

MINUTES
Barth Syndrome Foundation, Inc.
Board of Directors Meeting
April 29, 2026

Members in Attendance:

Jamie Baffa	Board Member, Vice-Chair
Megan Branagh	Board Member
BJ Develle	Board Member
Michelle Florez	Board Member
Steven Graessle	Board Member
Miriam Greenberg, PhD	Board Member
Mark Greene	Board Member, Treasurer
Kate McCurdy	Board Member, Chair
Emily Milligan	Board Member ex officio, CEO
Nina Russell, MD	Board Member
Jonathan Stokes	Board Member
Stacey Woodward	Board Member

Former Members in Attendance:

Susan McCormack	Former Board Chair
Steve McCurdy	Former Board Chair
Marc Sernel	Former Board Chair

Invited Guests:

Bill Belscher	Audit Committee Chair
Shelley Bowen	Staff, BSF
Natalie Cohn	Controller, BSF
Melissa Huang, PhD	Staff, BSF
Jessica Lee	Staff, BSF
Emily Madalinski	Staff, BSF
Lindsay Marjoram, PhD	Staff, BSF

Affiliate Leaders Attending as Observers:

Michaela Damin	Barth Syndrome UK
Ralph Easterbrook	Barth Syndrome UK
Susan Hone	Barth Syndrome Canada
Florence Mannes	Association Barth Syndrome de France
Daniela Toniolo, PhD	Barth Italia Onlus

The meeting was called to order by Chair Kate McCurdy on Wednesday, April 29, 2026, at 12:00 PM ET via videoconference. A quorum was confirmed.

I. WELCOME AND RECOGNITION OF BOARD SERVICE

Chair Kate McCurdy opened the annual meeting and recognized two departing board members. BJ Develle, one of BSF's longest-serving volunteers, reached his term limit after years of contributions spanning the website, conferences, programs for affected individuals and siblings, and advocacy.

Kate also announced the resignation of Secretary Brandi Dague, who stepped down due to significant new professional responsibilities. Brandi has been a great ambassador for BSF's mission and also has engaged some wonderful outside volunteers.

Kate noted that election of new board members will be deferred to the fall, following a planned discussion at the July in-person meeting on board evolution and organizational sustainability.

II. APPROVAL OF MEETING MINUTES

Two sets of minutes were presented for approval: the February 23, 2026 board meeting and the 2026 grant call which took place on March 28, 2026. No questions were raised.

MOTION to approve both sets of minutes as presented was approved unanimously.

Two offline votes taken since the February meeting were entered into the record: (1) approval of the 2026 Conference Family Travel Fund budget of \$43,096; and (2) approval of a \$14,400 contract with Rose Robinson as project manager for the 2026 website redesign, which is now underway.

III. 2025 AUDIT

Bill Belscher presented the 2025 audit results on behalf of Dorfman & Company. The audit is clean in draft form, pending board approval and issuance of the management representation letter. Two audit adjustments were noted: (1) recognition of \$29,270 in accrued interest income and receivable, identified for the first time this year (compared to \$24,000 in the prior year). No restatement of the prior year was necessary, as the amount was deemed immaterial on a cumulative results basis; and (2) a reclassification of Happy Heart Week revenue to present special event income net of direct expenses (\$296,000 net vs. \$320,000 gross), as required for events where donors received goods or services. This is a presentation change only. Mission-related program service spending was confirmed at approximately 77.2% of total expenditures for 2025, noted favorably by the auditors. No material weaknesses, illegal acts, or fraud were identified.

MOTION to accept the 2025 audit report and governance communication as presented was approved unanimously.

IV. TREASURER'S REPORT AND FUNDRAISING UPDATE

Natalie Cohn presented March 31, 2026 financials.

Key highlights:

- **YTD Operating Income:** BSF is running a year-to-date operating profit through March—an unusual and encouraging result at this point in the year. Contributions of \$276,000 in regular donations are tracking ahead of the prior year. Affiliate donations of \$165,000 reflect recently

approved affiliate grants. Conference revenue of \$194,000 in sponsorships and registrations has been committed, with nearly all physically received. Expenses are in line with budget and consistent with the prior year, with the exception of approved research grants, which are slightly higher.

- **Balance Sheet:** Cash is approximately \$300,000, consistent with prior periods. The investment portfolio reflects unrealized losses due to March market volatility; however, Mark noted that as of the meeting date the portfolio had substantially recovered. The interest receivable line of \$23,000 reflects the newly implemented monthly accrual. The Family Services Fund restricted balance declined from \$20,000 to approximately \$4,000, reflecting the advance payment to NORD for conference family travel fund fully underwritten by BSF.

V. 2026 CONFERENCE UPDATE AND 2028 SITE SELECTION

Jessica Lee reported that conference corporate sponsorships are nearly at forecast, with optimism about exceeding the target. Registrations are tracking slightly ahead of prior conference cycles; a decrease in international registrations has been noted. Emily reported that the Family Travel Fund application window closed with 16 families applying (18 affected individuals). Supporting all families requires approximately \$3,014 above the approved budget of \$43,096; BSF is pursuing third-party airfare support through Angel Flights and Mercy Medical that could help offset this amount. The proposed budget to support families requiring support and who meet eligibility requirements was revised to \$46,110 (which includes an \$8k carryforward from the 2024 Conference).

MOTION to increase the 2026 Conference Family Travel Fund budget by \$3,014 to support all applicant families was approved unanimously.

Shelley Bowen reported that Request for Proposals (RFPs) for the 2028 conference venue have been sent to 18 venues across 7 states. Site visits are planned for early June, with a board vote and public announcement targeted for the July 2026 conference.

VI. 2026–2028 STRATEGIC PLAN

Jamie Baffa presented the final components of the strategic plan approval process. A two-page executive summary was developed to serve as the primary community-facing communication vehicle, translating the full plan into accessible language organized around its core themes. Following further iteration since the February meeting, the mission statement was finalized with the word “tenaciously” replacing “relentlessly,” striking a balance that captures BSF’s determined focus while reflecting the spirit of the community. The final Mission statement is “To collectively and tenaciously work toward saving and improving the lives of those impacted by Barth syndrome.” The vision statement, approved in February, was unchanged.

MOTION to adopt the updated BSF mission statement was approved unanimously.

MOTION to approve the 2026–2028 Strategic Plan Executive Summary was approved unanimously.

Work will continue on a community rollout plan in advance of the July conference.

VII. ARRHYTHMIA PROJECT

An update was provided on the BSF-funded cardiac arrhythmia registry project. Significant delays in enrollment and data quality have been identified, stemming from contracting timelines, research

coordinator turnover, and data management challenges at the lead institution. BSF has engaged an external data analyst to evaluate the registry, and has established a May 18, 2026 deadline for the NYU-research team to demonstrate proof of concept. Emily committed to reporting back to the board following that evaluation, with a formal vote on next steps to follow.

VIII. PHASE IV EX-US CONFIRMATORY TRIAL

Emily provided an update on the FDA-mandated Phase IV confirmatory trial for FORZINITY™ (the FDA-approved drug name for elamipretide). The first site initiation visit has been completed at the lead UK site in Bristol. Challenges related to patient education materials, sponsor-community communications, and the complexity of multi-jurisdictional regulatory processes were discussed. Solution-focused discussion proceeded regarding BSF's role in supporting education of families, community communications, and affiliate capacity. The board received an update on the parallel regulatory and reimbursement landscape across European markets.

IX. EXECUTIVE SESSION

All staff (except Emily, Lindsay, and Natalie) and all affiliate and guest observers stepped off the call. The board proceeded to executive session.

The following changes in SMAB membership were proposed, discussed, voted on and approved with thanks:

- Ronald Wanders PhD - retiring from SMAB after long and illustrious service
- Michio Hirano MD – leaving the SMAB and changing to *ad hoc* Advisor status with BSF
- Borko Amulic PhD - serving for another 4-year term
- Brian Feingold MD – serving for another 4-year term
- Miriam Greenberg PhD – serving for another 4-year term
- Robin Duncan PhD – joining the SMAB with a 4-year term
- Christina Pacak PhD - joining the SMAB with a 4-year term
- Kathryn Chatfield Md PhD - joining the SMAB with a 4-year term

Then, all non-Board members and Megan Branagh were excused.

Megan Branagh, already a member of the BSF Executive Committee, was proposed, discussed and approved as the new BSF Board Secretary to fill that open position.

VIII. ADJOURNMENT

The meeting was adjourned at approximately 2:08 PM ET. Kate thanked all participants for their contributions.

Respectfully submitted,

Megan Branagh
Secretary