

MINUTES

Barth Syndrome Foundation, Inc.

Board of Directors Meeting

March 28, 2026

Members in Attendance:

BJ Develle	Board Member
Emily Milligan	Board Member <i>ex officio</i> , Chief Executive Officer
Jamie Baffa	Board Member, Vice Chair
Kate McCurdy	Board Member, Chair
Megan Branagh	Board Member
Peter van Loo	Board Member
Jonathan Stokes	Board Member
Michelle Florez	Board Member
Miriam Greenberg, PhD	Board Member
Nina Russell, MD	Board Member
Stacey Woodward	Board Member
Steve Graessle	Board Member

Invited Guests

Lindsay Marjoram, PhD	Chief Scientific Officer, BSF
Melissa Huang, PhD	Research Associate, BSF
Michaela Damin	Barth Syndrome UK
Florence Mannes	Barth Syndrome France
Susan Hone	Barth Syndrome Foundation of Canada
Christiane Hope	Barth Syndrome Foundation of Canada
Marilyn Pridgen	Barth Syndrome Foundation of Canada
Lynn Elwood	Barth Syndrome Foundation of Canada

Members in Not Attendance:

Brandi Dague	Board Member
Mark Greene	Board Member

The meeting, held via Zoom, was called to order by Kate McCurdy on Saturday, March 28 at 12:01 p.m. ET.

1. Welcome and Opening Remarks

- a. Kate McCurdy welcomed the Board and International Affiliates to the meeting.

- b. Kate noted that before the grant discussion, there were two time-sensitive items to discuss 1) updates to the strategic plan, vision and mission statement and 2) Varner Award nominee.
2. BSF Vision, Mission, and Strategy Statement
- a. Jamie Baffa shared the language being proposed for BSF's mission, vision, and strategy. These messages would inform how we talk about BSF's strategic plan externally
 - b. **APPROVED (in principle):** The mission statement as written with the potential to revise one word was unanimously approved.
 - c. **APPROVED:** Vision statement proposal was unanimously approved.
 - d. **APPROVED:** Message as written with revisions proposed was approved unanimously.
3. 2026 Varner Award Nominee
- a. The Varner Award is BSF's top professional honor given in recognition of exceptional contributions to the advancement of Barth syndrome scientific knowledge and/or care, and treatments.
 - b. **APPROVED:** The nominee was unanimously approved as the 2026 Varner Award recipient.
4. Review of Grant Proposals
- a. Lindsay Marjoram provided an overview of this funding cycle, research areas, and applicant pool. BSF received a record 25 applications, double the typical volume. For the first time, not all applications were discussed during the Scientific and Medical Advisory Board (SMAB) Grant Call.
 - b. Grant proposals spanned biochemical, cellular, systemic, and tissue-level approaches. Gastrointestinal research, a new and underdeveloped area for Barth syndrome, emerged in multiple applications. Applicant makeup was like years prior, with similar percentage of first-time applicants, repeat applicants, young investigators, senior and prior grant recipients, and U.S. and ex-U.S. representation.
 - c. Lindsay reviewed the top 5 grants and 1 grant that was at the cut-off point (requested by Barth Canada to be discussed). Each application has been evaluated by the SMAB and an external reviewer based on 1) the importance and impact to Barth syndrome, 2) feasibility of the proposed work, and 3) prospects for long-term funding.
 - d. Kate then moved that the board discuss and vote on the grant proposals, incorporating the recommendations of the SMAB and Chief Scientific Officer (Lindsay).
 - i. The budget for FY26 for the grant program including affiliate contributions was up to \$250,000. Affiliate contributions this year were as follows: Barth France for up to \$100,000 USD, Barth Syndrome UK for \$10,000, Barth Syndrome Foundation Canada for \$30,000, and Barth Italia for \$25,000.
 - ii. **APPROVED:** BSF to fund the following three BSF research grant proposals:
 - 1. *Novel ABHD18 inhibitor to treat Barth Syndrome* (Timothy Cardozo,

MD, PhD at NYU/ \$100,000)

- Barth France would like their contribution to go fully toward the Cardozo grant.

2. *Gut Microbiota and Metabolites in Barth Syndrome: Potential Mechanistic Links to Feeding and Gastrointestinal Dysfunction* (Todd Cade, PT, PhD, FAPTA at Duke University / \$70,752)

- Barth Canada would like their contribution to go fully toward the Cade grant.

3. *Regulation of cardiolipin metabolism by the mitochondrial phospholipase A1* (Itay Budin, PhD at University of California, San Diego/ \$75,000*)

Barth Syndrome UK and Barth Italia will confirm which grants they would like their funds to support offline.

5. Future Grant Cycle Process

- a. Given the large volume of applications and volatile funding landscape, BSF could consider the following: 1) Reinstate a Letter of Intent process to allow earlier programmatic-alignment screening; 2) Update Request For Applications language to include strong encouragement of preliminary data and language emphasizing innovation. No formal vote was taken, BSF R&D team will work with a small group including Miriam Greenberg to determine the best approach for next cycle.

6. Adjournment

- a. Kate McCurdy adjourned the meeting at 2:22 p.m. ET

Respectfully submitted,

Melissa Huang, BSF Research Associate