



Barth Syndrome
Foundation

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

YEARS ENDED DECEMBER 31, 2024 AND 2023

THE BARTH SYNDROME FOUNDATION, INC.

Years Ended December 31, 2024 and 2023

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INDEPENDENT AUDITORS' REPORT

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

Opinion

We have audited the accompanying financial statements of The Barth Syndrome Foundation, Inc. (a nonprofit organization), which comprise the balance sheets as of December 31, 2024 and 2023, 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 The Barth Syndrome Foundation, Inc. as of December 31, 2024 and 2023, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

Basis for Opinion

We conducted our audits 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 The Barth Syndrome Foundation, Inc. and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audits. 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 The 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 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 The 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 The 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 Abrams Music, LLC

Saddle Brook, New Jersey

April 15, 2025

THE BARTH SYNDROME FOUNDATION, INC.

BALANCE SHEETS

ASSETS

	December 31,	
	2024	2023
Cash	\$ 720,374	\$ 460,296
Investments	4,885,260	4,982,899
Contributions receivable	100	
Prepaid expenses	34,906	48,135
Total assets	<u>\$ 5,640,640</u>	<u>\$ 5,491,330</u>

LIABILITIES AND NET ASSETS

Liabilities:		
Accounts payable and accrued expenses	\$ 163,444	\$ 94,143
Deferred revenue		27,183
Grants payable	256,910	84,650
Total liabilities	<u>420,354</u>	<u>205,976</u>
Net assets:		
Without donor restrictions	1,121,367	1,322,181
With donor restrictions	4,098,919	3,963,173
Total net assets	<u>5,220,286</u>	<u>5,285,354</u>
Total liabilities and net assets	<u>\$ 5,640,640</u>	<u>\$ 5,491,330</u>

THE BARTH SYNDROME FOUNDATION, INC.

STATEMENTS OF ACTIVITIES

	Year ended December 31, 2024			Year ended December 31, 2023		
	Without donor restrictions	With donor restrictions	Total	Without donor restrictions	With donor restrictions	Total
Operating activities:						
Support and revenue:						
Contributions of cash and other financial assets						
Affiliates' donation for research grants	\$ 1,252,134	\$ 124,108	\$ 1,376,242	\$ 951,519	\$ 155,089	\$ 1,106,608
Contributions of nonfinancial assets	44,937	190,000	190,000		76,788	76,788
Grant income	8,500		44,937	95,875		95,875
Other revenue	9,362	100,000	108,500	95,000		95,000
Interest and dividend income	141,114		9,362			
			141,114	131,350		131,350
Total support and revenue	1,456,047	414,108	1,870,155	1,273,744	231,877	1,505,621
Net assets released from restrictions	278,362	(278,362)		283,298	(283,298)	
Total support and revenue	1,734,409	135,746	1,870,155	1,557,042	(51,421)	1,505,621
Expenses:						
Program services:						
Communication and awareness	130,319		130,319	134,459		134,459
BSF Regional Meetings	377,289		377,289	16,829		16,829
Family services	132,306		132,306	128,968		128,968
Advocacy and awareness	273,870		273,870	231,852		231,852
Barth registry and repository	43,118		43,118	12,376		12,376
Research grants	322,746		322,746	333,038		333,038
Science and medicine	496,586		496,586	330,860		330,860
Total program services	1,776,234		1,776,234	1,188,382		1,188,382
Supporting services:						
Management and general	183,908		183,908	208,812		208,812
Fundraising	178,686		178,686	170,398		170,398
Total supporting services	362,594		362,594	379,210		379,210
Total expenses	2,138,828		2,138,828	1,567,592		1,567,592
Change in net assets from operations	(404,419)	135,746	(268,673)	(10,550)	(51,421)	(61,971)
Nonoperating activities:						
Realized and unrealized gains on investments, net						
Total nonoperating activities	203,605		203,605	333,995		333,995
Change in net assets	(200,814)	135,746	(65,068)	323,445	(51,421)	272,024
Net assets, beginning of year	1,322,181	3,963,173	5,285,354	998,736	4,014,594	5,013,330
Net assets, end of year	\$ 1,121,367	\$ 4,098,919	\$ 5,220,286	\$ 1,322,181	\$ 3,963,173	\$ 5,285,354

See notes to financial statements.

THE BARTH SYNDROME FOUNDATION, INC.

STATEMENTS OF CASH FLOWS

	Year ended December 31,	
	2024	2023
Cash flows from operating activities:		
Change in net assets	\$ (65,068)	\$ 272,024
Adjustments to reconcile change in net assets to net cash provided (used) by operating activities:		
Contribution of stock	(7,602)	(27,492)
Realized and unrealized gains on investments, net	(203,605)	(333,995)
Changes in operating assets and liabilities:		
(Increase) decrease in:		
Contributions receivable	(100)	103,000
Prepaid expenses	13,229	(5,680)
Increase (decrease) in:		
Accounts payable and accrued expenses	69,301	5,705
Deferred revenue	(27,183)	
Grants payable	172,260	(158,399)
Net cash used by operating activities	(48,768)	(144,837)
Cash flows from investing activities:		
Purchases of investments	(666,556)	(140,639)
Proceeds from sale of investments	975,402	59,259
Net cash provided (used) by investing activities	308,846	(81,380)
Net change in cash	260,078	(226,217)
Cash, beginning of year	460,296	686,513
Cash, end of year	\$ 720,374	\$ 460,296

See notes to financial statements.

THE BARTH SYNDROME FOUNDATION, INC.

STATEMENTS OF FUNCTIONAL EXPENSES

Years Ended December 31, 2024 and 2023

	Communication and awareness		BSF Regional Meetings		Family services		Advocacy and awareness		Barth registry and repository		Research grants		Science and medicine		Total	
	2024	2023	2024	2023	2024	2023	2024	2023	2024	2023	2024	2023	2024	2023	2024	2023
Salaries	\$ 53,189	\$ 62,965	\$	\$	\$ 78,006	\$ 77,513	\$ 115,579	\$ 103,263	\$ 8,555	\$	\$	\$	\$ 310,568	\$ 214,796	\$ 565,897	\$ 458,537
Payroll taxes and benefits	6,543	9,878			16,641	17,277	18,613	19,504	896				36,120	32,730	78,813	79,399
Total salaries and related expenses	59,732	72,843			94,647	94,790	134,192	122,767	9,451				346,688	247,526	644,710	537,926
Research grant expense																
Grant expense											322,746	333,038			322,746	333,038
Research grants funded by affiliates																
Professional fees	52,250	39,145	62,000	6,000	26,196	6,336	50,000	10,000	32,794	11,500			16,803	63,672	240,043	130,317
Office and other expenses	6,909	6,079	32,250	585	9,360		3,370	396	128	131			9,070	6,033	61,087	19,560
In-kind professional services								95,875								95,875
Travel								2,814								42,542
Printing and publications	7,428	16,392	192,197	10,244	1,194	22,288	84,218		745	745			9,667	7,196	287,276	42,542
Dues and fees			13,554		403	2,560							3,720		20,982	18,952
Insurance						700								6,433	4,968	7,878
Telephone					506	695									506	695
Training and education						999										999
Public relations							2,090						638		638	
Audio visual	4,000		63,151			600									69,241	600
Event cost			14,137												14,137	
Total expenses	\$ 130,319	\$ 134,459	\$ 377,289	\$ 16,829	\$ 132,306	\$ 128,968	\$ 273,870	\$ 231,852	\$ 43,118	\$ 12,376	\$ 322,746	\$ 333,038	\$ 496,586	\$ 330,860	\$ 1,776,234	\$ 1,188,382

See notes to financial statements.

THE BARTH SYNDROME FOUNDATION, INC.

STATEMENTS OF FUNCTIONAL EXPENSES

Years Ended December 31, 2024 and 2023

	Management and general		Supporting services			Total		Total program and	
	2024	2023	2024	Fundraising	2023	2024	2023	2024	2023
Salaries	\$ 43,690	\$ 48,390	\$ 128,008	\$ 113,671	\$ 162,061	\$ 171,698	\$ 162,061	\$ 737,595	\$ 620,598
Payroll taxes and benefits	5,754	7,807	18,691	18,881	26,688	24,445	26,688	103,258	106,077
Total salaries and related expenses	49,444	56,197	146,699	132,552	188,749	196,143	188,749	840,853	726,675
Research grant expense									
Grant expenses								322,746	333,038
Professional fees	79,452	92,138	5,200	5,400	97,538	84,652	97,538	110,000	227,855
Office and other expenses	39,466	50,142	22,484	21,100	71,242	61,950	71,242	324,695	90,802
In-kind professional services								123,037	95,875
Travel		84		1,699	1,783		1,783	287,276	44,325
Printing and publications		289		7,269	7,558		7,558	25,047	26,510
Dues and fees	6,868	3,840	4,065	1,200	5,040	4,065	5,040	11,736	12,918
Insurance	7,724	4,379			4,379	7,724	4,379	7,724	4,979
Telephone	954	1,029			1,029	954	1,029	1,460	1,724
Training and education				646	646		646		646
Public relations		714	38	212	926	38	926	676	926
Audio visual			200	320	320	200	320	69,441	1,319
Event cost								14,137	
Total expenses	\$ 183,908	\$ 208,812	\$ 178,686	\$ 170,398	\$ 379,210	\$ 362,594	\$ 379,210	\$ 2,138,828	\$ 1,567,592

See notes to financial statements.

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2024 and 2023

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, treatments, 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 and development initiatives, among others.

2. Summary of significant accounting policies

Basis of presentation

The financial statements of the Organization have been prepared on the accrual basis of accounting 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 dividend income 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 in conformity with generally accepted accounting principles requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the date of the financial statements and the reported amount of revenues and expenses during the reporting period. Accordingly, actual results could differ from those estimates.

Cash

Cash consist of demand deposit accounts. 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, 2024 and 2023

2. Summary of significant accounting policies (continued)

Investments

Investments are recorded at cost, or if donated, at fair value on the date of donation. Thereafter, investments are reported at their fair values on the balance sheet. Unrealized gains and losses are included in the changes in net assets without donor restriction for the gains and losses that are unrestricted, and in the changes in net assets with donor restriction for the gains and losses that are restricted for the support of certain programs. Investment fees are netted against the investment income.

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.

The following is a description of the valuation methodologies used for assets measured at fair value.

Money market funds, fixed-income securities and equities - Valued at the closing price reported on the active market on which the individual securities are traded.

Convertible Promissory Note - There are no observable inputs and certain of the underlying investments are not publicly traded and there is no secondary market for such funds. These funds are valued by the managers of the underlying funds at the NAV of shares held by the Organization at year end or other pricing methodologies.

The methods described above may produce a fair value calculation that may not be indicative of net realizable value or reflective of future fair values. Furthermore, while the Organization believes its valuation methods are appropriate and consistent with other market participants, the use of different methodologies or assumptions to determine the fair value of certain financial instruments could result in a different fair value measurement at the reporting date.

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2024 and 2023

2. Summary of significant accounting policies (continued)

Contributions 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 contributions receivable. The allowance for doubtful accounts is based on prior years' experience and management's analysis of possible bad debt. As of December 31, 2024, and 2023, the Organization determined that an allowance was not necessary.

Revenue recognition

The Organization recognizes contributions when cash, investments 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 statement 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 event 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.

Contribution of nonfinancial assets

The Organization receives donated services from specialized providers and other volunteers that create or enhance non-financial assets and allow the Organization to fulfill its mission. Donated specialized services have been recognized on the accompanying financial statements at their fair value at the date of donation and are reported as support without donor restrictions unless explicit donor stipulations specify how donated assets must be used. These donated services require professional skills, and would typically need to be purchased if not provided by donation. Such specialized donated services amounted to \$44,937 and \$95,875 as of December 31, 2024 and 2023, respectively. (See Note 9).

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.

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2024 and 2023

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 is also exempt from New York State income taxes. The Organization has procedures 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 2023 financial statements have been reclassified to conform to the 2024 presentation.

3. Risks and uncertainties

Concentrations of credit risk

Financial instruments that potentially subject the Organization to concentrations of credit risk consist principally of cash, investments and contributions receivable. The Organization maintains its cash in bank deposit accounts, the balances of which, at times, may exceed federally insured limits. Investments are exposed to various risks. Due to the level of risk associated with certain investments, 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 contributions receivable are limited due to the short payment terms the Organization has with its creditors. The Organization has not experienced, nor does it anticipate, any losses with respect to such accounts.

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2024 and 2023

4. Availability and liquidity

The following represents the Organization's financial assets at December 31, 2024:

Financial assets at year-end:

Cash	\$ 720,374
Investments	4,885,260
Contributions receivable	100
Total financial assets	<u>5,605,734</u>

Less amounts not available to be used within one year:

Net assets with donor restrictions	4,098,919
Less net assets with purpose restrictions to be met in less than a year	<u>(338,179)</u>
Financial assets available to meet cash needs for general expenditures within one year	<u>\$ 1,844,994</u>

The Organization's goal is generally to maintain financial assets to meet 90 days of operating expenses, net of in-kind (approximately \$440,000). 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>2024</u>	<u>2023</u>
Cash and money market	\$ 483,147	\$ 810,405
Equities	1,748,677	1,660,527
Fixed income	2,628,436	2,486,967
Convertible Promissory Note	<u>25,000</u>	<u>25,000</u>
	<u>\$ 4,885,260</u>	<u>\$ 4,982,899</u>

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

	<u>2024</u>	<u>2023</u>
Investments:		
Interest and dividend income	\$ 141,114	\$ 131,350
Realized and unrealized gains, net	<u>203,605</u>	<u>333,995</u>
	<u>\$ 344,719</u>	<u>\$ 465,345</u>

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2024 and 2023

6. Fair value measurement

The classifications of the Organization's investment securities at fair value are as follows at December 31, 2024:

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Money market funds (at cost)	\$	\$	\$	\$ 483,147
Equities	1,748,677			1,748,677
Fixed income		2,628,436		2,628,436
Convertible promissory note			25,000	25,000
	<u>\$ 1,748,677</u>	<u>\$ 2,628,436</u>	<u>\$ 25,000</u>	<u>\$ 4,885,260</u>

The classifications of the Organization's investment securities at fair value are as follows at December 31, 2023:

	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	<u>Total</u>
Money market funds (at cost)	\$	\$	\$	\$ 810,405
Equities	1,660,527			1,660,527
Fixed income		2,486,967		2,486,967
Convertible promissory note			25,000	25,000
	<u>\$ 1,660,527</u>	<u>\$ 2,486,967</u>	<u>\$ 25,000</u>	<u>\$ 4,982,899</u>

7. Grants payable

Grants payable consist of research grants payable and a commitment to support the establishment of a Dutch center of expertise for Barth syndrome in the Netherlands.

Research grants payable as of December 31, 2024 and 2023 consists of amounts awarded but not paid, of \$146,910 and \$84,650, respectively. All are due to be paid within the next 12 months.

During September 2024, the Organization made a commitment of \$110,000 for funding of the Dutch center of expertise for Barth syndrome.

The Organization is committed to research grants awarded subsequent to year-end, up to the amount of \$260,000, of which \$125,000 is committed to be funded by affiliates (see Note 12).

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2024 and 2023

8. Net assets

Net assets were as follows for the years ended December 31, 2024 and 2023:

	2024			2023		
	Without donor restrictions	With donor restrictions	Total	Without donor restrictions	With donor restrictions	Total
Undesignated	\$ 1,121,367	\$	\$ 1,121,367	\$ 1,322,181	\$	\$ 1,322,181
Specific purpose:						
Restricted for Arrhythmia		88,923	88,923		10,150	10,150
Science and Medicine		161,718	161,718		157,192	157,192
Family Services Fund		12,457	12,457		30,684	30,684
Research grants		6,250	6,250			
Chan Zuckerberg Initiative - Rare as One Cycle 3		90,549	90,549			
Therapy Fund		3,739,022	3,739,022		3,765,147	3,765,147
Total net assets	<u>\$ 1,121,367</u>	<u>\$ 4,098,919</u>	<u>\$ 5,220,286</u>	<u>\$ 1,322,181</u>	<u>\$3,963,173</u>	<u>\$ 5,285,354</u>

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

	2024	2023
Satisfaction of purpose restrictions:		
Therapy fund	\$ 113,819	\$ 173,266
Research grants	83,750	76,788
Family service fund	37,836	
Restricted for Arrhythmia	21,227	33,244
Science and medicine	12,279	
Chan Zuckerberg Initiative – Rare as One Cycle 3	9,451	
	<u>\$ 278,362</u>	<u>\$ 283,298</u>

THE BARTH SYNDROME FOUNDATION, INC.

NOTES TO FINANCIAL STATEMENTS

December 31, 2024 and 2023

9. Contributed nonfinancial assets

Donated services have been recognized as support and revenue; and, related expense on the accompanying financial statements. Donated services require professional skills, and would typically be purchased if not provided by donation, and are valued based on current rates for similar services. These are reported as part of in-kind professional services in the statement of functional expenses.

	2024			
	Program services	Management and general	Fundraising	Total
Donated services – BSF Regional meetings	\$ 44,937	\$	\$	\$ 44,937
	<u>\$ 44,937</u>	<u>\$</u>	<u>\$</u>	<u>\$ 44,937</u>
	2023			
	Program services	Management and general	Fundraising	Total
Donated services - advocacy and awareness	\$ 95,875	\$	\$	\$ 95,875
	<u>\$ 95,875</u>	<u>\$</u>	<u>\$</u>	<u>\$ 95,875</u>

10. Conditional contributions

During October 2024, the Organization and the Silicon Valley Community Foundation entered into a contribution agreement for the Chan Zuckerberg Initiative - Rare as One Cycle 3 RFA project with a potential maximum contribution of \$800,000. The Organization recognized \$100,000 of this contribution during the year ended December 31, 2024 with payments to be received over four years. The remaining \$700,000 of the contribution is conditional to the performance of certain obligations that the Organization has to meet.

11. Major sources of support

Two donors accounted for approximately 23% and 27% of total support and revenues for the years ended December 31, 2024 and 2023, respectively.

THE BARTH SYNDROME FOUNDATION, INC.

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12. 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 \$322,746 and \$333,038 for the years ended December 31, 2024 and 2023, respectively. From time to time, the Organization receives assistance from affiliated entities to cover portions of the research grant awards. These amounts have been recorded on the statement of activities as affiliate donation for research grant. The affiliates' funding for the research grant were \$190,000 and \$76,788 for the years ended December 31, 2024 and 2023, respectively.

13. Retirement plans

The Organization has a 401(k) Plan covering all eligible employees upon hire. The Organization contributions are made on a per-pay period basis based on the amount of the employee's pre-tax and/or Roth contributions. The employer match is 100% of employee deferrals up to the first 3% of compensation for the period and 50% of the next 2% of compensation for the year, and is immediately vested. Contributions during the years ended December 31, 2024 and 2023 amounted to \$23,308 and \$22,411, respectively.

14. Subsequent events

The Organization has evaluated subsequent events through April 15, 2025 which is the date the financial statements were available to be issued. The Organization is not aware of any material subsequent events.