



**Barth Syndrome
Foundation**

***FINANCIAL STATEMENTS
WITH INDEPENDENT AUDITORS' REPORT***

YEARS ENDED DECEMBER 31, 2018 AND 2017

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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, 2018 and 2017, 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, 2018 and 2017, 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 2018 the Organization adopted Accounting Standards Update (ASU) No. 2016-14, Not-for-Profit Entities. Our opinion is not modified with respect to these matters.

Dorfman Abrams Music, LLC

Saddle Brook, New Jersey

April 25, 2019

THE BARTH SYNDROME FOUNDATION, INC.

BALANCE SHEETS

ASSETS

	December 31,	
	<u>2018</u>	<u>2017</u>
Cash	\$ 237,557	\$ 204,805
Investments	4,507,529	3,752,322
Accounts receivable	2,565	2,381
Prepaid expenses	<u>2,699</u>	<u>11,947</u>
 Total assets	 <u>\$ 4,750,350</u>	 <u>\$ 3,971,455</u>

LIABILITIES AND NET ASSETS

Liabilities:		
Accounts payable and accrued expenses	\$ 18,932	\$ 70,611
Deferred revenue		8,750
Grants payable	<u>140,147</u>	<u>179,423</u>
 Total liabilities	 <u>159,079</u>	 <u>258,784</u>
Net assets:		
Without donor restrictions	861,228	1,254,271
With donor restrictions	<u>3,730,043</u>	<u>2,458,400</u>
 Total net assets	 <u>4,591,271</u>	 <u>3,712,671</u>
 Total liabilities and net assets	 <u>\$ 4,750,350</u>	 <u>\$ 3,971,455</u>

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

THE BARTH SYNDROME FOUNDATION, INC.

STATEMENTS OF ACTIVITIES

	Year ended December 31, 2018			Year ended December 31, 2017		
	Without donor restrictions	With donor restrictions	Total	Without donor restrictions	With donor restrictions	Total
Operating activities:						
Support and revenue:						
Contributions	\$ 631,570	\$ 1,320,497	\$ 1,952,067	\$ 641,301	\$ 224,064	\$ 865,365
Conference revenue	60,266	96,500	156,766			
Grant income	45,000		45,000			
Interest and dividends	86,013		86,013	57,611		57,611
Total support and revenue	822,849	1,416,997	2,239,846	698,912	224,064	922,976
Net assets released from restrictions	145,354	(145,354)		424,335	(424,335)	
Total support and revenue	968,203	1,271,643	2,239,846	1,123,247	(200,271)	922,976
Expenses:						
Program services:						
Communication and awareness	93,414		93,414	103,494		103,494
BSF Conference	286,404		286,404			
Family services	73,145		73,145	110,244		110,244
Advocacy and awareness	90,213		90,213	32,860		32,860
Barth registry and repository	28,772		28,772	16,374		16,374
Research grants	253,199		253,199	256,449		256,449
Science and medicine	152,344		152,344	215,892		215,892
Total program services	977,491		977,491	735,313		735,313
Supporting services:						
General and administrative expenses	124,694		124,694	146,747		146,747
Fundraising expenses	53,125		53,125	48,772		48,772
Total supporting services	177,819		177,819	195,519		195,519
Total expenses	1,155,310		1,155,310	930,832		930,832
Change in net assets from operations	(187,107)	1,271,643	1,084,536	192,415	(200,271)	(7,856)
Nonoperating activities:						
Investment return, net	(205,936)		(205,936)	142,970		142,970
Total nonoperating activities	(205,936)		(205,936)	142,970		142,970
Change in net assets	(393,043)	1,271,643	878,600	335,385	(200,271)	135,114
Net assets, beginning of year	1,254,271	2,458,400	3,712,671	918,886	2,658,671	3,577,557
Net assets, end of year	\$ 861,228	\$ 3,730,043	\$ 4,591,271	\$ 1,254,271	\$ 2,458,400	\$ 3,712,671

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

THE BARTH SYNDROME FOUNDATION, INC.

STATEMENTS OF CASH FLOWS

	<u>Year ended December 31,</u>	
	<u>2018</u>	<u>2017</u>
Cash flows from operating activities:		
Change in net assets	\$ 878,600	\$ 135,114
Adjustments to reconcile change in net assets to net cash provided (used) by operating activities:		
Contribution of stock	(1,026,298)	(81,704)
Realized and unrealized (gain) loss on investments	197,179	(155,059)
Changes in operating assets and liabilities:		
(Increase) decrease in:		
Accounts receivable	(184)	5,518
Prepaid expenses	9,248	1,064
Increase (decrease) in:		
Accounts payable and accrued expenses	(51,679)	49,707
Deferred revenue	(8,750)	8,750
Grants payable	(39,276)	(16,052)
Net cash used by operating activities	<u>(41,160)</u>	<u>(52,662)</u>
Cash flows from investing activities:		
Purchases of investments	(447,326)	(514,673)
Proceeds from sale of investments	521,238	219,180
Net cash provided (used) by investing activities	<u>73,912</u>	<u>(295,493)</u>
Net increase (decrease) in cash	32,752	(348,155)
Cash, beginning of year	<u>204,805</u>	<u>552,960</u>
Cash, end of year	<u>\$ 237,557</u>	<u>\$ 204,805</u>

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

THE BARTH SYNDROME FOUNDATION, INC.

STATEMENTS OF FUNCTIONAL EXPENSES

Years Ended December 31, 2018 and 2017

	Program services															
	Communication and awareness		BSF Conference		Family services		Advocacy and awareness		Barth registry and repository		Research grants		Science and medicine		Total	
	2018	2017	2018	2017	2018	2017	2018	2017	2018	2017	2018	2017	2018	2017	2018	2017
Salaries	\$ 62,505	\$ 76,479	\$ 99,393	\$	\$ 55,674	\$ 89,885	\$ 16,490	\$ 25,695	\$	\$	\$	\$	\$ 126,388	\$ 171,799	\$ 360,450	\$ 363,858
Payroll taxes and benefits	8,777	10,897	13,399		8,157	14,974	2,402	4,242					17,984	23,193	50,719	53,306
Total salaries and related expenses	71,282	87,376	112,792		63,831	104,859	18,892	29,937					144,372	194,992	411,169	417,164
Grant expense											219,199	187,287			219,199	187,287
Professional fees	9,500						23,881		24,500	13,500					57,881	13,500
Meals		43	66,882		57	57	18,698	163					53	1,287	85,690	1,550
Transportation	316	357	64,286		533	288	5,706	2,100					2,322	7,567	73,163	10,312
Audio visual			28,314				15,938	250							44,252	250
Office expense	3,726	7,380	3,515		3,296	401	3,520	225	4	161			2,691	1,225	16,752	9,392
Printing and publications	8,467	7,809	470				1,151								10,088	7,834
Dues and fees															4,950	5,270
Other meeting expenses			10,145				2,409		125	2,079	2,045		2,871	3,100	12,554	
Telephone	123	529			5,428	4,565	18	60					35	121	5,604	5,275
Insurance																
Therapy development									2,189	668	34,000	69,162			36,189	69,830
Training and education						49								7,600		7,649
Total expenses	<u>\$ 93,414</u>	<u>\$ 103,494</u>	<u>\$ 286,404</u>	<u>\$</u>	<u>\$ 73,145</u>	<u>\$ 110,244</u>	<u>\$ 90,213</u>	<u>\$ 32,860</u>	<u>\$ 28,772</u>	<u>\$ 16,374</u>	<u>\$ 253,199</u>	<u>\$ 256,449</u>	<u>\$ 152,344</u>	<u>\$ 215,892</u>	<u>\$ 977,491</u>	<u>\$ 735,313</u>

THE BARTH SYNDROME FOUNDATION, INC.

STATEMENTS OF FUNCTIONAL EXPENSES

Years Ended December 31, 2018 and 2017

	Management and general		Supporting services				Total program and supporting services	
	2018	2017	Fundraising		Total		2018	2017
			2018	2017	2018	2017		
Salaries	\$ 23,342	\$ 23,235	\$ 38,769	\$ 36,436	\$ 62,111	\$ 59,671	\$ 422,561	\$ 423,529
Payroll taxes and benefits	3,182	3,444	3,065	4,962	6,247	8,406	56,966	61,712
Total salaries and related expenses	26,524	26,679	41,834	41,398	68,358	68,077	479,527	485,241
Grant expense							219,199	187,287
Professional fees	58,975	80,086			58,975	80,086	116,856	93,586
Meals		963	132	27	132	990	85,822	2,540
Transportation	6,673	6,217	274	136	6,947	6,353	80,110	16,665
Audio visual				250		250	44,252	500
Office expense	21,591	21,014	5,241	2,228	26,832	23,242	43,584	32,634
Printing and publications	56	16	3,792	2,473	3,848	2,489	13,936	10,323
Dues and fees	6,023	6,848	1,746	1,900	7,769	8,748	12,719	14,018
Other meeting expenses							12,554	
Telephone	1,290	890	106	360	1,396	1,250	7,000	6,525
Insurance	3,562	4,034			3,562	4,034	3,562	4,034
Therapy development							36,189	69,830
Training and education								7,649
Total expenses	<u>\$ 124,694</u>	<u>\$ 146,747</u>	<u>\$ 53,125</u>	<u>\$ 48,772</u>	<u>\$ 177,819</u>	<u>\$ 195,519</u>	<u>\$ 1,155,310</u>	<u>\$ 930,832</u>

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

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

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.

2. Summary of significant accounting policies

New accounting pronouncement

During 2018, the Organization adopted Accounting Standards Update (ASU) 2016-14, *Not-for-Profit Entities (Topic 958) – Presentation of Financial Statements of Not-for-Profit Entities*. This guidance is intended to improve the net asset classification requirements and the information presented in the financial statements and notes about a not-for-profit entity's liquidity, financial performance, and cash flows. Main provisions of this guidance include: presentation of two classes of net assets versus the previously required three; recognition of capital gifts for construction as a net asset without donor restrictions when the associated long-lived asset is placed in service; and recognition of underwater endowment funds as a reduction in net assets with donor restrictions. The guidance also enhances disclosures for board designated amounts, composition of net assets without donor restrictions, liquidity, and expenses by both their natural and functional classification.

As a result of the adoption of ASU, net assets as of December 31, 2017 were reclassified as follows:

	ASU Classifications		
	Without donor restrictions	With donor restrictions	Total net assets
Net asset classifications			
As previously presented:			
Unrestricted	\$ 1,254,271	\$	\$ 1,254,271
Temporarily restricted		2,458,400	2,458,400
Total net assets	<u>\$ 1,254,271</u>	<u>\$ 2,458,400</u>	<u>\$ 3,712,671</u>

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

2. Summary of significant accounting policies (continued)

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:

Net assets without donor restrictions - 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.

Net assets with donor restrictions - 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.

Donor restricted contributions are reported as increases in net assets with donor restrictions. When a restriction expires, net assets are reclassified from net assets with donor restrictions to net assets without donor restrictions in the statement of activities.

Measure of operations

The statements 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.

Cash

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.

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

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 statement of financial position.

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.

Accounts receivable

Accounts receivable consist of amounts unpaid from events. All accounts receivable are expected to be collected within one year.

Allowance for doubtful accounts

The Organization uses the allowance method to account for uncollectible accounts receivable. The allowance is based on prior years' experience and management's analysis of possible bad debt. As of December 31, 2018 and 2017, the Organization determined that an allowance was not necessary.

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

2. Summary of significant accounting policies (continued)

Contributions

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. Contributions that are restricted by the donor are reported as an increase in net assets with donor restrictions, depending on the nature of restriction. 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.

Contributed property and equipment are recorded at fair value at the date of donation. 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.

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.

Reclassifications

Certain amounts in the 2017 financial statements have been reclassified to conform to the 2018 presentation.

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

3. Concentration of credit risk

Financial instruments that potentially subject the Organization to concentrations of credit risk consist principally of cash, investments, and accounts 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.

4. Availability and liquidity

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

Financial assets at year end	<u>2018</u>	<u>2017</u>
Cash	\$ 237,557	\$ 204,805
Investments	4,507,529	3,752,322
Accounts receivable	<u>2,565</u>	<u>2,381</u>
Total financial assets	<u>4,747,651</u>	<u>3,959,508</u>
Less amounts not available to be used within one year:		
Net assets with donor restrictions	3,683,118	2,458,400
Less net assets with purpose restrictions to be met in less than a year	<u>(200,000)</u>	<u>(85,779)</u>
	<u>3,483,118</u>	<u>2,372,621</u>
Financial assets available to meet cash needs for general expenditures within one year	<u>\$ 1,264,533</u>	<u>\$ 1,586,887</u>

The Organization's goal is generally to maintain financial assets to meet 90 days of operating expenses, net of in-kind (approximately \$300,000). As part of its liquidity plan, excess cash is invested in short-term investments, including money market accounts.

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

5. Investments

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

	<u>2018</u>	<u>2017</u>
Cash and money market	\$ 925,705	\$ 736,664
Equities	943,142	935,046
Fixed income	<u>2,638,682</u>	<u>2,080,612</u>
	<u>\$ 4,507,529</u>	<u>\$ 3,752,322</u>

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

	<u>2018</u>	<u>2017</u>
Investments:		
Interest and dividends	\$ 86,013	\$ 57,611
Realized and unrealized gain (loss)	<u>(205,936)</u>	<u>142,970</u>
	<u>\$ (119,923)</u>	<u>\$ 200,581</u>

6. Fair value measurement

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

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

The classification of the Organization's investment securities at fair value are as follows at December 31, 2017:

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Money market funds	\$ 736,664	\$	\$	\$ 736,664
Equities	935,046			935,046
Fixed income	<u>2,080,612</u>			<u>2,080,612</u>
	<u>\$ 3,752,322</u>	<u>\$</u>	<u>\$</u>	<u>\$ 3,752,322</u>

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

7. Commitments

Grants payable as of December 31, 2018 and 2017, consists of amounts awarded, but not paid, of \$140,147 and \$179,423, 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 \$400,000, of which \$80,000 is committed to be paid by affiliates.

8. Net assets

Net assets were as follows for the years ended December 31, 2018 and 2017:

	2018			2017		
	Without donor restrictions	With donor restrictions	Total	Without donor restrictions	With donor restrictions	Total
Undesignated	\$ 861,228	\$	\$ 861,228	\$1,254,271	\$	\$1,254,271
Specific purpose:						
Drug Development		36,575	36,575			
Communications Platform		10,350	10,350			
Paul & Woody Varner Science and Medical Fund		125,418	125,418		148,469	148,469
Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome		3,557,700	3,557,700		2,309,931	2,309,931
Total net assets	<u>\$ 861,228</u>	<u>\$3,730,043</u>	<u>\$4,591,271</u>	<u>\$1,254,271</u>	<u>\$2,458,400</u>	<u>\$3,712,671</u>

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

	2018	2017
Satisfaction of purpose restrictions:		
Drug Development	\$ 49,925	\$
Communications Platform	9,650	
Paula & Woody Varner Science and Medical Fund	40,000	21,324
Science and Medical Fund	11,779	209,173
Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome	34,000	193,838
	<u>\$ 145,354</u>	<u>\$ 424,335</u>

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2018 and 2017

9. Major sources of support

For the year ended December 31, 2018, one donor accounted for approximately 45% of total support and revenues. For the year ended December 31, 2017, two donors accounted for approximately 31% of total support and revenues.

10. Subsequent events

The Organization has evaluated subsequent events through April 25, 2019 which is the date the financial statements were available to be issued. The Organization is not aware of any material subsequent events.