



Barth Syndrome
Foundation

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

YEARS ENDED DECEMBER 31, 2020 AND 2019

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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, 2020 and 2019, 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, 2020 and 2019, 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.

Dorfman Abrams Music, LLC

Saddle Brook, New Jersey

April 15, 2021

THE BARTH SYNDROME FOUNDATION, INC.

BALANCE SHEETS

ASSETS

	December 31,	
	<u>2020</u>	<u>2019</u>
Cash	\$ 311,285	\$ 384,847
Investments	5,161,737	4,472,545
Grants receivable	20,000	67,917
Due from affiliates		30,000
Other receivables		649
Prepaid expenses	<u>60,177</u>	<u>37,285</u>
Total assets	<u>\$ 5,553,199</u>	<u>\$ 4,993,243</u>

LIABILITIES AND NET ASSETS

Liabilities:		
Accounts payable and accrued expenses	\$ 59,227	\$ 26,869
Deferred revenue	27,183	376
Research grants payable	<u>186,150</u>	<u>259,580</u>
Total liabilities	<u>272,560</u>	<u>286,825</u>
Net assets:		
Without donor restrictions	1,482,290	914,227
With donor restrictions	<u>3,798,349</u>	<u>3,792,191</u>
Total net assets	<u>5,280,639</u>	<u>4,706,418</u>
Total liabilities and net assets	<u>\$ 5,553,199</u>	<u>\$ 4,993,243</u>

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

THE BARTH SYNDROME FOUNDATION, INC.

STATEMENTS OF CASH FLOWS

	Year ended December 31,	
	2020	2019
Cash flows from operating activities:		
Change in net assets	\$ 574,221	\$ 115,147
Adjustments to reconcile change in net assets to net cash provided (used) by operating activities:		
Contribution of stock	(125,221)	(34,142)
Realized and unrealized (gain) loss on investments	(351,248)	(385,757)
Changes in operating assets and liabilities:		
(Increase) decrease in:		
Grants receivable	47,917	(67,917)
Due from affiliates	30,000	(27,435)
Other receivables	649	(649)
Prepaid expenses	(22,892)	(34,586)
Increase (decrease) in:		
Accounts payable and accrued expenses	32,358	7,937
Deferred revenue	26,807	376
Research grants payable	(73,430)	119,433
Net cash provided (used) by operating activities	<u>139,161</u>	<u>(307,593)</u>
Cash flows from investing activities:		
Purchases of investments	(866,570)	(123,948)
Proceeds from sale of investments	653,847	578,831
Net cash provided (used) by investing activities	<u>(212,723)</u>	<u>454,883</u>
Net increase (decrease) in cash	(73,562)	147,290
Cash, beginning of year	<u>384,847</u>	<u>237,557</u>
Cash, end of year	<u>\$ 311,285</u>	<u>\$ 384,847</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, 2020 and 2019

	Program services										Total				
	Communication and awareness		Family services		Advocacy and awareness		Barth registry and repository		Research grants			Science and medicine			
	2020	2019	2020	2019	2020	2019	2020	2019	2020	2019		2020	2019		
Salaries	\$ 65,477	\$ 63,910	\$ 70,889	\$ 68,353	\$ 88,906	\$ 89,039	\$	\$	\$	\$	\$ 154,776	\$ 189,572	\$ 380,048	\$ 410,874	
Payroll taxes and benefits	8,552	6,556	12,837	11,883	13,095	10,419					18,722	23,372	53,206	52,030	
Total salaries and related expenses	74,029	70,466	83,726	80,036	102,001	99,458					173,498	212,944	433,254	462,904	
Research grant expense															
Research grants funded by affiliates									243,167	400,000		56,917	243,167	456,917	
Professional fees	38,475	59,796	2,836	4,490	7,839	7,988	43,000	18,000	(41,580)	(40,000)	5,797	4,886	(41,580)	(40,000)	
Office expense	8,742	10,063			547	1,055	141	16	9,017		1,794	3,476	104,128	90,470	
Printing and publications	9,996	1,377				838							14,060	19,100	
Dues and fees		303	208		4,936	1,200	671	2,302			3,119	3,833	9,996	2,215	
Transportation			2,034	16,242		13,411	94	31			512	18,962	3,998	7,638	
Telephone				3,687									2,034	3,687	
Insurance															
Public relations	867	866											867	866	
Audio visual				51	25	12,000		140				18	25	12,000	
Training and education				2,046		144						97	97	484	
Meals														2,287	
Total expenses	\$ 132,109	\$ 142,871	\$ 88,804	\$ 106,552	\$ 115,348	\$ 136,369	\$ 43,906	\$ 20,489	\$ 210,604	\$ 360,000	\$ 184,720	\$ 300,933	\$ 775,491	\$ 1,067,214	

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

THE BARTH SYNDROME FOUNDATION, INC.
STATEMENTS OF FUNCTIONAL EXPENSES

Years Ended December 31, 2020 and 2019

	Management and general		Supporting services		Total		Total program and supporting services	
	2020	2019	2020	2019	2020	2019	2020	2019
Salaries	\$ 45,195	\$ 44,909	\$ 50,700	\$ 47,500	\$ 95,895	\$ 92,409	\$ 475,943	\$ 503,283
Payroll taxes and benefits	7,040	3,553	5,617	2,831	12,657	6,384	65,863	58,414
Total salaries and related expenses	52,235	48,462	56,317	50,331	108,552	98,793	541,806	561,697
Research grant expense							243,167	456,917
Research grants funded by affiliates							(41,580)	(40,000)
Professional fees	51,018	61,162	9,000	4,592	60,018	65,754	164,146	156,224
Office expense	33,143	31,954	10,162	13,984	43,305	45,938	57,365	65,038
Printing and publications		920	2,480	2,080	2,480	3,000	12,476	5,215
Dues and fees	7,028	8,712		1,794	7,028	10,506	11,026	18,144
Transportation		2,853	97	1,402	97	4,255	5,639	52,901
Telephone	1,198	914			1,198	914	3,232	4,601
Insurance	3,204	3,801			3,204	3,801	3,204	3,801
Public relations		925	200	25	200	950	1,067	1,816
Audio visual			360	125	360	125	360	12,125
Training and education		30				30	25	514
Meals		96				96		2,383
Total expenses	\$ 147,826	\$ 159,829	\$ 78,616	\$ 74,333	\$ 226,442	\$ 234,162	\$ 1,001,933	\$ 1,301,376

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

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2020 and 2019

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.

2. 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:

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.

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.

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, 2020 and 2019

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, 2020 and 2019, the Organization determined that an allowance was not necessary.

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2020 and 2019

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.

Paycheck Protection Program - grant

In the second quarter of 2020, the Organization was granted a loan in the amount of \$92,673 pursuant to the Paycheck Protection Program (the PPP) by the U.S. Small Business Administration (the SBA). The PPP, established as part of the Coronavirus Aid, Relief and Economic Security Act (the Act), provides for loans to qualifying businesses for amounts up to 2.5 times a company's average monthly payroll expenses. The loans and accrued interest are forgivable as long as the Organization uses the loan proceeds for eligible purposes, including payroll, employee benefits, rent and utilities. For purposes of loan forgiveness, not more than 40% of the proceeds can be used for non-payroll costs. In addition, the amount of loan forgiveness will be reduced if the Organization fails to maintain its pre-pandemic payroll levels during the covered period, unless one of the safe harbor provisions within the Act is satisfied. The unforgiven portion, if any, would be payable over two to five years, depending upon the SBA approval date, at an interest rate of 1%, with a deferral of payments for the first ten months. While formal forgiveness has not yet been received by the SBA, the Organization has determined that the loan will be a forgivable grant, substantiated by eligible payroll expenses, and meeting all requirements as set by the SBA. As a result, the Organization recorded forgiveness of this grant during the year ended December 31, 2020.

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.

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2020 and 2019

2. Summary of significant accounting policies (continued)

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.

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.

Pandemic

In the first quarter of 2020, the outbreak of a novel strain of coronavirus, COVID-19, was declared a pandemic. The Pandemic did not have an impact on the Organization until mid-March 2020. The Pandemic's impact was largely limited to canceling the 2020 conference and rescheduling this conference to 2021 year end. The Organization had previously become fully remote and does not maintain a brick and mortar office, and therefore, the pandemic did not require any significant change to their procedures and operations.

Due to the fluidity of the pandemic, uncertainties as to its scope and duration, and ongoing changes in the way that governments, businesses and individuals react and respond to the Pandemic, management is unable at this time to predict the Pandemic's future impact on the Organization.

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2020 and 2019

4. Availability and liquidity

The following represents the Organization's financial assets at December 31, 2020:

Financial assets at year end:

Cash	\$ 311,285
Investments	5,161,737
Grants receivable	<u>20,000</u>
Total financial assets	<u>5,493,022</u>

Less amounts not available to be used within one year:

Net assets with donor restrictions	3,798,349
Less net assets with purpose restrictions to be met in less than a year	<u>(150,000)</u>
	<u>3,648,347</u>
Financial assets available to meet cash needs for general expenditures within one year	<u>\$ 1,844,675</u>

The Organization's goal is generally to maintain financial assets to meet 90 days of operating expenses, net of in-kind (approximately \$250,000). 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.

5. Investments

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

	<u>2020</u>	<u>2019</u>
Cash and money market	\$ 753,055	\$ 371,037
Equities	1,295,831	1,113,932
Fixed income	<u>3,112,851</u>	<u>2,987,576</u>
	<u>\$ 5,161,737</u>	<u>\$ 4,472,545</u>

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

	<u>2020</u>	<u>2019</u>
Investments:		
Interest and dividends	\$ 62,700	\$ 95,117
Realized and unrealized gain (loss)	<u>351,248</u>	<u>385,757</u>
	<u>\$ 413,948</u>	<u>\$ 480,874</u>

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2020 and 2019

6. Fair value measurement

The classification of the Organization's investment securities at fair value are as follows at December 31, 2020:

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Money market funds	\$ 753,055	\$	\$	\$ 753,055
Equities	1,295,831			1,295,831
Fixed income	<u>3,112,851</u>			<u>3,112,851</u>
	<u>\$ 5,161,737</u>	<u>\$</u>	<u>\$</u>	<u>\$ 5,161,737</u>

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

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

7. Commitments

Research grants payable as of December 31, 2020 and 2019 consists of amounts awarded but not paid, of \$186,150 and \$259,580, 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 \$250,000, of which \$50,000 is committed to be funded by affiliates (see Note 10).

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2020 and 2019

8. Net assets

Net assets were as follows for the years ended December 31, 2020 and 2019:

	2020			2019		
	Without donor restrictions	With donor restrictions	Total	Without donor restrictions	With donor restrictions	Total
Undesignated	\$1,482,290	\$	\$1,482,290	\$ 914,227	\$	\$ 914,227
Specific purpose:						
Drug Development					8,942	8,942
Paula & Woody Varner Science and Medical Fund		131,434	131,434		120,622	120,622
Science and Medical Fund					97,917	97,917
Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome		3,666,915	3,666,915		3,564,710	3,564,710
Total net assets	<u>\$1,482,290</u>	<u>\$3,798,349</u>	<u>\$5,280,639</u>	<u>\$ 914,227</u>	<u>\$3,792,191</u>	<u>\$4,706,418</u>

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

	2020	2019
Satisfaction of purpose restrictions:		
Drug Development	\$ 8,942	\$ 27,633
Communications Platform		10,350
Paula & Woody Varner Science and Medical Fund		20,000
Science and Medical Fund	154,850	12,157
Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome	50,000	200,000
	<u>\$ 213,792</u>	<u>\$ 270,140</u>

9. Major sources of support

For the year ended December 31, 2020, two donors accounted for approximately 24% of total support and revenues. For the year ended December 31, 2019, two donors accounted for approximately 28% of total support and revenues.

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2020 and 2019

10. Research 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 research grants which it records as research grants payable on the balance sheet, upon approval of the award. The related research 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 research grant awards. These amounts have been recorded on the statement of functional expenses as research grants funded by affiliates, which are presented as a contra expense in the amount of \$41,580 and \$40,000 for the years ended December 31, 2020 and 2019, respectively.

11. Subsequent events

The Organization has evaluated subsequent events through April 15, 2021 which is the date the financial statements were available to be issued. The Organization is not aware of any material subsequent events.