market funds	294,945			342,387
Municipal bonds	 1,027,772			901,595
	\$ 3,302,434		\$	2,690,843

Fair values are determined by reference to quoted market prices and other relevant information generated by market transactions. Mutual funds and common stock are categorized using Level 1 inputs. 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. There were no valuations using Level 3 inputs.

NOTE 4 PLEDGES RECEIVABLE

Pledges receivable at December 31 consisted of the following:

	201	9	 2018
Due within one year	\$ 13	30,204	\$ 308,013
Due in one to five years	12	25,000	298,514
Due in more than five years	6	3,900	201,200
	31	19,104	807,727
Less allowance for uncollectible pledges		(5,000)	(219,200)
Less discount on pledges receivable		(3,194)	(21,771)
	\$ 31	10,910	\$ 566,756

A discount rate of 1.720% and 2.145% was applied to long-term pledges receivable at December 31, 2019 and 2018, respectively.

Notes to Financial Statements (Continued)

NOTE 5 GRANTS PAYABLE TO RESEARCHERS

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

	2019	2018
Due in one year Due in one to five years	\$ 1,496,546 319,763	\$ 2,196,121 854,575
Less discounts on long-term grants	1,816,309 (6,941)	3,050,696 (33,752)
	\$ 1,809,368	\$ 3,016,944

Discount rates of 1.580% and 2.545% were applied to long-term grants payable at December 31, 2019 and 2018, respectively.

NOTE 6 IN-KIND DONATIONS AND DONATED SERVICES

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

	 2019		2018		
Professional services Office space	\$ - 12,900		\$	30,375 12,900	
	\$ 12,900		\$	43,275	

NOTE 7 NET ASSETS WITH DONOR RESTRICTIONS

Net assets with donor restrictions at December 31 consisted of the following:

	2019			2018	
Subject to the passage of time: For periods after December 31	\$	6,690		\$ 83,013	
Subject to expenditure for specified purpose: Research		312,414		509,514	
Subject to spending policy and appropriations: Helen M. McLoraine Endowment Fund Beneficial interest in perpetual trust		1,203,115 21,382		1,011,194 18,719	
	\$	1,543,601		\$ 1,622,440	

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

Notes to Financial Statements (Continued)

NOTE 7 NET ASSETS WITH DONOR RESTRICTIONS (CONTINUED)

	2019			2018
Research	\$	46,221		\$ 207,108
Time restrictions expired		285,271		302,379
Endowment fund earnings appropriated			-	55,478
	\$	331,492	-	\$ 564,965

NOTE 8 ENDOWMENTS

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.

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 net assets with donor restrictions. The remaining portion of the donor-restricted endowment fund that is not classified as endowment corpus is classified as accumulated earnings 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:

	Accumulated Earnings		Endowment Corpus	Total
Endowment net assets, December 31, 2017	\$	130,621	\$ 1,000,000	\$ 1,130,621
Investment loss, net Appropriated for expenditure		(63,949) (55,478)		(63,949) (55,478)
Endowment net assets, December 31, 2018		11,194	1,000,000	1,011,194
Investment return, net		191,921		191,921
Endowment net assets, December 31, 2019	\$	203,115	\$ 1,000,000	\$ 1,203,115

Notes to Financial Statements (Continued)

NOTE 8 ENDOWMENTS (CONTINUED)

Investment Policy

Endowment assets include those assets of donor-restricted funds that IRSF must hold in perpetuity. In accordance with its Investment Policy, the Board of Trustees will select an Investment Manager who shall make reasonable efforts to control risk and maintain diversification among endowment assets to ensure preservation of the entire portfolio. To the extent possible, the endowment investment portfolio should be rebalanced on an on-going basis to within 5-10% of target percentages, as follows: 60-70% equity securities and mutual funds; 30-40% fixed income securities and mutual funds.

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.

NOTE 9 SIGNIFICANT CONCENTRATIONS

Accounting principles generally accepted in the United States of America require disclosure of current vulnerabilities due to certain concentrations. At December 31, 2019 and 2018, two donors and five donors represented substantially all of pledges receivable, respectively.