

**MINUTES**  
**Barth Syndrome Foundation, Inc.**  
**Board of Directors Meeting**  
**February 23, 2026**

**Members in Attendance:**

<b>Jamie Baffa</b>	Board Member, Vice-Chair
<b>Megan Branagh</b>	Board Member (absent during portions; attending Rare Disease Week in DC)
<b>Brandi Dague</b>	Board Member, Secretary
<b>BJ Develle</b>	Board Member
<b>Michelle Florez</b>	Board Member
<b>Steven Graessle</b>	Board Member
<b>Miriam Greenberg, PhD</b>	Board Member
<b>Mark Greene</b>	Board Member, Treasurer
<b>Kate McCurdy</b>	Board Member, Chair
<b>Emily Milligan</b>	Board Member ex officio, CEO
<b>Nina Russell, MD</b>	Board Member
<b>Jonathan Stokes</b>	Board Member
<b>Peter van Loo</b>	Board Member
<b>Stacey Woodward</b>	Board Member

**Former Members in Attendance:**

<b>Susan McCormack</b>	Former Board Chair
<b>Steve McCurdy</b>	Former Board Chair

**Invited Guests:**

<b>Natalie Cohn</b>	Controller, BSF
<b>Jessica Lee</b>	Staff, BSF
<b>Emily Madalinski</b>	Staff, BSF

**Affiliate Leaders Attending as Observers:**

<b>Mathieu Beaudouin</b>	Association Barth Syndrome de France
<b>Michaela Damin</b>	Barth Syndrome UK
<b>Ralph Easterbrook</b>	Barth Syndrome UK
<b>Susan Hone</b>	Barth Syndrome Canada
<b>Christiane Hope</b>	Barth Syndrome Canada
<b>Florence Mannes</b>	Association Barth Syndrome de France
<b>Daniela Toniolo, PhD</b>	Barth Italia Onlus

The meeting was called to order by Chair Kate McCurdy on Monday, February 23, 2026, at 10:00 AM ET via videoconference. A quorum was confirmed. The meeting was held concurrently with Rare Disease Week in Washington, D.C., and several staff members and BSF representatives were participating from the field in DC.

## I. WELCOME AND ANNOUNCEMENTS

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Chair Kate McCurdy welcomed all participants, including new BSF staff member Jessica Lee, Director of Communication and Development, who joined BSF full-time in late January 2026 following years as a consultant to the organization. Kate noted that Jess had already made significant contributions in her short tenure.

Kate also brought to the board's attention recent news regarding Dr. Bill Pu's gene therapy program for Barth syndrome.

## II. APPROVAL OF MEETING MINUTES

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Secretary Brandi Dague presented the December 16, 2025, draft minutes.

**MOTION** to approve the December 16, 2025, minutes as written and circulated was approved unanimously.

## III. RARE DISEASE WEEK UPDATE

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Emily Milligan reported that BSF had approximately 30 representatives on the ground in Washington, D.C., for Rare Disease Week — a remarkable showing for an ultra-rare disease community. BSF was participating along with its EveryLife Foundation partners and the broader rare disease community.

BSF's priorities for the week included:

- Presenting to the broader Rare Disease Week community (approximately 500–700 attendees) on BSF's journey with FDA accelerated approval for FORZINITY™ (elamipretide), with emphasis on the need to ensure the accelerated approval pathway remains truly accelerated.
- Supporting legislative asks through EveryLife Foundation, including policy priorities affecting the broader rare disease community.
- Initiating conversations with legislators about a faster pathway for label expansion of FORZINITY™, particularly to include younger and transplant patient populations.
- Advancing the House resolution for Barth Syndrome Awareness Day for April 5, 2026.

Emily noted that a partial government shutdown and severe weather were creating logistical challenges; BSF was monitoring which legislators were physically present in DC and adapting accordingly. The Chair expressed gratitude to the entire DC team on behalf of the board.

## IV. TREASURER'S UPDATE AND 2025 FISCAL YEAR PRELIMINARY RESULTS

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Treasurer Mark Greene presented preliminary, unaudited 2025 financial results. These figures are expected to be finalized within approximately 45 days and are not anticipated to change materially.

Key highlights:

- **Operating income:** A loss of approximately \$41,000, about \$100,000 better than the late-November forecast and approximately \$400,000 better than the \$439,000 budgeted deficit.

- **Revenue drivers:** Strong performance in donations and grants, as well as portfolio income, drove the favorable results. Donations outperformed budget by approximately \$300,000, partially offsetting lower-than-budgeted grant income.
- **Expense performance:** Expenses were lower than budget primarily in SciMed, fundraising, and family services. Variance in family services reflects staff time allocation since resources were heavily concentrated on elamipretide/FORZINITY™ advocacy efforts.
- **Comparison to 2024:** Excluding conference activity (2024 was a conference year), revenues were approximately \$400,000 better and operating expenses grew approximately \$300,000 year-over-year, driven largely by the addition of the Director of Fundraising position and increased research agreements (including gene therapy payments and arrhythmia milestones).
- **Balance sheet:** BSF holds approximately \$5.9 million in cash and investment portfolio resources at year-end 2025, roughly consistent with the prior year. Restricted gift balances total approximately \$3.9 million.
- **990 reporting note:** The public 990 will reflect unrealized investment gains of approximately \$328,000, which are treated differently in internal financials. The 990 operating result will therefore be more favorable than the internal operating loss figure.

Mark concluded that BSF is in a strong financial position heading into 2026.

## V. 2025 FUNDRAISING SNAPSHOT

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Emily Milligan introduced a new fundraising dashboard, developed by Jessica Lee, designed to provide the board with high-level visibility into BSF's revenue performance and opportunities. The board was invited to provide feedback on the tool as it continues to evolve.

Jessica Lee presented the following highlights:

- **Total giving in 2025:** \$1,918,928, including grants, donations, and affiliate support. Donations from individuals and organizations comprised 80% of total revenue.
- **Key fundraising events:** Happy Heart Week (\$320,657), Giving Tuesday (\$119,772), and the NY Islanders Hockey Game (\$101,589) were among the top-performing standalone events.
- **Donor concentration:** 9.1% of donors (98 individuals) account for approximately 79% of donation revenue, representing a risk to organizational sustainability. Growing the number of major donors (those giving \$2,500+) is a key 2026 priority as is identifying opportunities for all supporters of BSF's mission to contribute at levels they are able.
- **Grant opportunities:** Increasing grant revenue — particularly corporate grants accounting for 10-15% of planned revenue — is a key 2026 opportunity to be able to pursue BSF ambitions for this year and beyond.

## VI. 2026-2028 STRATEGIC PLAN

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Kate McCurdy provided context for the strategic plan's development timeline, noting that the process had been necessarily compressed: BSF had planned to begin strategic planning in early 2025, but the effort was appropriately deferred pending the outcome of the FORZINITY™ FDA review. Following approval on September 19, 2025, BSF conducted two off-site retreats — one focused on organizational

strategy (including board members, executive committee, senior staff, former board chairs, and affiliate input) and one focused on science and medicine (organized by Lindsay Marjoram, bringing together 19 academic and industry experts as well as staff and volunteer leadership in January 2026). Kate acknowledged Jamie Baffa's wonderful leadership of the strategic planning process and expressed gratitude to all who contributed.

Emily Milligan presented a summary of the plan's key themes:

- Continuing to support Barth families through high-touch, sustainable family services
- Continuing to pursue development of additional therapies for Barth syndrome, especially given the breadth of ages and clinical presentations of our multi-faceted and complex syndrome
- Maintaining and advancing BSF's research and development pipeline
- Supporting patient education around the Phase IV confirmatory trial for elamipretide (FORZINITY™)
- Identifying ways BSF will need to complement patient access efforts led by Stealth/Anovo through reimbursement advocacy for FORZINITY™
- Sustaining and strengthening BSF's position as a trusted source on Barth syndrome
- Investing in organizational sustainability, including fundraising infrastructure, website redesign, and leadership transition planning

#### **Discussion: Mission and Vision Statements**

The board discussed proposed revisions to BSF's mission and vision statements, which have been largely unchanged for 25 years. Jamie Baffa framed the process: the vision should answer "what world are we trying to create?" while the mission should answer "why do we exist?"

Following discussion, Kate McCurdy invited the board to vote to approve the strategic plan in principle, with the understanding that a final version incorporating feedback from today's meeting — along with finalized mission and vision statements — will be circulated and voted on at a later date.

**MOTION** to approve the 2026–2028 Strategic Plan in principle was approved unanimously.

Affiliate leaders departed the call following the vote on the strategic plan.

## **VII. 2026 BUDGET PROPOSAL**

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Emily Milligan presented the proposed 2026 operating budget, structured in three components: (1) Base Operating Budget, (2) Conference, and (3) New/Expanded Programs Reflective of the Strategic Plan.

**Summary:** The proposed 2026 total operating deficit is \$(277,000), in the context of a projected total revenue of \$2,518,000 — which would represent the largest operating revenue budget in BSF's history. This deficit is \$(236,000) worse than the 2025 preliminary operating result of \$(41,000), reflecting significant planned investments in strategic priorities and the inclusion of conference costs.

## 1. Base Operating Budget

The base operating budget projects revenue of \$1.846M (compared to \$2.024M in 2025 preliminary) and expenses of \$1.932M, for a deficit of \$(86k). The year-over-year revenue decrease is driven primarily by Happy Heart Week: the Branagh family, who have graciously organized this signature event, is taking a year off from the major reception format. The May online fundraiser component is expected to continue and is budgeted at \$150,000. Revenue from grants includes Year 3 of the Chan Zuckerberg Initiative (CZI) grant. The budget reflects a full year of the new Director of Communication and Development position, while also capturing approximately \$28,000 in savings from the elimination of a consulting contract. Health insurance costs are expected to increase materially in the second half of 2026 when BSF's benefit year renews.

## 2. Conference

Conference revenue is budgeted at \$332,000, with expenses of \$400,000 (including \$14,000 for 2028 site selection), for a net cost of \$(68,000) — more than \$110,000 improvement over the 2024 conference net cost of \$(182,000). Importantly, for the first time ever, BSF is tracking toward a break-even conference budget. As of the meeting date, \$190,000 in corporate sponsorship commitments have been received. Lindsay Marjoram was recognized for her role in securing corporate sponsorships. Emily noted that NIH conference grant funding forecast has been reduced under the current federal environment; BSF had previously received \$40,000 and now expects a maximum of \$25,000 if awarded the grant.

## 3. New/Expanded Programs Reflective of the Strategic Plan

This budget component projects \$340,000 in revenue (primarily an unrestricted \$300,000 core operating grant from corporate partners, with a stretch goal of \$400,000, plus approximately \$40,000 from commercial webinars and website partnerships) against \$463,000 in expenses, for a deficit of \$(123,000). As of February 1, nearly the entire revenue budget is verbally committed or under funding agreement review.

Key investments include:

- **Family Services (\$15,000):** Travel to Europe by BSF leadership to cultivate relationships with the Center of Expertise at Amsterdam and meet with affiliates, contingent on grant funding.
- **SciMed (\$290,000 expenses / \$240,000 revenue):** Continued seed grant funding; affiliate capacity-building grants (\$50,000) to support clinical trial readiness; hiring a consultant/contractor to support affiliates and BSF in staffing patient education, reimbursement work, and other critical components of the Phase IV (\$80,000); travel to Europe (\$12,500); funding for research-enabling tools including biomarker identification, preclinical models, and clinical endpoint development (\$123,000); sponsored webinars and an industry advisory council; and engagement of a business development consultant to assess new funding mechanisms for curative therapy advancement (\$25,000).
- **Advocacy (\$70,000 expenses / \$100,000 revenue):** Retaining and potentially adding advocacy personnel (consultant/contractor/FTE) to maintain federal and policy relationships and support FORZINITY™ label expansion efforts.
- **Communications and Operations (\$88,000 expenses):** Expanded communications consultant support and reinstatement of print newsletter (\$37,500); website overhaul — a full rebuild to

modernize BSF's digital presence (\$40,000); and acquisition of a donor analytics platform (\$10,000).

Emily noted that several significant program expenditures (affiliate grants, advocacy hire) will require separate board approval as plans are defined. This vote approves the overall budget framework, not each individual expense.

Discussion noted the favorable nature of the deficit given that 2026 is a conference year, and board members expressed comfort with the proposed level of investment given BSF's financial resources and track record. It was observed that the budget reflects realistic planning for needed investments and that BSF has strong resources to absorb the projected deficit.

**MOTION** to approve the 2026 Budget as presented was approved unanimously.

## **VIII. ADJOURNMENT**

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The meeting was adjourned. Kate McCurdy thanked all participants for their contributions to a meeting of exceptional importance for the organization.

Respectfully submitted,

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Emily Milligan  
Chief Executive Officer