

### FINANCIAL STATEMENTS WITH INDEPENDENT AUDITORS' REPORT

YEARS ENDED DECEMBER 31, 2022 AND 2021

### CONTENTS

|                                   | Page   |
|-----------------------------------|--------|
| Independent Auditors' Report      | 1 - 2  |
| Financial Statements:             |        |
| Balance Sheets                    | 3      |
| Statements of Activities          | 4      |
| Statements of Cash Flows          | 5      |
| Statements of Functional Expenses | 6 - 7  |
| Notes to Financial Statements     | 8 - 14 |



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.
Larchmont, New York

### Opinion

We have audited the accompanying financial statements of The Barth Syndrome Foundation, Inc., which comprise the balance sheets as of December 31, 2022 and 2021, 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, 2022 and 2021, 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 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, 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 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 Ahams music, LLC Saddle Brook, New Jersey

April 27, 2023

### **BALANCE SHEETS**

### <u>ASSETS</u>

|  | Decem  | nber 31,                                    |
|--|--|---|
|  | 2022   | 2021  |
| Cash<br>Investments<br>Grants receivable<br>Prepaid expenses                                   | \$ 686,513<br>4,540,032<br>103,000<br>42,455 | \$ 697,821<br>5,211,353<br>30,000<br>47,767 |
| Total assets   | \$ 5,372,000                                 | \$ 5,986,941                                |
| LIABILITIES AND NET ASSETS Liabilities: Accounts payable and accrued expenses Deferred revenue | <u>S</u><br>\$ 88,438<br>27,183              | \$ 88,869<br>27,183                         |
| Research grants payable  | 243,049                                      | 169,200                                     |
| Total liabilities  | 358,670                                      | 285,252                                     |
| Net assets: Without donor restrictions With donor restrictions                                 | 998,736<br>4,014,594                         | 1,787,258<br>3,914,431                      |
| Total net assets   | 5,013,330                                    | 5,701,689                                   |
| Total liabilities and net assets   | \$ 5,372,000                                 | \$ 5,986,941                                |

### STATEMENTS OF ACTIVITIES

Operating activities:
Support and revenue:
Contributions of cash and other financial assets
Contributions of nonfinancial assets

Net assets released from restrictions

Total support and revenue

Program services:

Expenses:

Total support and revenue

Other grant income Interest and dividends

Other income

| , 2021                       | Total                      | \$ 1,151,518 | 60,000<br>43,567<br>2,818  | 1,257,903 |           | 1,257,903 | 132,154 | 96,953            | 95,538  | 204 594 | 193,353 | 741,408   | 195,733<br>73,591 |         | 269,324 | 1,010,732 | 247,171 | 010 | 1/3,8/9   | 173,879   | 421,050<br>5,280,639   | \$ 5,701,689 |
|------------------------------|----------------------------|--------------|----------------------------|-----------|-----------|-----------|---------|-------------------|---------|---------|---------|-----------|-------------------|---------|---------|-----------|---------|-----|-----------|-----------|------------------------|--------------|
| Year ended December 31, 2021 | restrictions               | \$ 247,332   |                            | 247,332   | (131,250) | 116,082   |         |                   |         |         |         |           |                   |         |         |           | 116,082 |     |           |           | 116,082<br>3,798,349   | \$ 3,914,431 |
| Year e                       | restrictions               | \$ 904,186   | 60,000<br>43,567<br>2,818  | 1,010,571 | 131,250   | 1,141,821 | 132,154 | 96,953            | 95,538  | 18,816  | 193,353 | 741,408   | 195,733           | 180,07  | 269,324 | 1,010,732 | 131,089 |     | 173,879   | 173,879   | 304,968<br>1,482,290   | \$ 1,787,258 |
| 1, 2022                      | Total                      | \$ 1,327,138 | 70,000                     | 1,546,178 |           | 1,546,178 | 90,746  | 111,467           | 113,967 | 18,141  | 327,973 | 1,030,989 | 252,373           | 161,416 | 413,789 | 1,444,778 | 101,400 |     | (789,759) | (789,759) | (688,359)<br>5,701,689 | \$ 5,013,330 |
| Year ended December 31, 2022 | With donor restrictions    | \$ 339,169   |                            | 339,169   | (239,006) | 100,163   |         |                   |         |         |         |           |                   |         |         |           | 100,163 |     |           |           | 100,163<br>3,914,431   | \$ 4,014,594 |
| Yeare                        | Without donor restrictions | 696'286 \$   | 70,451<br>70,000<br>71,589 | 1,207,009 | 239,006   | 1,446,015 | 90,746  | 65,922<br>111,467 | 113,967 | 18,141  | 302,773 | 1,030,989 | 252,373           | 161,416 | 413,789 | 1,444,778 | 1,237   |     | (789,759) | (789,759) | (788,522)<br>1,787,258 | \$ 998,736   |

Management and general expenses

Supporting services:

Total program services

Fundraising expenses

Total supporting services

Total expenses

Change in net assets from operations

Total nonoperating activities

Nonoperating activities: Investment return, net Change in net assets Net assets, beginning of year

Net assets, end of year

Communication and awareness BSF Regional Meetings Family services Advocacy and awareness Barth registry and repository Research grants Science and medicine The accompanying notes are an integral part of these financial statements.

### STATEMENTS OF CASH FLOWS

|   |                      | Year ended I        | Decem | nber 31,              |
|---|----------------------|---------------------|-------|-----------------------|
|   |                      | 2022                |       | 2021                  |
| Cash flows from operating activities: Change in net assets Adjustments to reconcile change in net assets  | \$                   | (688,359)           | \$    | 421,050               |
| to net cash provided (used) by operating activities:  Contribution of stock  Realized and unrealized (gain) loss on investments  Changes in operating assets and liabilities: |                      | (22,011)<br>789,759 |       | (32,169)<br>(173,879) |
| (Increase) decrease in: Grants receivable Prepaid expenses  |                      | (73,000)<br>5,312   |       | (10,000)<br>12,410    |
| Increase (decrease) in: Accounts payable and accrued expenses Research grants payable   | <b>6</b> gencyamosya | (431)<br>73,849     |       | 29,642<br>(16,950)    |
| Net cash provided by operating activities   |                      | 85,119              |       | 230,104               |
| Cash flows from investing activities: Purchases of investments Proceeds from sale of investments  |                      | (169,661)<br>73,234 | -     | (228,261)<br>384,693  |
| Net cash provided (used) by investing activities  |                      | (96,427)            |       | 156,432               |
| Net increase (decrease) in cash   |                      | (11,308)            |       | 386,536               |
| Cash, beginning of year   |                      | 697,821             |       | 311,285               |
| Cash, end of year   | \$                   | 686,513             | \$    | 697,821               |

THE BARTH SYNDROME FOUNDATION, INC.

STATEMENTS OF FUNCTIONAL EXPENSES

| 2021    |
|---------|
| and     |
| 2022    |
| 31,     |
| embe    |
| Dec     |
| nded    |
| Years E |
|         |

|              |                   | - 1                   | 1707 | \$ 352,401<br>53,853                   | 406,254                             | 254,594 | (20'000)               | 81,494                               | 19,583            |                | 1,491                         | 18 121         | 101                       | 4,703         | 400        |              | 2.467     | 1 275     | 926              | 224                    | \$ 741,408           |
|--------------|-------------------|-----------------------|------|--|-------------------------------------|---------|------------------------|--------------------------------------|-------------------|----------------|-------------------------------|----------------|---------------------------|---------------|------------|--------------|-----------|-----------|------------------|------------------------|----------------------|
|              |                   | Total                 | 2022 | \$ 404,004                             | 480,787                             | 352,773 | (20,000)               | 103,453                              | 15,090            | 37,474         | 55,099                        | 23.70R         | 0000                      | 4,813         | 020,1      | 4,024        | 2 148     | i         |                  |                        | \$ 1,030,989         |
|              |                   | d medicine            | 2021 | \$ 147,752                             | 166,864                             |         |                        | 20,106                               | 1.080             | -              | 1 491                         | :<br>:         | 4 4 4                     | 3,812         |            |              |           |           |                  |                        | \$ 193,353           |
|              |                   | Science and medicine  | 2022 | \$ 187,332<br>31,772                   | 219,104                             |         |                        | 60,153                               | 4.589             | 37 474         | 112                           |                |                           | 3,500         |            | 3,024        |           |           |                  |                        | \$ 327,973           |
|              |                   | Research grants       | 2021 | 89                                     |                                     |         | (20,000)               |                                      |                   |                |                               |                |                           |               |            |              |           |           |                  |                        | \$ 204,594           |
|              |                   | Researc               | 2022 | 69                                     |                                     | 352,773 | (20,000)               |                                      |                   |                |                               |                |                           |               |            |              |           |           |                  |                        | \$ 302,773           |
|              | Barth registry    | and repository        | 2021 | €>                                     |                                     |         |                        | 18,000                               | 145               | 2              |                               |                |                           | 671           |            |              |           |           |                  |                        | \$ 18,816            |
| Program serv | Barth             | and re                | 2022 | ь                                      |                                     |         |                        | 18.000                               | 177               | Ī              |                               |                |                           |               |            |              |           |           |                  |                        | \$ 18,141            |
|              |                   | awareness             | 2021 | \$ 81,897<br>13,195                    | 95,092                              |         |                        |                                      | 306               | 080            |                               |                |                           | 20            |            |              |           |           |                  |                        | \$ 95,538            |
|              | Advocacy and      | aware                 | 2022 | \$ 88,918<br>18,153                    | 107,071                             |         |                        | 6 500                                | 900,0             | 080            |                               |                |                           |               |            |              |           |           |                  |                        | \$ 113,967           |
|              |                   | services              | 2021 | \$ 66,380                              | 79,451                              |         |                        |                                      | 7.7               | 12,439         |                               |                | 1,006                     | 252           |            | 1,108        |           | 2,467     |                  | 230                    | \$ 96,953            |
|              |                   | Family 8              | 2022 | \$ 67,714                              | 84,083                              |         |                        | 17 000                               | 00,0              | 3,520          |                               | 1,103          | 939                       | 1,313         | 761        | 009          |           | 2,148     |                  |                        | \$ 111,467           |
|              |                   | BSF Regional Meetings | 2021 | ↔                                      |                                     |         |                        |                                      |                   |                |                               |                |                           |               |            |              |           |           |                  |                        | \$                   |
|              |                   | BSF Regio             | 2022 | ь                                      |                                     |         |                        | 1 800                                | 000,1             | 2,880          |                               | 53,884         | 6009                      | -             | 259        | 1,000        |           |           |                  |                        | \$ 65,922            |
|              | Comminication and | awareness             | 2021 | \$ 56,372                              | 64,847                              |         |                        | 42 200                               | 000,04            | 5,523          |                               |                | 17.115                    |               |            |              |           |           | 1,275            | 9                      | \$ 132.154 \$ 65,922 |
|              | u muo             | i awa                 | 2022 | \$ 60,040                              | 70,529                              |         |                        | ស្                                   |                   | 3,564          |                               |                | 16 653                    | 1             |            |              |           |           |                  |                        | \$ 90,746            |
|              |                   |                       |      | Salaries<br>Pavroll taxes and benefits | l otal salanes and related expenses |         | Research grant expense | Research grants funded by arrillates | Professional rees | Office expense | In-kind professional services | Transportation | Printing and publications | Dues and fees | Event cost | Audio visual | Insurance | Telephone | Public relations | Training and education | Total expenses       |

THE BARTH SYNDROME FOUNDATION, INC.

# STATEMENTS OF FUNCTIONAL EXPENSES

Years Ended December 31, 2022 and 2021

| n and               | rvices              | 2021 | 478,609<br>66,683                      | 545,292                             | 254,594                | (35,253)<br>135,253                                       | 81,398         |                               | 3,466          | 19,242                    | 10,580        |            | 1,108        | 3,374  | 3,493        | 1,926            | 1,006                  | \$ 1,010,732   |
|---------------------|---------------------|------|--|-------------------------------------|------------------------|---|----------------|-------------------------------|----------------|---------------------------|---------------|------------|--------------|--|--------------|------------------|------------------------|----------------|
| Total program and   | supporting services | 2022 | \$ 575,909 \$ 100,812                  | 676,721                             | 352,773                | 177,830   | 84,052         | 77,451                        | 69,319         | 25,990                    | 9,274         | 8,736      | 4,944        | 4,067  | 3,166        | 455              |                        | \$ 1,444,778   |
|                     |                     | 2021 | \$ 126,208<br>12,830                   | 139,038                             |                        | 53,759  | 61,815         |                               | 1,975          | 1,121                     | 5,795         |            |              | 3,374  | 1,026        | 651              | 770                    | \$ 269,324     |
|                     | Total               | 2022 | \$ 171,905<br>24,029                   | 195,934                             |                        | 74,377  | 68,962         | 39,977                        | 14,220         | 2,282                     | 4,461         | 7,716      | 320          | 4,067  | 1,018        | 455              |                        | \$ 413,789     |
| y services          | aising              | 2021 | \$ 43,893<br>5,399                     | 49,292                              |                        | 389   | 20,353         |                               | 1,975          | 931                       |               |            |              |  |              | 651              |                        | \$ 73,591      |
| Supporting services | Fundraising         | 2022 | \$ 81,454<br>13,795                    | 95,249                              |                        | 18,750  | 23,324         |                               | 14.206         | 1.776                     | 75            | 7,716      | 320          |  |              |                  |                        | \$ 161,416     |
|                     | and general         | 2021 | \$ 82,315<br>7,431                     | 89,746                              |                        | 53.370  | 41,462         | •                             |                | 190                       | 5.795         | -          |              | 3.374  | 1,076        | )                | 770                    | \$ 195,733     |
|                     | Management and      | 2022 | \$ 90,451<br>10,234                    | 100,685                             |                        | 55.627  | 45,638         | 39,977                        | 14             | 506                       | 4.386         |            |              | 4.067  | , 1, 0, 0, 1 | 455              |                        | \$ 252,373     |
|                     |                     |      | Salaries<br>Payroll taxes and benefits | Total salaries and related expenses | Research grant expense | Research grants funded by affiliates<br>Professional fees | Office expense | In-kind professional services | Transportation | Printing and publications | Dues and fees | Event cost | Andio visual | לימיניים לימינים | Tologon      | Public relations | Training and education | Total expenses |

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

### NOTES TO FINANCIAL STATEMENTS

December 31, 2022 and 2021

### 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, 2022 and 2021

### 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.

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.

### NOTES TO FINANCIAL STATEMENTS

December 31, 2022 and 2021

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

### 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, 2022 and 2021, the Organization determined that an allowance was not necessary.

### 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 of nonfinancial assets are reflected as contributions 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 (see Note 8).

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.

### 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, 2022 and 2021

### 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, 2022:

Financial assets at year-end:

| Cash  | \$<br>686,513   |
|---|-----------------|
| Investments   | 4,540,032       |
| Grants receivable   | 103,000         |
| Total financial assets  | <br>5,329,545   |
| Less amounts not available to be used within one year:                                    |                 |
| Net assets with donor restrictions<br>Less net assets with purpose restrictions to be met | 4,014,594       |
| in less than a year   | <br>(150,000)   |
| Financial assets available to meet cash needs for   | <br>3,864,594   |
| general expenditures within one year  | \$<br>1,464,951 |
|   |                 |

The Organization's goal is generally to maintain financial assets to meet 90 days of operating expenses, net of in-kind (approximately \$360,000). 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, 2022 and 2021

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

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

|   |           | 2022  | 2021                                    |
|---|-----------|---|---|
| Cash and money market Equities Fixed income Convertible Promissory Note | \$        | 574,785<br>1,341,130<br>2,599,117<br>25,000 | \$<br>571,001<br>1,721,152<br>2,919,200 |
|   | <u>\$</u> | 4,540,032                                   | \$<br>5,211,353                         |

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

|   | Mark Common | 2022                | <br>2021                |
|---|-------------|---------------------|-------------------------|
| Investments: Interest and dividends Realized and unrealized gain (loss) | \$          | 71,589<br>(789,759) | \$<br>43,567<br>173,879 |
|   | <u>\$</u>   | (718,170)           | \$<br>217,446           |

### 6. Fair value measurement

The classifications of the Organization's investment securities at fair value are as follows at December 31, 2022:

|  | Level 1                              | Level 2 | Level 3   | Total  |
|--|--------------------------------------|---------|-----------|--|
| Money market funds Equities Fixed income Convertible promissory note | \$ 574,785<br>1,341,130<br>2,599,117 | \$      | \$ 25,000 | \$ 574,785<br>1,341,130<br>2,599,117<br>25,000 |
|  | \$ 4,515,032                         | \$      | \$ 25,000 | \$ 4,540,032                                   |

The classifications 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<br>Equities<br>Fixed income | \$ 571,001<br>1,721,152<br>2,919,200 | \$      | \$      | \$ 571,001<br>1,721,152<br>2,919,200 |
|  | \$ 5,211,353                         | \$      | \$      | \$ 5,211,353                         |

### NOTES TO FINANCIAL STATEMENTS

December 31, 2022 and 2021

### 7. Commitments

Research grants payable as of December 31, 2022 and 2021 consists of amounts awarded but not paid, of \$243,049 and \$169,200, 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 \$249,854, of which \$25,000 is committed to be funded by affiliates (see Note 11).

### 8. Net assets

Net assets were as follows for the years ended December 31, 2022 and 2021:

|   | 2022                       |                         |              | 2021                       |                         |              |
|---|----------------------------|-------------------------|--------------|----------------------------|-------------------------|--------------|
|   | Without donor restrictions | With donor restrictions | Total        | Without donor restrictions | With donor restrictions | Total        |
| Undesignated  | \$ 998,736                 | \$                      | \$ 998,736   | \$ 1,787,258               | \$                      | \$ 1,787,258 |
| Specific purpose:<br>Arrhythmia Study                                       |                            | 43,394                  | 43,394       |                            |                         |              |
| Paula & Woody Varner<br>Science and Medical Fund                            |                            | 136,592                 | 136,592      |                            | 107,718                 | 107,718      |
| Will McCurdy Fund for the<br>Advancement of Therapies<br>for Barth Syndrome |                            | 3,834,608               | 3,834,608    |                            | 3,806,713               | 3,806,713    |
| Total net assets  | \$ 998,736                 | \$4,014,594             | \$ 5,013,330 | \$ 1,787,258               | \$ 3,914,431            | \$ 5,701,689 |

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

|  | <br>2022      |    | 2021    |  |
|--|---------------|----|---------|--|
| Satisfaction of purpose restrictions:                                    |               |    |         |  |
| Will McCurdy Fund for the Advancement of<br>Therapies for Barth Syndrome | \$<br>182,400 | \$ | 80,000  |  |
| Arrhythmia Study   | 56,606        |    |         |  |
| Paula & Woody Varner Science and Medical Fund                            |               |    | 50,000  |  |
| Science and Medical Fund   |               |    | 1,250   |  |
|  | \$<br>239,006 | \$ | 131,250 |  |

### NOTES TO FINANCIAL STATEMENTS

December 31, 2022 and 2021

### 9. Contributed nonfinancial assets

Donated legal 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. The Foundation received contributed legal services from an attorney which were valued based on current rates for similar legal services during the year ended December 31, 2022. These are reported as part of in-kind professional services in the statement of functional expenses.

The Foundation did not receive donated services for the year ended December 31, 2021.

|                |                  | 2022                   |             |           |  |  |
|----------------|------------------|------------------------|-------------|-----------|--|--|
|                | Program services | Management and general | Fundraising | Total     |  |  |
| Legal services | \$ 37,474        | \$ 39,977              | \$          | \$ 77,451 |  |  |
|                | \$ 37,474        | \$ 39,977              | \$          | \$ 77,451 |  |  |

### 10. Major sources of support

For the year ended December 31, 2022, two donors accounted for approximately 23% of total support and revenues. For the year ended December 31, 2021, three donors accounted for approximately 35% of total support and revenues.

### 11. 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 \$352,773 and \$254,594 for the years ended December 31, 2022 and 2021, 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 for each of the years ended December 31, 2022 and 2021.

### 12. Subsequent events

The Organization has evaluated subsequent events through April 27, 2023 which is the date the financial statements were available to be issued. The Organization is not aware of any material subsequent events.