

### FINANCIAL STATEMENTS WITH INDEPENDENT AUDITORS' REPORT

YEARS ENDED DECEMBER 31, 2017 AND 2016

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Park 80 West, Plaza Two 250 Pehle Ave., Suite 702 Saddle Brook, NJ 07663-5837 Tel: (201) 403-9750

Fax: (201) 403-9755 www.dorfman.com

### 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 statements of financial position as of December 31, 2017, and the related statements of activities, cash flows, and functional expenses for the year 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 audit. We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free 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, 2017, and the changes in net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

### **Prior Period Financial Statements**

Dorfman Alrans music, LLC

The financial statements of The Barth Syndrome Foundation, Inc., as of December 31, 2016, were audited by other auditors whose report, dated May 2, 2017, expressed an unmodified opinion on those statements.

Saddle Brook, New Jersey

April 23, 2018

### STATEMENTS OF FINANCIAL POSITION

### **ASSETS**

	Decem	nber 3	1,
	2017		2016
Cash Investments Accounts receivable Prepaid expenses	\$ 204,805 3,752,322 2,381 11,947	\$	552,960 3,220,066 7,899 13,011
Total assets	\$ 3,971,455	\$	3,793,936
<u>LIABILITIES AND NET ASSETS</u> Liabilities:			
Accounts payable and accrued expenses Deferred revenue	\$ 70,611 8,750	\$	20,904
Grants payable	 179,423		195,475
Total liabilities	 258,784		216,379
Net assets:			
Unrestricted	1,254,271		918,886
Temporarily restricted	 2,458,400		2,658,671
Total net assets	 3,712,671		3,577,557
Total liabilities and net assets	\$ 3,971,455	\$	3,793,936

### STATEMENTS OF ACTIVITIES

	Year er	Year ended December 31, 2017	1, 2017	Yearen	Year ended December 31, 2016	1, 2016
	Unrestricted	Temporarily restricted	Total	Unrestricted	Temporarily restricted	Total
Support and revenue:		80 700	9 2 2 3 2 3 2	\$ 635 857	303 149	\$ 939 006
Confributions Conference revenue	\$ 641,301	\$ 224,004	000,000			
orant income Investment income	200,581		200,581	92,101		92,101
Total support and revenue	841,882	224,064	1,065,946	815,568	303,149	1,118,717
Net assets released from restrictions	424,335	(424,335)		616,830	(616,830)	
Total support and revenue	1,266,217	(200,271)	1,065,946	1,432,398	(313,681)	1,118,717
Expenses:						
Togram Scriptor. Communication and awareness RSE Conference	136,354		136,354	140,368 164,146		140,368 164,146
Family services Barth Registry and Repository	110,244		110,244 16,374	107,663 20,342		107,663 20,342
Research grants Science and medicine	256,449 215,892		256,449 215,892	410,648 197,295		410,648 197,295
Total program services	735,313		735,313	1,040,462		1,040,462
Supporting services: General and administrative expenses Fundraising expenses	146,747 48,772		146,747 48,772	93,684 80,093		93,684 80,093
Total supporting services	195,519		195,519	173,777		173,777
Total expenses	930,832		930,832	1,214,239		1,214,239
Change in net assets	335,385	(200,271)	135,114	218,159	(313,681)	(95,522)
Net assets, beginning of year	918,886	2,658,671	3,577,557	700,727	2,972,352	3,673,079
Net assets, end of year	\$ 1,254,271	\$ 2,458,400	\$ 3,712,671	\$ 918,886	\$ 2,658,671	\$ 3,577,557

### STATEMENTS OF CASH FLOWS

	Year ended December 31,				
		2017		2016	
Cash flows from operating activities:	•	405 444	•	(05.500)	
Change in net assets  Adjustments to reconcile change in net assets  to net cash provided (used) by operating activities:	\$	135,114	\$	(95,522)	
Contribution of stock		(81,704)		(66,323)	
Realized and unrealized gain on investments		(155,059)		(52,881)	
Changes in operating assets and liabilities: (Increase) decrease in:					
Accounts receivable		5,518		(5,546)	
Prepaid expenses		1,064		3,484	
Increase (decrease) in:					
Accounts payable and accrued expenses		49,707		4,178	
Deferred revenue		8,750			
Grants payable		(16,052)		(28,626)	
Net cash used by operating activities		(52,662)		(241,236)	
Cash flows from investing activities:					
Purchases of investments		(514,673)		(2,618,947)	
Proceeds from sale of investments		219,180		1,820,783	
Net cash used by investing activities		(295,493)	landorine de la constantina della constantina de	(798,164)	
Net decrease in cash		(348,155)		(1,039,400)	
Cash, beginning of year		552,960		1,592,360	
Cash, end of year	\$	204,805	\$	552,960	

THE BARTH SYNDROME FOUNDATION, INC.

## STATEMENTS OF FUNCTIONAL EXPENSES

Years Ended December 31, 2017 and 2016

	<del>-</del>	1	2016	\$ 355,000 47,674		402,674	347,254	67,167	19,981	78,852	62,065	20,347	19,894	4,298	4,949	12,860	7	171	\$ 1,040,462		
	Total		2017	\$ 363,858 53,306		417,164	187,287	69,830	13,500	10,312	1,550	9,392	250	5,270	5,275	7,834	1	7,649	\$ 735,313		
	Science and medicine	O I I O I I I	2016	\$ 165,572 21,314		186,886		2,113	1,308	2,252	483	845		2,029	128	1,251			\$ 197,295		
	Science	201000	2017	\$ 171,799 23,193		194,992				7,567	1,287	1,225		3,100	121		1	7,600	\$ 215,892		
	Decearch grants	ori grants	2016	€			347,254	63,394											\$ 410,648		
	reased	ואבפכמו	2017	€			187,287	69,162											\$ 256,449		
Program services	Registry	DOSITOI Y	2016	↔					18,673	454	21			1,194					\$ 20,342		
Program	Barth Registry			2017	₩				899	13,500	•		161		2,045					\$ 16,374	
		mily services		and Repos	2016	\$ 88,543 12,013		100,556				650	06	2,295		107	3,905			09	\$ 107,663
	- Alienda		2017	\$ 89,885 14,974		104,859				288	22	401			4,565	25		46	\$ 110,244		
		BSF Cornerence	2016	₩				1.660		73,420	61,250	6,849	19,745	475		747			\$ 164,146		
	L	באר ככ	2017	<del>69</del>															s		
	ation and	Suess	2016	\$ 100,885 14,347		115,232				2.076	221	10.358	149	493	916	10,862		61	\$ 140,368		
	Communication and	awareness	2017	\$ 102,174 15,139		117,313				2.457	206	7.605	250	125	583	7,809			\$ 136,354		
				Salaries Pavroll taxes and benefits	toto coirolos lotoT	related expenses	Grant expense	Therapy development	Professional fees	Transportation	Meals	Office expense	Andio visual	Diles and fees	Telephone	Printing and publications	Insurance	Training and education	Total expenses		

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

THE BARTH SYNDROME FOUNDATION, INC.

# STATEMENTS OF FUNCTIONAL EXPENSES

Years Ended December 31, 2017 and 2016

						Supporting services	g serv	ices					Total	Total program and	n and
		Management and general	t and	general		Fundraising	aising			Total	tal		oddns	supporting services	rvices
		2017		2016		2017		2016		2017		2016	2017	-	2016
Salaries Payroll taxes and benefits	€	23,235	↔	22,703 3,264	↔	36,436 4,962	€	42,233 5,978	€	59,671 8,406	₩	64,936 9,242	\$ 423,529 61,712	6 2	419,936 56,916
Total salaries and related expenses		26,679		25,967		41,398		48,211		68,077		74,178	485,241	<del>-</del>	476,852
Grant expense Therapy development													187,287 69,830	20	347,254 67,167
Professional fees		80,086		34,654				20,000		980,08		54,654	93,586	ပ	74,635
Transportation		6.217		(337)		136		3,246		6,353		2,909	16,665	2	81,761
Meals		963		, 20 20		27		418		066		438	2,540	0	62,503
Office expense		21,014		22,055		2,228		3,746		23,242		25,801	32,634	4	46,148
Audio visual		-				250				250			200	0	19,894
Dues and fees		6,848		5,604		1,900		2,589		8,748		8,193	14,018	80	12,491
Telephone		890		1,603		360		473		1,250		2,076	6,525	2	7,025
Printing and publications		16		12		2,473		1,410		2,489		1,422	10,323	8	14,282
Insurance		4,034		4,106						4,034		4,106	4,034	4	4,106
Training and education													7,649	၂ ၀	121
Total expenses	S	\$ 146,747	ь	\$ 93,684	s	48,772	છ	80,093	8	195,519	S	\$ 173,777	\$ 930,832	 N	\$ 1,214,239

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

### NOTES TO FINANCIAL STATEMENTS

December 31, 2017 and 2016

### 1. Summary of significant accounting policies

This summary of significant accounting policies of The Barth Syndrome Foundation, Inc. (the Foundation) is presented to assist in understanding the Foundation's financial statements. The financial statements and notes are representations of the Foundation's management, which is responsible for their integrity and objectivity. These accounting policies conform to accounting principles generally accepted in the United States of America as promulgated in *FASB Accounting Standards Codification* (the Codification), and have been consistently applied in the preparation of the financial statements.

### Objectives of the Foundation

The Foundation 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.

### Basis of presentation

The accompanying financial statements have been prepared on the accrual basis of accounting in accordance with generally accepted accounting principles. Net assets, revenues, gains and losses are classified based on the existence or absence of donor-imposed restrictions. Accordingly, net assets of the Foundation and changes therein are classified and reported as follows:

<u>Unrestricted net assets</u> – Net assets that are not subject to donor-imposed stipulations.

<u>Temporarily restricted net assets</u> – Net assets subject to donor-imposed stipulations that may or will be met, either by actions of the Foundation and/or the passage of time. When a restriction expires, temporarily restricted net assets are reclassified to unrestricted net assets and reported in the statement of activities as net assets released from restrictions.

<u>Permanently restricted net assets</u> – Net assets subject to donor-imposed stipulations that they be maintained permanently by the Foundation. Generally, the donors of these assets permit the Foundation to use all or part of any income earned on any related investments for general or specific purposes. There were no permanently restricted net assets as of December 31, 2017 or 2016.

### Cash

Cash includes cash in bank deposit accounts. Money market funds held as a portion of the investment portfolio are not considered cash equivalents for the purposes of the statement of cash flows. Cash in bank deposit accounts, at times, may exceed federally insured limits (FDIC). The Foundation has not experienced any losses in such accounts and believes it is not exposed to any significant credit risk on cash or cash equivalents.

### <u>Investments</u>

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. Investments that are donated are measured at the fair market value at the date of acquisition. Unrealized gains and losses are reported in the changes in net assets on the statement of activities based on the existence or absence of donor imposed restrictions.

### NOTES TO FINANCIAL STATEMENTS

December 31, 2017 and 2016

### 1. Summary of significant accounting policies (continued)

### Allowance for doubtful accounts

The Foundation provides for losses on receivables using the allowance method to account for uncollectible receivables. The allowance is based on experience and knowledge about the donors or service recipients. The Foundation determined that no allowance for doubtful accounts was necessary at December 31, 2017 and 2016.

### Deferred income

Payments received for special events to be held after December 31, 2017 are recorded as deferred income and recognized as revenue when the events occur and the funds are earned.

### Grant payable

Grants are recognized at the date of a formal, unconditional promise to give commitment. Grants that are expected to be paid in future years are recorded at present value of expected future payments.

### Contributions

Contributions, including unconditional pledges, are recorded as made. All contributions are available for unrestricted use unless specifically restricted by the donor. Contributions are recognized when the conditions on which they depend are substantially met. Donor-restricted contributions are reported as increases in temporarily or permanently restricted net assets depending on the nature of the restrictions. When a restriction expires, temporarily restricted net assets are reclassified to unrestricted net assets.

### **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.

### NOTES TO FINANCIAL STATEMENTS

December 31, 2017 and 2016

### 1. <u>Summary of significant accounting policies</u> (continued)

### 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. Accordingly, certain expenses have been allocated among the programs and supporting services based on management's best estimates.

### Income taxes

The Foundation is a tax-exempt organization as defined by Section 501(c)(3) of the Internal Revenue Code. Accordingly, no provision has been made for income taxes.

### Uncertain tax positions

As of December 31, 2017, management believes that based on evaluation of the Foundation's tax positions that any liability as a result of uncertain tax positions would not be material. Management evaluates expiring statutes of limitations, changes in tax law, and new authoritative rulings to assist in evaluating the Foundation's tax positions. Accrued interest and penalties associated with uncertain tax positions, if any, would be recognized as part of the income tax provision. Income tax returns are filed in the U.S. federal jurisdiction and state jurisdictions. U.S. federal and state income tax returns prior to fiscal year 2014 are closed.

### Reclassifications

Certain amounts from the 2016 financial statements have been reclassified to conform to the 2017 presentation.

### 2. Risks and uncertainties

Financial instruments that potentially subject the Foundation to concentrations of credit risk consist principally of cash, investments, and accounts receivable. The Foundation maintains its cash in demand deposit accounts, the balances of which, at times, may exceed federally insured limits. Exposure to credit risk is reduced by placing such deposits in high quality financial institutions. Investments 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 values of investment securities will occur in the near term and those changes could materially affect the amounts reported in the statement of financial position. Concentration of credit risk with respect to accounts receivable is reduced due to the fact that the receivables are from prominent individuals and/or corporations.

### NOTES TO FINANCIAL STATEMENTS

December 31, 2017 and 2016

### 3. Fair value measurements

The Codification 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 measurements) 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 Foundation 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 Foundation. The Foundation 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 Foundation's perceived risk of that investment.

Investment securities are carried at fair value and consist of the following at December 31:

	20	17	2016			
	Cost	Fair value	Cost	Fair value		
Money market funds Equities Fixed income	\$ 736,664 758,844 <u>2,093,939</u>	\$ 736,664 935,046 2,080,612	\$ 635,684 673,330 1,877,552	\$ 635,684 732,884 1,851,498		
	\$3,589,447	\$3,752,322	\$3,186,566	\$3,220,066		

### NOTES TO FINANCIAL STATEMENTS

December 31, 2017 and 2016

### 3. <u>Fair value measurements</u> (continued)

The classification of The Foundation's investment securities at fair value are as follows at December 31:

		2	017	
	Level 1	Level 2	Level 3	Total
Money market funds Equities Fixed income	\$ 736,664 935,046 2,080,612	\$	\$	\$ 736,664 935,046 2,080,612
	\$3,752,322	\$	\$	\$3,752,322
		2	016	
	Level 1	Level 2	Level 3	Total
Money market funds Equities Fixed income	\$ 635,684 732,884 1,851,498	\$	\$	\$ 635,684 732,884 1,851,498
	\$3,220,066	\$	\$	\$3,220,066

The following schedule summarizes the investment return for the years ended December 31, 2017 and 2016. All investment earnings are available for the unrestricted use of the Foundation.

		2017	 2016
Dividend and interest income Realized and unrealized gains on investments Investment fees	\$	64,702 155,059 (19,180)	\$ 56,492 52,881 (17,272)
	<u>\$</u>	200,581	\$ 92,101

### NOTES TO FINANCIAL STATEMENTS

December 31, 2017 and 2016

### 4. Program grants

The following grants were authorized and payable by the Foundation in support of Barth Syndrome research as of and for the years ended December 31:

		20	17			2016			
	aı	Grant uthorized		Payable	a	Grant uthorized	F	Payable	
Grantee:	_			== 000	•		•	00.047	
University of Florida University of Bordeaux	\$	100,000 50,000	\$	75,000	\$		\$	33,917	
Washington University, MO		71,000		46,090		50,000		2,904	
University of Miami		50,000		25,000					
University of Texas				33,333		100,000		66,667	
University of Tuebingen						50,000		25,000	
University of Waterloo						50,000		21,153	
Wayne State University						50,000			
Emory University						50,000			
University of Pittsburgh								33,334	
NYU School of Medicine								12,500	
	\$	271,000	<u>\$</u>	179,423	\$	350,000	\$	195,475	

The following summarizes grant activity for the years ended December 31:

	2017	2016
Grants payable, beginning of year	\$ 195,475	\$ 224,101
Grants awarded Payments made	271,000 (209,148)	350,000 (349,780)
Grants write-offs Grants paid by BSF affiliates	(2,904) (75,000)	(28,846)
Grants payable, end of the year	\$ 179,423	\$ 195,475

Future minimum payments under these grants are as follows for years ending December 31:

2018	\$ 145,743
2019	 33,680
	\$ 179,423

### NOTES TO FINANCIAL STATEMENTS

December 31, 2017 and 2016

### 5. Temporarily restricted net assets

Temporarily restricted net assets are available as follows at December 31:

	2017	2016
Paula & Woody Varner Science and Medical Fund Science and Medical Fund Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome	\$ 148,469	\$ 149,362 204,904
	2,309,931	2,304,405
	\$ 2,458,400	\$ 2,658,671

Net assets were released from restrictions as follows during the year ended December 31:

	2017		2016	
Paula & Woody Varner Science and Medical Fund Science and Medical Fund	\$	21,324 209,173	\$	6,835 474,466
Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome		193,838	-	135,529
	\$	424,335	\$	616,830

### 6. Major sources of support

For the year ended December 31, 2017, two donors accounted for approximately 27% of total support and revenues. For the year ended December 31, 2016, two donors accounted for approximately 26% of total support and revenues.

### 7. Subsequent events

Subsequent events have been evaluated through April 23, 2018, which is the date the financial statements were available to be issued.