

## MINUTES

Barth Syndrome Foundation, Inc.

Board of Directors Meeting

February 23, 2021

### **Members in Attendance:**

Kate McCurdy	Board Member, Chair
Emily Milligan	Board Member <i>ex officio</i> , Executive Director
Kevin Woodward	Board Member, Treasurer
Jamie Baffa	Board Member, Acting Secretary
David Axelrod, MD	Board Member
Matthew Blumenthal	Board Member
Megan Branagh	Board Member
Brandi Dague	Board Member
B.J. Develle	Board Member
Michelle Florez	Board Member
Florence Mannes	Board Member
Nina Russell, MD	Board Member
Peter van Loo	Board Member

### **Invited Guests**

Shelley Bowen	Director of Family Services, BSF
Erik Lontok	Director of Research, BSF
Susan McCormack	Chair, Policies & Agreements Committee
Brett Smith	Operations & Communications Lead, BSF
Stacey Woodward	Chair, Fundraising Committee

### **AGENDA**

1. *Welcome*
2. *VOTE: Approval of August 2020 and December 2020 Board Minutes*
3. *Discussion: Committee Initiatives*
4. *VOTE: New and Modified BSF Policies*
5. *VOTE: Candidates to Join Board of Directors in April 2021*
6. *VOTE: Candidate to Join Finance Committee in April 2021*
7. *Discussion: Update on 2020 Financials*
8. *Discussion & Approval: 2021-2023 Strategic Plan*
9. *Discussion & Approval: 2021 Strategic Priorities*
10. *Discussion & Approval: 2021 Operating Budget*
11. *Update: BSF Conference*
12. *Update: FDA Interaction*
13. *Other Business*
14. *VOTE: Additional Term for Board of Directors Members*
15. *Adjournment*

The meeting, held via Zoom, was called to order by Kate McCurdy on Tuesday, February 23 at 12 p.m. ET.

1. Welcome
  - a. Kate McCurdy welcomed everyone and called the meeting to order at 12:05 p.m. ET
2. VOTE: Approval of August 2020 and December 2020 Board Minutes
  - a. **APPROVED:** Board meeting minutes from August 2020
  - b. **APPROVED:** Board meeting minutes from December 2020
3. DISCUSSION: Committee Initiatives
  - a. Executive Committee
    - i. No update of substance from the Executive Committee
  - b. Board Development Committee
    - i. Our focus is on building the leadership pipeline—bringing people into the fold with experience that will help BSF over the long-term
    - ii. Built an experience grid that captures key areas of expertise for current board members so we can better anticipate current and future gaps
    - iii. Due to upcoming board departures, there will be future gaps in legal expertise, personal experience with heart transplants, and cardiology
    - iv. Proposed board members will help address these gaps
    - v. We have identified experience in BioTech, non-profit finance, and more as other areas of expertise we should bring into BSF
  - c. Finance & Investments Committee
    - i. We have worked on a proposed budget for 2021 and it is ready for board to review
    - ii. We have reviewed 2020 financials and will shared a detailed overview later this meeting
    - iii. Rebalanced our investment portfolio to move some assets away from cash and into equities
    - iv. We still have a conservative investment portfolio, overall
    - v. Setting up quarterly meetings with our investment manager, US Trust
    - vi. Reviewing retirement plan options for staff and expect to share options at a future board meeting
  - d. Fundraising Committee
    - i. Goals for 2021 include:
      1. Establish a major donor strategy
      2. Encourage our community to hold fundraisers even in a virtual environment
      3. Work with Christy to develop a sponsorship template—exploring conference specific and year-long options
      4. Identify another BSF-led fundraising opportunity outside of Giving Tuesday
      5. See if we can establish a permanent, on-demand shop for BSF merchandise

- 6. Working on a donor acknowledgement strategy
- e. Inclusion Committee
  - i. Just getting started
  - ii. B.J. is talking to individuals to get their input on the right structure, the right representation, and where the committee's focus should be
- f. Policy & Agreements Committee
  - i. BSF has a total of about 30 policies
  - ii. Goal is that we review these every three years, though we have fallen behind on this in the past
  - iii. Some of these policies are requirements, others are considered good practice
  - iv. Will present seven updated policies to the board today
  - v. Following the updates to these seven, there are only three policies that have not been reviewed and updated in the last three years
- 4. VOTE: New and Modified BSF Policies
  - a. Donor's Bill of Rights
    - i. Borrowed directly from the Association of Fundraising Professionals
    - ii. If we use this policy un-amended, need to be sure to accept and acknowledge that it came from the AFP
    - iii. **APPROVED** without amendment
  - b. Restricted Fund Usage Policy
    - i. Previous policy focused on specific funds controlled by BSF
    - ii. Revised the policy to generalized our approach
    - iii. There are two types of restricted funds
      - 1. Board restricted funds – those that the board has decided to restrict in a particular way
      - 2. Donor restricted funds – those that individual donors have decided to restrict in a particular way
    - iv. **APPROVED**
  - c. Privacy Policy
    - i. Significant overhaul of our privacy policy to generalize, removing references to specific people who are no longer with BSF, and to raise to current standards
    - ii. Unknown time of origin
    - iii. We are working on a separate record retention policy
    - iv. This policy will require further updates as we clarify the effects of GDPR and other similar laws across the world
    - v. **APPROVED**
  - d. Donor Confidentiality Policy
    - i. This policy hadn't been updated since 2005—our goal was to raise to contemporary standards
    - ii. Question was raised regarding other confidentiality policies (i.e., patient confidentiality)

- iii. No decision made on other confidentiality policies, but it was agreed that we would research other possible confidentiality policies that BSF should have and what they should look like
      - iv. **APPROVED**
    - e. Employment Policies
      - i. Relatively minor updates have been made to the employment policies
      - ii. Question was raised as to whether or not we need to include an affirmative action policy
      - iii. Matt Blumenthal raised that an affirmative action policy is not required
      - iv. Decision was made that we should remove reference to an affirmative action policy since BSF does not have one
      - v. **APPROVED** pending the removal of the reference to the affirmative action policy
    - f. Code of Ethics
      - i. Minor changes made to the code of ethics
      - ii. Ask that we update the values statement to reflect the addition of inclusion as a value
      - iii. **APPROVED** pending the addition of inclusion to the values statement and fixing of typos
    - g. Nomination Procedures for Board Members
      - i. Request for an additional change to indicate that BSF will coordinate the nomination processes for individual board members so that all members can begin their terms at the same time
      - ii. **APPROVED** pending updated language around timing
- 5. VOTE: New Board Members for April 2021
  - a. Kate McCurdy nominated Andrew Buddemeyer, JD to join the BSF Board of Directors in April 2021
    - i. **APPROVED**
  - b. Brandi Dague nominated Maryanne Chrisant, MD to join the BSF Board of Directors in April 2021
    - i. **APPROVED**
- 6. VOTE: New member of the Finance & Investments Committee for April 2021
  - a. Kevin Woodward nominated Mark Greene to join the Finance & Investments Committee in April 2021
    - i. **APPROVED**
- 7. Update on 2020 Financials
  - a. Our financials are in a strong position
  - b. BSF has ~ \$5.5mm in assets against ~\$200k in liabilities, putting us in position to meet our obligations and do all the things that we want to do as an organization
  - c. BSF had ~\$1.5mm in revenue in 2020, which may have been a record except for the year in which we received a \$1 million gift
  - d. ~\$330k came in the form of unrealized investment gains

- e. Want to acknowledge ~\$56k in donations from our affiliates above and beyond what they already do for our community
  - f. We had adjusted our revenue forecast down to \$800k due to uncertainty related to the pandemic
  - g. Because we have had surpluses in the last three years, totaling over \$1.5 million, we are now in a position to make important investments captured in the 2021 budget proposal
  - h. All of these figures include ~\$90k from a PPP loan that has yet to be forgiven, though we do not foresee any reason why it will not be forgiven
8. Update on 2021-2023 Strategic Plan
- a. The document presented is a single page representation of our strategic plan, designed primarily for communication purposes
  - b. Mission and Vision statements have not changed
  - c. Key change for the board to note is the addition of “development” to the research and development pillar
  - d. Represents that BSF is at a stage where we have a greater focus on therapies than we were able to in the past
  - e. Plan will be to share this slide during a town hall with our community in April
  - f. No changes or suggestions were offered to this draft
  - g. **APPROVED**
9. Update on 2021 Strategic Priorities
- a. Our strategic priorities are the actions we have planned for the next year to support our strategic plan
  - b. We have priorities across five categories
    - i. Research and Development
    - ii. Family Services
    - iii. Advocacy
    - iv. Fundraising and Communications
    - v. BSF Conference
  - c. Reviewed the priorities with minor comments throughout
  - d. Reviewed the annual scorecard with minor comments
10. Adjournment
- a. Kate McCurdy adjourned the meeting at 2 p.m. ET, as scheduled, with several items remaining on our agenda. Participants agreed to convene an additional meeting to discuss the 2021 budget proposal, hear updates on the upcoming conference and recent FDA interactions, and vote for additional terms for current board members. This meeting has since been scheduled for Friday, February 24 at 12 p.m. ET.

Respectfully submitted,

Jamie Baffa – Secretary