

### FINANCIAL STATEMENTS WITH INDEPENDENT AUDITORS' REPORT

YEARS ENDED DECEMBER 31, 2021 AND 2020

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### INDEPENDENT AUDITORS' REPORT

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

### **Opinion**

We have audited the accompanying financial statements of Barth Syndrome Foundation, Inc. (a nonprofit organization), which comprise the balance sheet as of December 31, 2021 and 2020, and the related statements of activities, cash flows, and functional expenses for the years then ended, and the related notes to the financial statements.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Barth Syndrome Foundation, Inc. as of December 31, 2021 and 2020, and the changes in its net assets and its cash flows for the period then ended in accordance with accounting principles generally accepted in the United States of America.

### Basis for Opinion

We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Our responsibilities under those standards are further described in the Auditors' Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of Barth Syndrome Foundation, Inc. and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audit. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

### Responsibilities of Management for the Financial Statements

Management is responsible for the preparation and fair presentation of the financial statements in accordance with accounting principles generally accepted in the United States of America, and for 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.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about Barth Syndrome Foundation, Inc.'s ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

### Auditors' Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with generally accepted auditing standards will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements, including omissions, are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with generally accepted auditing standards, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit 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 Barth Syndrome Foundation, Inc.'s internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about Barth Syndrome Foundation, Inc.'s ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control related matters that we identified during the audit.

Dorfman Ahams music, LLC Saddle Brook, New Jersey

April 25, 2022

### **BALANCE SHEETS**

### **ASSETS**

	Decem	ber 31,
	2021	2020
Cash Investments Grants receivable Prepaid expenses	\$ 697,821 5,211,353 30,000 47,767	\$ 311,285 5,161,737 20,000 60,177
Total assets	\$ 5,986,941	\$ 5,553,199
LIABILITIES AND NET ASSETS Liabilities:		
Accounts payable and accrued expenses	\$ 88,869	\$ 59,227
Deferred revenue	27,183	27,183
Research grants payable	169,200	186,150
Total liabilities	285,252_	272,560
Net assets:		
Without donor restrictions	1,787,258	1,482,290
With donor restrictions	3,914,431	3,798,349
Total net assets	5,701,689_	5,280,639
Total liabilities and net assets	\$ 5,986,941	\$ 5,553,199

### STATEMENTS OF ACTIVITIES

Contributions Grant income from affiliates Other grant income Paycheck Protection Program - grant Interest and dividends

Support and revenue:

Operating activities:

Net assets released from restrictions

Total support and revenue

Total support and revenue

Other Income

Communication and awareness

Program services:

Expenses:

Family services
Advocacy and awareness
Barth registry and repository
Research grants
Science and medicine

Year ended December 31, 2020 donor With donor ions restrictions Total	\$ 164,950 \$ 969,533 50,000 50,000 5,000 50,000 62,000 92,673	219,950 1,224,906
Year en Without donor restrictions	8 \$ 804,583 0 45,000 92,673 7 62,700	3 1,004,956
Year ended December 31, 2021 donor With donor Total Institutions Total	32 \$ 1,151,518 60,000 43,567 2,818	32 1,257,903 50)
With donor restrictions	\$ 247,332	247,332
Year (Without donor restrictions	904,186 60,000 43,567 2,818	1,010,571

Supporting services: General and administrative expenses Fundraising expenses

Total program services

Total supporting services

Total expenses

Change in net assets from operations

Total nonoperating activities

Nonoperating activities: Investment return, net

Net assets, beginning of year

Net assets, end of year

Change in net assets

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

### STATEMENTS OF CASH FLOWS

		Year ended [	Decem	ıber 31,
		2021		2020
Cash flows from operating activities:	•	404.050	•	574004
Change in net assets Adjustments to reconcile change in net assets to net cash provided (used) by operating activities:	\$	421,050	\$	574,221
Contribution of stock		(32,169)		(125,221)
Realized and unrealized (gain) loss on investments Changes in operating assets and liabilities: (Increase) decrease in:		(173,879)		(351,248)
Grants receivable Due from affiliates Other receivables		(10,000)		47,917 30,000 649
Prepaid expenses		12,410		(22,892)
Increase (decrease) in:		12, 110		(22,002)
Accounts payable and accrued expenses  Deferred revenue		29,642		32,358 26,807
Research grants payable		(16,950)	-	(73,430)
Net cash provided by operating activities		230,104		139,161
Cash flows from investing activities:				
Purchases of investments		(228,261)		(866,570)
Proceeds from sale of investments		384,693		653,847
Net cash provided (used) by investing activities		156,432		(212,723)
Net increase (decrease) in cash		386,536		(73,562)
Cash, beginning of year		311,285		384,847
Cash, end of year	\$	697,821	\$	311,285

THE BARTH SYNDROME FOUNDATION, INC.

## STATEMENTS OF FUNCTIONAL EXPENSES

Years Ended December 31, 2021 and 2020

							Program	Program services						
	Commur	Communication and			Advocacy and	icy and	Barth registry	egistry						
	awa	awareness	Family services	ervices	awareness	ness	and repository	ository	Research grants	h grants	Science and medicine	d medicine	Total	<u>a</u>
	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020
Salaries Payroll taxes and benefits	\$ 56,372 8,475	\$ 65,477	\$ 66,380	\$ 70,889	\$ 81,897 13,195	\$ 88,906	↔	<del>69</del>	€9	<b>↔</b>	\$ 147,752 19,112	\$ 154,776 18,722	\$ 352,401 53,853	\$ 380,048 53,206
Total salaries and											700	60	430.00	N 30 00N
related experises	64,847	74,029	/9,451	83,726	35,092	102,001					166,864	173,498	400,254	433,234
Research grant expense									254,594	243,167			254,594	243,167
Research grants funded by affiliates									(20,000)	(41,580)			(20'000)	(41,580)
Professional fees	43,388	38,475				7,839	18,000	43,000		9,017	20,106	5,797	81,494	104,128
Office expense	5,523	8,742	12,439	2,836	396	547	145	141			1,080	1,794	19,583	14,060
Printing and publications	17,115	966'6	1,006										18,121	966'6
Dues and fees			252	208	20		671	671			3,812	3,119	4,785	3,998
Telephone			2,467	2,034									2,467	2,034
Transportation						4,936		94			1,491	512	1,491	5,542
Insurance														
Public relations	1,275	867											1,275	867
Audio visual			1,108										1,108	
Training and education	9		230			25							236	25

\$ 775,491

\$ 741,408

\$ 184,720

\$ 193,353

\$ 18.816 \$ 43.906 \$ 204,594 \$ 210,604

\$ 115,348

\$ 95,538

\$ 88,804

\$ 96,953

\$ 132,109

\$ 132,154

Total expenses

THE BARTH SYNDROME FOUNDATION, INC.

# STATEMENTS OF FUNCTIONAL EXPENSES

Years Ended December 31, 2021 and 2020

	-		4	0.00		Supporting services	ng ser	vices		F	-		⊢ ;	otal prog	Total program and	
	2	2021 2020 2020	<u>a</u> a	general 2020		2021	rundiaising	2020		2021		2020	2021	17	Supporting Services 021 2020	1
	}															
Salaries	₩	82,315	↔	45,195	↔	43,893	↔	50,700	₩	126,208	↔	95,895	\$ 478	478,609	\$ 475,943	က္
Payroll taxes and benefits		7,431		7,040		5,399		5,617		12,830		12,657	9	66,683	65,863	က္ဆ
Total salaries and																
related expenses		89,746		52,235		49,292		56,317		139,038		108,552	54	545,292	541,806	9
															:	ļ
Research grant expense													52	254,594	243,167	7
Research grants funded by affiliates													(2)	(20,000)	(41,580)	<u>(</u>
Professional fees		53,370		51,018		389		9,000		53,759		60,018	13	135,253	164,146	မှ
Office expense		41,462		33,143		20,353		10,162		61,815		43,305	ò	81,398	57,365	ίζ
Printing and publications		190				931		2,480		1,121		2,480	<del>*</del>	19,242	12,476	9.
Dues and fees		5,795		7,028						5,795		7,028	7	10,580	11,026	9:
Telephone		1,026		1,198						1,026		1,198	•	3,493	3,232	ŭ
Transportation						1,975		26		1,975		26	•	3,466	5,639	6
Insurance		3,374		3,204						3,374		3,204	•	3,374	3,204	4
Public relations						651		200		651		200	•	1,926	1,067	7
Audio visual								360				360	•	1,108	360	0
Training and education		770								770			•	1,006	25	55
																1
Total expenses	8	\$ 195,733 \$ 147,826	ક	147,826	\$	73,591	8	78,616	S	269,324	s	226,442	\$ 1,010,732	0,732	\$ 1,001,933	22

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

### NOTES TO FINANCIAL STATEMENTS

December 31, 2021 and 2020

### 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:

<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.

### 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.

### NOTES TO FINANCIAL STATEMENTS

December 31, 2021 and 2020

### 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, 2021 and 2020, the Organization determined that an allowance was not necessary.

### NOTES TO FINANCIAL STATEMENTS

December 31, 2021 and 2020

### 2. <u>Summary of significant accounting policies</u> (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.

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.

### 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, 2021 and 2020

### 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**

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, 2021:

Financial assets at year-end:

Cash	\$ 697,821
Investments	5,211,353
Grants receivable	 30,000
Total financial assets	 5,939,174
Less amounts not available to be used within one year:	
Net assets with donor restrictions	2 04 4 424
Less net assets with purpose restrictions to be met	3,914,431
in less than a year	 (150,000)
Einonoial apparta available to want apple woods for	 3,764,431
Financial assets available to meet cash needs for general expenditures within one year	\$ 2,174,743

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.

### NOTES TO FINANCIAL STATEMENTS

December 31, 2021 and 2020

### 5. <u>Investments</u>

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

	_	2021	 2020
Cash and money market	\$	571,001	\$ 753,055
Equities Fixed income		1,721,152 2,919,200	 1,295,831 3,112,851
	\$	5,211,353	\$ 5,161,737

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

	Page 1997	2021	 2020
Investments: Interest and dividends Realized and unrealized gain (loss)	\$	43,567 173,879	\$ 62,700 351,248
	\$	217,446	\$ 413,948

### 6. Fair value measurement

The classification of the Organization's investment securities at fair value are as follows at December 31, 2021:

	Level 1	Level 2	Level 3	Total
Money market funds Equities Fixed income	\$ 571,001 1,721,152 2,919,200	\$	\$	\$ 571,001 1,721,152 2,919,200
	\$ 5,211,353	\$	\$	\$ 5,211,353

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

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

### NOTES TO FINANCIAL STATEMENTS

December 31, 2021 and 2020

### 7. <u>Commitments</u>

Research grants payable as of December 31, 2021 and 2020 consists of amounts awarded but not paid, of \$169,200 and \$186,150, 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 \$232,000, of which \$50,000 is committed to be funded by affiliates (see Note 10).

### 8. Net assets

Net assets were as follows for the years ended December 31, 2021 and 2020:

		2021			2020	
	Without donor restrictions	With donor restrictions	Total	Without donor restrictions	With donor restrictions	Total
Undesignated	\$ 1,787,258	\$	\$ 1,787,258	\$ 1,482,290	\$	\$ 1,482,290
Specific purpose: Paula & Woody Varner Science and Medical Fund		107,718	107,718		131,434	131,434
Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome		3,806,713	3,806,713		3,666,915	3,666,915
Total net assets	\$ 1,787,258	\$ 3,914,431	\$ 5,701,689	\$ 1,482,290	\$ 3,798,349	\$ 5,280,639

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

	2021		2020	
Satisfaction of purpose restrictions:				
Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome	\$	80,000	\$	50,000
Paula & Woody Varner Science and Medical Fund		50,000		
Science and Medical Fund		1,250		154,850
Drug Development			***************************************	8,942
	\$	131,250	\$	213,792

### NOTES TO FINANCIAL STATEMENTS

December 31, 2021 and 2020

### 9. Major sources of support

For the year ended December 31, 2021, three donors accounted for approximately 35% of total support and revenues. For the year ended December 31, 2020, two donors accounted for approximately 24% of total support and revenues.

### 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 of \$254,594 and \$243,167 for the year ended December 31, 2021 and 2020, respectively. 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 \$50,000 and \$41,580 for the years ended December 31, 2021 and 2020, respectively.

### 11. Subsequent events

The Organization has evaluated subsequent events through April 25, 2022 which is the date the financial statements were available to be issued. The Organization is not aware of any material subsequent events.