

MINUTES

Barth Syndrome Foundation, Inc.

Board of Directors Meeting

December 20, 2023

Members in Attendance:

BJ Develle	Board Member
Brandi Dague	Board Member
Emily Milligan, MPH	Board Member <i>ex officio</i> , Executive Director
Kate McCurdy	Board Member, Chair
Mark Greene	Board Member, Treasurer
Andrew Buddemeyer	Board Member
Peter van Loo	Board Member
Megan Branagh	Board Member
Miriam Greenberg, PhD	Board Member
Nina Russell, MD	Board Member

Invited Guests

Emily Madalinski	Development and Stewardship, BSF
Kevin Woodward	Finance & Investments Committee
Lindsay Marjoram, PhD	Director of Research, BSF
Melissa Huang, PhD	Clinical Research Coordinator, BSF
Natalie Cohn	Controller

Members in Not Attendance:

Florence Mannes	Board Member
Jamie Baffa	Board Member, Secretary
Jonathan Stokes	Board Member
Michelle Florez	Board Member

The meeting, held via Zoom, was called to order by Kate McCurdy on Wednesday, December 20th at 12:00 p.m. ET.

1. Welcome
2. Meeting Minutes
 - a. In Jamie Baffa's absence, Kate McCurdy asked for approval and edits for the November 2nd minutes.
 - b. **APPROVED:** November minutes as written
3. Treasurer Report

- a. Mark Greene shared that the forecasts have not materially changed since the last board meeting
 - b. Natalie Cohn shared a high-level view of current numbers, all of which are in expected ranges
 - c. Emily Milligan reviewed Giving Tuesday
 - i. \$130,000 was a stretch goal, and BSF expects the final fundraising to be over \$102,000
 - ii. Affiliates were unable to contribute
 - iii. Final Giving Tuesday numbers resulted in minor changes to the forecast
 - iv. Leaves a gap of \$440,000 to BSF's revenue goal which is significant, but doable by year-end
 - v. Kate shared that Steve McCurdy has been in contact with nearly every major donor and they have gifts in process, which should help close the existing gap
 - vi. Reinforced that lower donations are part of a larger trend
 - d. Mark reviewed a new schedule that breaks out material commitments that the foundation has made that have yet to hit the actual balance sheet
 - e. Goal is to quantify existing commitments before they show up on our books, and we will update this document on a regular basis
4. UPDATE: Elamipretide and Ultra-Rare Disease Advocacy
- a. Kate shared the latest on Stealth's engagement with the FDA
 - b. Emily and Kate discussed the latest with BSF's petition that the foundation is doing to garner government and media attention, including the recent news story highlighting Declan Comerford and his mother, Jamie Dubuque
5. 2023 Year in Review and 2024 Horizon
- a. Emily spoke to the success of BSF across advocacy, family services, and research, and in particular thanked staff and volunteers for everything they've done despite challenges and staff changes.
 - b. Board members thanked Emily for the summary, calling it remarkable to see everything that staff and volunteers have accomplished
 - c. Discussion about how to be successful in 2024
6. VOTE: BSF – NORD Agreement: The BSF Family Services Fund
- a. Emily asked for approval to have the Family Services Fund (pending approval of its creation later this meeting), administered by NORD, to provide financial assistance for participation in BSF sponsored conferences, programs, and workshops

- b. Initial funding level would be for \$20,000 plus 10% administrative fee and \$500 setup fee. Funding is aimed at assisting family travel (domestic and international) to the 2024 Conference
 - c. Goal is to help eight to 10 families, recognizing that the fund will not cover all costs for all families
 - d. Emily clarified that this is separate from the NORD-administered emergency relief fund
 - e. **APPROVED:** BSF to contract with NORD to administer a fund of \$20,000 to support travel to the 2024 conference, plus additional fees to cover the establishment and administration of the fund for a total commitment of \$22,500.
7. UPDATE: 2024 International Conference Draft Budget
- a. Michael Bowen reviewed the most recent conference budget:
 - i. Current expected cost is \$321,872
 - ii. Current expected deficit, after offsets, is \$166,389
8. VOTE: Restricted Gift Policy and BSF Restricted Funds
- a. All staff and invited guests left the meeting, except Emily
 - b. Kate reviewed the current BSF restricted funds, that total over \$4 million
 - c. Recommends a shift from funds named in honor of individuals to purpose funds and a broadening of several of the fund descriptions to be more closely in line with our mission statement
 - d. All three families involved in the creation of the current restricted funds, the McCurdys, Wilkins, and Woodwards, have endorsed removing family names from these funds to make it easier and more appealing for a wider group to fundraise for them and also are supportive of the revised fund definitions; each family has written a letter to the Board requesting these changes to the relevant fund
 - e. The new funds would be:
 - i. BSF Science and Medicine Fund
 - ii. BSF Therapy Development Fund
 - iii. BSF Family Services Fund
 - f. Kate reviewed the Restricted Gift Policy
 - i. Reinforced that once the funds have been donated, they are entirely within the control of the foundation within the guidelines for each fund
 - g. **APPROVED:** BSF Restricted Gift Policy
 - h. **APPROVED:** All three restricted fund name changes and descriptions

9. Executive Session took place exclusively with Board members in attendance.

10. Adjournment

a. Kate adjourned the meeting at 2:00 p.m. ET

Respectfully submitted,

Jamie Baffa – Secretary