

**MINUTES**  
**Barth Syndrome Foundation, Inc.**  
**Board of Directors Meeting**  
**October 28, 2025**

**Members in Attendance:**

Kate McCurdy	Board Member, Chair
Megan Branagh	Board Member
Brandi Dague	Board Member, Secretary
BJ Develle	Board Member
Michelle Florez	Board Member
Steven Graessle	Board Member
Miriam Greenberg, PhD	Board Member
Mark Greene	Board Member, Treasurer
Emily Milligan	Board Member <i>ex officio</i> , Executive Director
Nina Russell, MD	Board Member
Jonathan Stokes	Board Member
Peter van Loo	Board Member
Stacey Woodward	Board Member

**Invited Guests**

Michael Bowen	Volunteer
Shelley Bowen	Staff, BSF
Natalie Cohn	Controller, BSF
Laura Duvelius	Staff, BSF
Melissa Huang, PhD	Staff, BSF
Lindsay Marjoram, PhD	Staff, BSF

**Members in Not Attendance:**

Jamie Baffa	Board Member, Vice-Chair
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**Affiliate Leaders Attending as Observers**

Elena Bilcu	Barth Italia Onlus
Susan Hone	Barth Syndrome Canada
Christiane Hope	Barth Syndrome Canada
Florence Mannes	Association Barth Syndrome de France

The meeting, held via Zoom, was called to order by Kate McCurdy on Tuesday, October 28<sup>th</sup> at 12:00 p.m. ET.

## 1. Welcome

Kate McCurdy welcomed attendees and outlined the meeting structure.

## 2. Meeting Minutes

BJ Develle moved to accept the July 29 and August 27, 2025 meeting minutes as presented.

**MOTION** to approve the July 29, 2025, minutes as written was made and **APPROVED** unanimously.

**MOTION** to approve the August 27, 2025, minutes as written was made and **APPROVED** unanimously.

Kate McCurdy invited feedback on the appropriate level of detail in meeting minutes, noting the balance between comprehensive historical records and the public nature of the documents. None was offered.

## 3. Financials

Natalie Cohn presented financials through September 2025:

- Revenues were \$982K (compared to \$995K in 2024)
- Operating expenses were \$1,365K (compared to \$1,550K in 2024)
- Resulting operating net deficit was \$383K (compared to \$555K in 2024)
- With strong investment portfolio performance generating approximately \$313K in gains, a total net deficit of \$70K resulted in 2025 (compared to \$231K in 2024)
- Balance sheet remains strong with over \$1 million in unrestricted funds and \$4 million in restricted funds.

Emily Milligan noted BSF expects to meet or exceed 2025 budget, with an updated forecast coming in December. She reported a new opportunity for additional corporate grant support may emerge in the 4<sup>th</sup> quarter of 2025. BSF has had to cover almost exclusively all advocacy and family education costs without corporate grant support this year, although details were being explored with potential funders for substantial support in 2026 following drug approval.

## 4. 2026 Conference Planning

Shelley Bowen, Michael Bowen, Laura Duvelius, and Emily Milligan presented comprehensive conference planning updates for the June 2026 conference, projecting 350 attendees.

Program: On-site research will be expanded to take advantage of the fact that ~ ¼ world's population of affected individuals attends. Being able to conduct research in a single location over a short period of time increases comparability of data and saves hundreds of thousands of dollars in research grant expenses. Additionally, the data collected ultimately can be used in our natural history. As a result, we have expanded our research to three days and we also will have four days of meeting sessions, for a total of a seven-day conference.

Overall, we feel we have the right format.

After some concern about how many international families might attend, it looks as though many will.

We will launch registration in early 2026.

We again will offer patient financial assistance programs in 2026.

Expenses: Top budget items include food/beverage, travel/lodging (\$71K, utilizing Mercy Medical Airlift for free flights), audio-visual (\$60K), Family Travel Scholarships (\$33.5K), and project management. Merchandise will shift to a pre-order Bonfire model eliminating upfront inventory costs.

Revenue: Approximately \$310K projected from corporate sponsorships, NIH grant, registrations, affiliate support, and various fundraising initiatives. Laura Duvelius outlined a prospect pipeline with opportunities across multiple sponsorship tiers.

Financial Outlook: Projected net deficit of approximately \$73K represents substantial progress from the \$175K deficit in 2024 and moving toward the goal of financial sustainability. Kate McCurdy noted that while many variables remain in flux, the board approved the approach in principle, with a formal budget vote to occur once details are finalized. BJ Develle noted this represents the most encouraging conference financial outlook in his board tenure.

#### **5. Conference Project Manager Contract**

Emily Milligan proposed engaging Lauren of Whiptail Consulting as project manager for the 2026 conference at approximately \$26K, comparable to or less than 2024 costs. Lindsay Marjoram provided strong recommendation based on previous professional collaboration.

**MOTION** to approve contract to Whiptail Consulting up to \$26k, was made and **APPROVED** unanimously.

#### **6. FORZINITY Access and Phase 4 Clinical Trial**

Kate McCurdy outlined five major workstreams following FORZINITY's accelerated approval:

- 1) U.S. Market Access: Supporting insurance coverage efforts for on-label patients (66+ pounds), leveraging patient advocacy and small population size. Emily Milligan noted anticipated coverage challenges given high therapy costs and some insurers' policies against covering accelerated approvals.
- 2) Phase 4 Confirmatory Trial: Three-year trial launching March 2026 at international sites (possibly Bristol, Paris, Sydney) using composite endpoint including knee extensor strength. Trial success is essential to maintain U.S. approval and support future therapeutic development.
- 3) Label Expansion: Working to expand approval to ages 2-12, as current label covers only ~50% of patient population.
- 4) International Approvals: Supporting regulatory approval efforts in other countries/regions.
- 5) Policy Leadership: Contributing to ultra-rare disease policy discussions at FDA and with advocacy organizations.

#### **7. Strategic Planning Update**

Kate McCurdy and Emily Milligan presented strategic planning progress, noting BSF is at a critical inflection point. The preliminary draft plan (subject to financial pressure-testing) identifies key priorities:

- 1) Phase 4 Trial success as top priority for next three years
- 2) Strengthening affiliate relationships with capacity building, clear expectations, and parity in support
- 3) Dedicated payer access and advocacy support (Shelley Bowen's capacity significantly overextended)

- 4) Maintaining seed grant program and enabling science infrastructure
- 5) Continuing biennial conferences, exploring European meetup possibilities

Also, the strategic plan likely will recommend that our gene therapy program be contingent on federal funding.

Additional initiatives include brand refresh, website modernization, and mission/vision statement updates to reflect serving lives from prenatal through adulthood. Jamie Baffa will lead refinement with board approval anticipated in early 2026.

#### **8. Giving Tuesday Board Match**

Laura Duvelius presented a proposal for board members to collectively commit \$10K for Giving Tuesday (December 2) matching funds, as we have in the past. Megan Branagh raised thoughtful questions about timing of board fundraising requests and potential donor fatigue, suggesting consideration of whether funds might support a specific strategic priority.

Kate McCurdy acknowledged these concerns and noted that while it's too late in 2025 to identify an alternative targeted initiative for Giving Tuesday funding, the board should revisit its overall approach to fundraising early in 2026 once strategic priorities are finalized.

Consensus supported proceeding with Giving Tuesday match for 2025.

**MOTION** to approve the \$10k board match at 100% participation, was made and **APPROVED** unanimously.

Laura Duvelius will coordinate collection of commitments.

#### **9. Former Board Chairs as Observers**

Kate McCurdy proposed inviting former Board Chairs (Steve McCurdy, Marc Sernel, and Susan McCormack) to attend board meetings as non-voting observers/participants, similar to affiliate leaders. Their participation in strategic planning provided great value through professional expertise and institutional knowledge, and we would like to continue their active involvement.

Mark Greene seconded, noting many organizations miss opportunities by failing to maintain former leader engagement. The motion passed unanimously.

#### **10. Adjournment**

Kate McCurdy thanked board members for their engagement and encouraged ongoing communication. Meeting adjourned at 1:55 p.m. ET.

Respectfully submitted,

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Emily Milligan  
Executive Director