

FINANCIAL STATEMENTS WITH INDEPENDENT AUDITORS' REPORT

YEARS ENDED DECEMBER 31, 2019 AND 2018

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INDEPENDENT AUDITORS' REPORT

To The Board of Directors
The Barth Syndrome Foundation, Inc.
New York, New York

We have audited the accompanying financial statements of The Barth Syndrome Foundation, Inc., which comprise the balance sheets as of December 31, 2019 and 2018, and the related statements of activities, cash flows, and functional expenses for the years then ended, and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditors' 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 audits to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of The Barth Syndrome Foundation, Inc. as of December 31, 2019 and 2018, and the changes in net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

Emphasis of Matters

As discussed in Note 2 to the financial statements, in 2019 the Organization adopted Accounting Standards Update (ASU) No. 2018-08 Not for Profit Entities: Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made (Topic 605); and, No. 2014-09 Revenue from Contracts with Customers (Topic 606).

Dorfman Alrams music, LLC Saddle Brook, New Jersey

April 13, 2020

BALANCE SHEETS

ASSETS

	Decem	ber 31,
	2019	2018
Cash Investments Grants receivable	\$ 384,847 4,472,545 67,917	\$ 237,557 4,507,529
Due from affiliates Other receivables Prepaid expenses	30,000 649 37,285	2,565 2,699
Total assets	\$ 4,993,243	\$ 4,750,350
<u>LIABILITIES AND NET ASSETS</u>		
Liabilities:		
Accounts payable and accrued expenses Deferred revenue	\$ 26,869 376	\$ 18,932
Grants payable	259,580	140,147
Total liabilities	286,825	159,079
Net assets:		
Without donor restrictions With donor restrictions	914,227 3,792,191	861,228 3,730,043
Total net assets	4,706,418	4,591,271
Total liabilities and net assets	\$ 4,993,243	\$ 4,750,350

STATEMENTS OF ACTIVITIES

	Year en	Year ended December 31, 2019	1, 2019	Year en	Year ended December 31, 2018	1, 2018
	Without donor restrictions	With donor restrictions	Total	Without donor restrictions	With donor restrictions	Total
Operating activities: Support and revenue:						
Contributions Conference reviews	\$ 603,361	\$ 224,371	\$ 827,732	\$ 631,570	\$ 1,320,497	\$ 1,952,067
Grant income		107,917	107,917	45,000	5	45,000
Interest and dividends	95,117		95,117	64,775		64,775
Total support and revenue	698,478	332,288	1,030,766	801,611	1,416,997	2,218,608
Net assets released from restrictions	270,140	(270,140)		145,354	(145,354)	
Total support and revenue	968,618	62,148	1,030,766	946,965	1,271,643	2,218,608
Expenses: Program services:				;		3
Communication and awareness BSF Conference	142,871		142,871	93,414 286,404		93,414 286,404
Family services	106,552		106,552	73,145		73,145
Advocacy and awareness Barth registry and repository	136,369 20.489		136,369 20.489	90,213 28.772		90,213 28,772
Research grants	360,000		360,000	253,199		253,199
Science and medicine	300,933		300,933	152,344		152,344
Total program services	1,067,214		1,067,214	977,491		977,491
Supporting services: General and administrative expenses Fundraising expenses	159,829 74,333		159,829 74,333	124,694 53,125		124,694 53,125
Total supporting services	234,162		234,162	177,819		177,819
Total expenses	1,301,376		1,301,376	1,155,310		1,155,310
Change in net assets from operations	(332,758)	62,148	(270,610)	(208,345)	1,271,643	1,063,298
Nonoperating activities: Investment return, net	385,757		385,757	(184,698)		(184,698)
Total nonoperating activities	385,757		385,757	(184,698)		(184,698)
Change in net assets	52,999	62,148	115,147	(393,043)	1,271,643	878,600
Net assets, beginning of year	861,228	3,730,043	4,591,271	1,254,271	2,458,400	3,712,671
Net assets, end of year	\$ 914,227	\$ 3,792,191	\$ 4,706,418	\$ 861,228	\$ 3,730,043	\$ 4,591,271

The accompanying notes are an integral part of these financial statements.

STATEMENTS OF CASH FLOWS

	Year ended [Decer	nber 31,
	 2019		2018
Cash flows from operating activities:			
Change in net assets Adjustments to reconcile change in net assets to net cash provided (used) by operating activities:	\$ 115,147	\$	878,600
Contribution of stock	(34,142)		(1,026,298)
Realized and unrealized (gain) loss on investments Changes in operating assets and liabilities: (Increase) decrease in:	(385,757)		184,698
Grants receivable Due from affiliates Other receivables	(67,917) (27,435) (649)		(184)
Prepaid expenses Increase (decrease) in:	(34,586)		9,248
Accounts payable and accrued expenses	7,937		(51,679)
Deferred revenue	376		(8,750)
Grants payable	 119,433		(39,276)
Net cash used by operating activities	 (307,593)	-	(53,641)
Cash flows from investing activities:			
Purchases of investments	(123,948)		(434,845)
Proceeds from sale of investments	 578,831		521,238
Net cash provided by investing activities	 454,883		86,393
Net increase in cash	147,290		32,752
Cash, beginning of year	 237,557		204,805
Cash, end of year	\$ 384,847	\$	237,557

THE BARTH SYNDROME FOUNDATION, INC. STATEMENTS OF FUNCTIONAL EXPENSES

Years Ended December 31, 2019 and 2018

								Program services	services							
	Commun	Communication and					Advocacy and	cy and	Barth registry	egistry						
	awaı	awareness	BSF Co	BSF Conference	Family services	ervices	awareness	ness	and repository	ository	Research grants	h grants	Science and medicine	medicine	Total	-
	2019	2018	2019	2018	2019	2018	2019	2018	2019	2018	2019	2018	2019	2018	2019	2018
Salaries Payroll taxes and benefits	\$ 63,910 6,556	\$ 62,505	ω	\$ 99,393	\$ 68,353 11,683	\$ 55,674 8,157	\$ 89,039	\$ 16,490 2,402	€	∞	€	€	\$ 189,572 23,372	\$ 126,388 17,984	\$ 410,874 52,030	\$ 360,450 50,719
Total salaries and related expenses	70,466	71,282		112,792	80,036	63,831	99,458	18,892					212,944	144,372	462,904	411,169
Grant expense Grants funded by affiliates											400,000	303,105	56,917		456,917	303,105
Professional fees	59,796	9,500					7,988	23,881	18,000	24,500	(10,000)	(200, 200)	4,686		90,470	57,881
Office expense	10,063	3,726		3,515	4,490	3,296	1,055	3,520	16	4			3,476	2,691	19,100	16,752
Transportation		316		64,286	16,242	533	13,411	5,706	31				18,962	2,322	48,646	73,163
Dues and fees	303						1,200		2,302	2,079			3,833	2,871	7,638	4,950
Audio visual				28,314			12,000	15,938							12,000	44,252
Printing and publications	1,377	8,467		470			838	1,151							2,215	10,088
Telephone		123			3,687	5,428		18						32	3,687	5,604
Insurance																
Meals				66,882	2,046	22	144	18,698					26	53	2,287	85,690
Public relations	998														998	
Training and education					51		275		140				18		484	
Therapy development										2,189		34,000				36,189
Other meeting expenses				10,145				2,409								12,554
Total expenses	\$ 142,871	\$ 93,414	s	\$ 286,404	\$ 106,552	\$ 73,145	\$ 136,369	\$ 90,213	\$ 20,489	\$ 28,772	\$ 360,000	\$ 253,199	\$ 300,933	\$ 152,344	\$ 1,067,214	\$ 977,491

STATEMENTS OF FUNCTIONAL EXPENSES

Years Ended December 31, 2019 and 2018

			7			Supporting services	g serv	rices		H	-			Total program and	gram a	pui
	⁻	2019 2018		2018		2019		2018		2019		2018		2019 201	100	2018
Salaries Payroll taxes and benefits	ω	44,909 3,553	↔	23,342 3,182	↔	47,500 2,831	↔	38,769	↔	92,409 6,384	φ	62,111 6,247	₩	503,283 58,414	↔	422,561 56,966
Total salaries and related expenses		48,462		26,524		50,331		41,834		98,793		68,358		561,697		479,527
Grant expense Grants funded by affiliates										!		1		456,917 (40,000)		303,105 (83,906)
Professional fees Office expense		61,162 31,954		58,975 21,591		4,592 13,984		5,241		65,754 45,938		58,975 26,832		156,224 65,038		116,856 43,584
Transportation		2,853		6,673		1,402		274		4,255		6,947		52,901		80,110
Dues and fees		8,712		6,023		1,794		1,746		10,506		7,769		18,144		12,719
Audio visual						125				125				12,125		44,252
Printing and publications		920		56		2,080		3,792		3,000		3,848		5,215		13,936
Telephone		914		1,290				106		914		1,396		4,601		7,000
Insurance		3,801		3,562						3,801		3,562		3,801		3,562
Meals		96						132		96		132		2,383		85,822
Public relations		925				25				950				1,816		
Training and education		30								30				514		
Therapy development Other meeting expenses																36,189 12,554
Total expenses	·	\$ 159,829	s	\$ 124,694	6	74,333	မ	53,125	ક	234,162	8	177,819	φ,	\$ 1,301,376	⊗	\$ 1,155,310

The accompanying notes are an integral part of these financial statements.

NOTES TO FINANCIAL STATEMENTS

December 31, 2019 and 2018

1. Nature of the Organization

The Barth Syndrome Foundation, Inc. (the Organization) is a not-for-profit organization incorporated under the laws of the State of Delaware on September 8, 2000 to be operated for the following purposes: a) to support and educate families with children suffering from Barth Syndrome; b) to fund and facilitate research addressing the causes, diagnosis, treatment, and cure of Barth Syndrome; and c) to raise physician awareness regarding Barth Syndrome. The Organization has entered into licensing agreements with several not-for-profit entities dedicated to Barth syndrome in other countries. The agreements allow for each of these entities (the affiliates) to use the Barth Syndrome Foundation, Inc. brand in their various communications and to share in the Organization's programs including the biennial International Barth Syndrome Scientific, Medical and Family Conference, newsletters, websites and research grants among others.

Summary of significant accounting policies

Basis of presentation

The financial statements of the Organization have been prepared in accordance with U.S. generally accepted accounting principles (U.S. GAAP), which require the Organization to report information regarding its financial position and activities according to the following net asset classifications:

<u>Net assets without donor restrictions</u> - Net assets that are not subject to donor-imposed restrictions and may be expended for any purpose in performing the primary objectives of the organization. These net assets may be used at the discretion of the Organization's management and the board of directors.

<u>Net assets with donor restrictions</u> - Net assets subject to stipulations imposed by donors, and grantors. Some donor restrictions are temporary in nature; those restrictions will be met by actions of the Organization or by the passage of time. Other donor restrictions are perpetual in nature, where by the donor has stipulated the funds be maintained in perpetuity.

Measure of operations

The statement of activities reports all changes in net assets, including changes in net assets from operating and nonoperating activities. Operating activities consist of those items attributable to the Organization's ongoing services and interest and dividends earned on investments. Nonoperating activities are limited to resources that generate return from investments and other activities considered to be of a more unusual or nonrecurring nature.

Estimates

The preparation of financial statements requires management to make estimates and assumptions that affect certain reported amounts and disclosures. Accordingly, actual results could differ from those estimates.

<u>Cash</u>

Cash consists of demand deposit accounts with maturities of three months or less. Money market funds, held as a portion of the Organization's investment portfolio, are classified as investments and are not considered to be cash equivalents for purposes of the statement of cash flows.

NOTES TO FINANCIAL STATEMENTS

December 31, 2019 and 2018

2. Summary of significant accounting policies (continued)

Investments

Investments in marketable securities with readily determinable fair values and all investments in debt securities are valued at their fair values in the balance sheet.

Fair value measurement

U.S. GAAP establishes a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value. The hierarchy gives the highest priority to unadjusted quoted prices in active markets for identical assets and liabilities (level 1 measurement) and the lowest priority to unobservable inputs (level 3 measurements).

The three levels of the fair value hierarchy are as follows:

- Level 1 Inputs that reflect unadjusted quoted prices in active markets for identical assets or liabilities that the Organization has the ability to access at the measurement date;
- Level 2 Inputs other than quoted prices that are observable for the assets or liability either directly or indirectly, including inputs that are not considered to be active;
- Level 3 Inputs that are unobservable.

Inputs are used in applying the various valuation techniques and broadly refer to the assumptions that market participants use to make valuation decisions, including assumptions about risk. Inputs may include price information, volatility statistics, specific and broad criteria data, liquidity statistics, and other factors. An investment's level within the fair value hierarchy is based on the lowest level of any input that is significant to the fair value measurement. However, the determination of what constitutes "observable" requires significant judgment by the Organization. The Organization considers observable data to be that market data which is readily available, regularly distributed or updated, reliable and verifiable, not proprietary, provided by multiple, independent sources that are actively involved in the relevant market. The categorization of an investment within the hierarchy is based upon the pricing transparency of the investment and does not necessarily correspond to the Organization's perceived risk of that investment.

Grants receivable

Unconditional promises to give that are expected to be collected within one year are recorded at net realizable value. Unconditional promises to give that are expected to be collected in future years are recorded at the present value of their estimated future cash flows. The discounts on those amounts are computed using risk-adjusted interest rates applicable to the years in which the promises are received. Conditional promises to give are not included as support until the conditions are met.

Allowance for doubtful accounts

The Organization uses the allowance method to account for uncollectible grants receivable. The allowance is based on prior years' experience and management's analysis of possible bad debt. As of December 31, 2019 and 2018, the Organization determined that an allowance was not necessary.

NOTES TO FINANCIAL STATEMENTS

December 31, 2019 and 2018

2. Summary of significant accounting policies (continued)

Revenue and revenue recognition

The Organization recognizes contributions when cash, securities or other assets; an unconditional promise to give; or a notification of a beneficial interest is received. Contributions received are recorded as net assets without donor restrictions or net assets with donor restrictions, depending on the existence and/or nature of any donor-imposed restrictions. When a restriction expires (that is, when a stipulated time restriction ends or purpose restriction is accomplished), net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the statements of activities as net assets released from restrictions. Conditional promises to give – that is, those with a measurable performance or other barrier and a right of return – are not recognized until the conditions on which they depend have been met.

Contributions with donor-imposed stipulations regarding how long the contributed assets must be used are recorded as net assets with donor restrictions; otherwise, the contributions are recorded as net assets without donor restrictions.

The Organization receives grants from its affiliate organizations to fund a portion of the grants the Organization pays to the grantees. This revenue is recognized when the grants are committed to being paid by the affiliate organizations. The Organization recognizes revenue from conferences when the events takes place. Conferences are generally held every other year. Amounts received prior to the commencement of the conference, including deposits, are deferred to the applicable period.

The Organization has adopted Accounting Standards Update (ASU) No. 2018-08 Not for Profit Entities: Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made (Topic 605); and, No. 2014-09 Revenue from Contracts with Customers (Topic 606) as management believes the standards improve the usefulness and understandability of the Organization's financial reporting.

Analysis of various provisions of these standards resulted in no significant change in the way the Organization recognizes revenue, and therefore no changes to the previously issued audited financial statements were required on a retrospective basis. The presentation and disclosures of revenue have been enhanced in accordance with the standard.

Functional allocation of expenses

The costs of providing various programs and support services have been summarized on a functional basis in the statement of activities and in the statement of functional expenses. Accordingly, natural expenses attributable to more than one functional expense category are allocated using a variety of cost allocation techniques such as time and effort and square footage.

Income taxes

The Organization is a tax-exempt organization as defined by Section 501(c)(3) of the Internal Revenue Code, though it is subject to tax on income unrelated to its exempt purpose, unless that income is otherwise excluded by the Code. The Organization has processes presently in place to ensure the maintenance of its tax-exempt status; to identify and report unrelated income; to determine its filing and tax obligations in jurisdictions for which it has nexus; and to identify and evaluate other matters that may be considered tax positions. The Organization has determined that there are no material uncertain tax positions that require recognition or disclosure in the financial statements.

NOTES TO FINANCIAL STATEMENTS

December 31, 2019 and 2018

3. Risks and uncertainties

Financial instruments that potentially subject the Organization to concentrations of credit risk consist principally of cash, investments, and grants receivable. The Organization maintains its cash in bank deposit accounts, the balance, of which, at times, may exceed federally insured limits. Investment securities are exposed to various risks. Due to the level of risk associated with certain investment securities, it is at least reasonably possible that changes in the value of investments will occur in the near term and that such changes could materially affect the amount reported on the financial statements. Concentrations of credit risk with respect to the accounts receivable are limited due to the balance being historically low at any point in time. The Organization has not experienced, nor does it anticipate, any losses with respect to such accounts.

The Organization has reviewed its operations in light of the COVID-19 pandemic. Based on that review, it does not anticipate that the COVID-19 pandemic will have a material impact on its operations. However, events surrounding the Federal and State responses to the COVID-19 virus, and changes to those responses could change that analysis, and that change could be material.

4. Availability and liquidity

The following represents the Organization's financial assets at December 31, 2019:

Financial assets at year end:

Cash	\$ 384,847
Investments	4,472,545
Grants receivable	67,917
Due from affiliates	30,000
Other receivables	649
Total financial assets	4,955,958
Less amounts not available to be used within one year:	
Net assets with donor restrictions Less net assets with purpose restrictions to be met	3,792,191
in less than a year	(105,000)
Financial assets available to meet cash needs for	3,687,191
general expenditures within one year	\$ 1,268,767

The Organization's goal is generally to maintain financial assets to meet 90 days of operating expenses, net of in-kind (approximately \$325,000). As part of its liquidity plan, excess cash is invested in short-term investments, including money market accounts. In addition to their available financial assets, a significant portion of the Organization's annual expenditures will be funded by current year operating revenues including grants and contributions.

NOTES TO FINANCIAL STATEMENTS

December 31, 2019 and 2018

5. <u>Investments</u>

Investment securities are stated at fair value and summarized as follows at December 31:

	20	019	 2018
Cash and money market	•	371,037	\$ 925,705
Equities	1,1	113,932	943,142
Fixed income		987,576	 2,638,682
	\$ 4,4	<u> 172,545</u>	\$ 4,507,529

The following schedule summarizes the investment return and its classification in the statement of activities for the years ended December 31:

	 2019	 2018
Investments: Interest and dividends Realized and unrealized gain (loss)	\$ 95,117 385,757	\$ 64,775 (184,698)
	\$ 480,874	\$ (119,923)

6. Fair value measurement

The classification of the Organization's investment securities at fair value are as follows at December 31, 2019:

	Level 1	Level 2	Level 3	Total
Money market funds Equities Fixed income	\$ 371,037 1,113,932 2,987,576	\$	\$	\$ 371,037 1,113,932 2,987,576
	<u>\$ 4,472,545</u>	\$	\$	\$ 4,472,545

The classification of the Organization's investment securities at fair value are as follows at December 31, 2018:

	Level 1	Level 2	Level 3	Total
Money market funds Equities Fixed income	\$ 925,705 943,142 2,638,682	\$	\$	\$ 925,705 943,142 2,638,682
	\$ 4,507,529	\$	\$	\$ 4,507,529

NOTES TO FINANCIAL STATEMENTS

December 31, 2019 and 2018

7. Commitments

Grants payable as of December 31, 2019 and 2018 consists of amounts awarded but not paid, of \$259,580 and \$140,147, respectively. All are due to be paid within the next 12 to 24 months.

The Foundation is committed to research grants awarded subsequent to year-end, up to the amount of \$191,580, of which \$91,580 is committed to be funded by affiliates (see note 10).

8. Net assets

Net assets were as follows for the years ended December 31, 2019 and 2018:

		2019			2018	
	Without donor restrictions	With donor restrictions	Total	Without donor restrictions	With donor restrictions	Total
Undesignated	\$ 914,227	\$	\$ 914,227	\$ 861,228	\$	\$ 861,228
Specific purpose: Drug Development		8,942	8,942		36,575	36,575
Communications Platform					10,350	10,350
Paula & Woody Varner Science and Medical Fund		120,622	120,622		125,418	125,418
Science and Medical Fund		97,917	97,917			
Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome		3,564,710	3,564,710		3,557,700	3,557,700
Total net assets	\$ 914,227	\$3,792,191	\$4,706,418	\$ 861,228	\$3,730,043	\$4,591,271

Releases from net assets with donor restrictions are as follows at December 31:

	2019		2018	
Satisfaction of purpose restrictions:				
Drug Development	\$	27,633	\$	49,925
Communications Platform		10,350		9,650
Paula & Woody Varner Science and Medical Fund		20,000		40,000
Science and Medical Fund		12,157		11,779
Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome		200,000		34,000
	\$	270,140	\$	145,354

NOTES TO FINANCIAL STATEMENTS

December 31, 2019 and 2018

9. Major sources of support

For the year ended December 31, 2019, two donors accounted for approximately 28% of total support and revenues. For the year ended December 31, 2018, one donor accounted for approximately 45% of total support and revenues.

10. Grant expenses

The Organization, as part of its mission to fund and facilitate research addressing the causes, diagnosis, treatment, and cure of Barth Syndrome, commits to certain grants which it records as grants payable on the balance sheet upon approval of the award. The related grant award is reported on the statement of functional expenses to reflect the full grant expenditure amount. From time to time, the Organization subsequently receives assistance from affiliated entities to cover portions of the grant awards. These amounts have been recorded on the statement of functional expenses as grants funded by affiliates, which are presented as a contra expense in the amount of \$40,000 and \$83,906 for the years ended December 31, 2019 and 2018, respectively.

11. Subsequent events

The Organization has evaluated subsequent events through April 13, 2020 which is the date the financial statements were available to be issued. The Organization is not aware of any material subsequent events.