

MINUTES

Barth Syndrome Foundation, Inc.

Board of Directors Meeting

April 15, 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, Secretary
Florence Mannes	Board Member
Michelle Florez	Board Member
Peter van Loo	Board Member
Nina Russell, MD	Board Member
Brandi Dague	Board Member
B.J. Develle	Board Member
Megan Branagh	Board Member
Andrew Buddemeyer	Board Member
Maryanne Chrisant, MD	Board Member

Invited Guests

Shelley Bowen	Director of Family Services, BSF
Erik Lontok	Director of Research, BSF
Brett Smith	Operations & Communications Lead, BSF
Christy Balcells	Communications Consultant
Natalie Cohn	Controller
Stacey Woodward	Fundraising Committee, Chair
Bill Belcher	Audit Committee, Chair
Ed Baltazar	Auditor

AGENDA

1. *Vote: 2020 Financial Results and Audit*
2. *Discussion: Treasurer Update on 2021 Financials*
3. *Discussion and Approval: 2021 Fundraising Strategy and Plans*
4. *Discussion and Approval: 2022 and 2024 BSF Conferences*
5. *Discussion: BSF Interactions with FDA*
6. *Appreciation to Retiring Board Members*
7. *Vote: Board Secretary Officer*

The meeting, held via Zoom, was called to order by Kate McCurdy on Friday, April 15 at 12:03 p.m. ET.

1. Welcome

- a. Kate McCurdy welcomed everyone and called the meeting to order at 12:03 p.m. ET
- b. Kate specifically welcomed our two new board members: Dr. Maryanne Chrisant and Andrew Buddemeyer
- c. Andrew brings deep legal expertise to the BSF board as well as the perspective of an individual affected by Barth Syndrome who has had a heart transplant
- d. As a leading expert in pediatric cardiology and heart transplants Dr. Chrisant brings valuable insight and perspective to the BSF board
- e. Both Andrew and Maryanne introduced themselves to the rest of the board and shared their history with the Barth Syndrome Foundation
- f. Kate asked the board of directors to review the previously sent BOD reference materials
 - i. These materials are designed to serve as a living resources for members of the board and Kate welcomed feedback on the documents
- g. Next Kate moved to vote to approve minutes from previous meetings
- h. **APPROVED:** Minutes from February 2021 board meetings (2/23/21 and 2/26/21)
- i. **APPROVED:** Minutes from March research grant review meeting (3/13/21)
- j. Kate shared that the board had previously voted by email to approve Bill Pu at Boston Children's Hospital to reallocate \$2,500 of BSF grant funds that had previously earmarked for research into Barth genetic modifiers to other Barth research
 - i. Bill has received a Department of Defense (DoD) grant with significant overlap with BSF's award, which created this opportunity

2. Treasurer Update

- a. Kevin began by introducing himself to new board members
- b. Overall, Q1 was uneventful financially
 - i. Cancellation of the virtual conference resulted in no major changes to our full-year forecast
 - ii. We expect an extra \$25,000 in video service expenses, due to a desire to increase the use of multi-media as part of BSF's educational series
 - iii. We redeemed some credit card rewards
- c. BSF's finances remain on track with minimal reforecasting necessary
 - i. Most of BSF's revenue comes in the second half of the year
- d. BSF did experience a small loss in our investment portfolio and have a planned meeting with US Trust to discuss
- e. Kate reiterated that the plan is for BSF to run a deficit in 2021 to fund strategic initiatives

3. 2020 Audit Results

- a. Bill Belscher introduced Ed Baltazar as BSF's auditor
- b. Overall, the audit process went very smoothly
- c. Ed reviewed the balance sheets with the board and highlighted notable differences between 2019 and 2020
 - i. BSF's PPP loan was recorded as a grant since BSF meets the requirements for loan forgiveness

- d. Ed then reviewed the Statement of Functional Expenses and Notes to Financial Statement
 - i. Ed noted that nothing in these documents was surprising to him and there were no issues to elevate
 - e. Ed highlighted that BSF does not have any liquidity issues or concerns
 - f. For the Governance Report, the audit found no significant issues
 - g. Ed commended BSF for following through on recommendations from the previous audit
 - h. Management representation letters will be filled out at a later date
 - i. BSF internal reports align with what the auditors found
 - j. Ed was offered the chance to speak with the board without staff present to raise any questions or concern, but declined
 - i. Believe there was nothing that required a confidential conversation with the board
 - ii. Offered to speak with board members individually if they had questions
 - k. Kate opened the floor to comments, and none were received
 - l. **ACCEPTED:** The board voted to accept the findings from the 2020 audit
4. Fundraising Strategy
- a. Emily introduced the strategy and highlighted that it was informed by the fundraising committee
 - b. Christy Balcells shared the high-level thinking that went into the strategy
 - c. Stacey Woodward walked through BSF's fundraising priorities
 - i. HIGH PRIORITY
 - 1. Major donor strategy
 - 2. Corporate sponsorships
 - 3. Personalized donor acknowledgement
 - ii. MEDIUM PRIORITY
 - 1. Virtual fundraising event
 - 2. Increase grassroots participation
 - iii. LOW PRIORITY
 - 1. Advertising to attract new donors
 - 2. Gala-style events
 - 3. Swag shop
 - d. Looking at the data, most donations are driven by a personal connection and we want to take care of those who are already connected to BSF
 - e. High priorities
 - i. Major donor strategy
 - 1. 85% of BSF donations come from the top 10% of donors
 - 2. Major donors are those who donate \geq \$5,000
 - 3. Major donor prospects are those who donate \geq \$1,000
 - 4. Goal is to formalize a program to engage the individuals, retain their donation, and grow their commitment
 - ii. Corporate sponsorships

1. There's an opportunity to leverage existing programs and create sponsorship opportunities within them
 - iii. Personalized donor acknowledgements
 1. Proposed a tiered approach to acknowledging donors based on contribution level
 - f. The fundraising committee proposed a total incremental investment in fundraising of \$16,000
 - i. ~\$13,500 would go toward the cost of human labor required to formalize a major donor program in 2021-2022
 1. Volunteers can help, but need to account for additional human effort beyond that
 2. Final determination to be made whether to bring on new individuals or to reallocate efforts of existing staff
 - ii. ~\$2,500 would go toward material expense related to updated donor acknowledgement program
 - g. Emily opened the floor for discussion and questions
 - h. Members of the board raised questions regarding staff capacity, potential financial headwinds in 2021, the financial cost of these programs, and donor retention data
 - i. Various members of the board participated in the discussion with staff and members of the fundraising committee addressing any questions before moving to a vote
 - j. **APPROVED:** The board voted to approve the fundraising strategy and the required investment, as described above (\$16,000)
5. 2022 and 2024 BSF Conference Update
 - a. Emily and Shelley Bowen put forth the staff's proposal for the conference moving forward, which included:
 - i. Cancellation of the planned virtual conference in 2021
 - ii. Host the 2022 conference in person at the Hilton Clearwater
 - iii. Host the 2024 conference in person at the Hyatt Clearwater
 1. This would require Hyatt amending our current contract from 2023
 - b. This proposal was designed based on feedback from families and researchers in our community
 - c. Given the complexity and volume of contract negotiations associated with the conference, Michael Bowen has asked for assistance
 - i. Kirkland, LLP is connecting BSF with the American Bar Association (ABA) to see how they can help
 - d. Board members then raised questions about international participation given the slower vaccine rollout in certain parts of the world
 - e. Discussion ensued with staff ultimately acknowledging that we expect lower in-person turnout in 2022 than we have had historically but that it is incredibly important to bring together as many as can come from our community given how long it has been
 - f. We expect the 2022 conference to have a virtual component so we can be inclusive of those families unable to attend

- g. **APPROVED:** The board voted to approve staff working with the ABA to develop a contract for 2022 conference and explore an amendment for the 2024 conference with the Hyatt, with the goal to mitigate BSF's financial exposure in fees and penalties
- 6. Inclusion Committee
 - a. Kate reminded the board that we have added inclusion as a BSF value
 - b. The board had previously discussed creating an inclusion committee
 - c. BJ Develle then shared the proposal to lead a diversity and inclusion forum for the BSF community to inform future efforts
 - i. Jon Stokes and Iyar Mazar have agreed to assist with facilitation
 - d. **APPROVED:** The board voted to approve BJ moving forward with the diversity and inclusion forum as a Q2 initiative
- 7. FDA Update
 - a. There have been three meetings with the FDA since the previous board meeting in February
 - b. FDA is still looking for more data and we are working with Stealth to coordinate
 - c. Stealth remains committed to moving forward
 - d. Maryanne asked for the trial protocol which Kate promised to share, if able
 - i. Some discussion followed
- 8. Appreciation for Retiring Board Members
 - a. Kate acknowledged the contributions of David Axelrod and Matt Blumenthal and thanked them for their years of service
 - b. David and Matt were the first board members who were not direct family members and David was also the first physician. As such, both facilitated an important step in BSF's history in addition to their personal contributions to the organization
- 9. Vote to Approve Board Secretary
 - a. Kate asked Jamie Baffa to leave the meeting
 - b. Kate proposed to appoint Jamie as Board Secretary, removing "acting" from his title
 - c. The board discussed Jamie's nomination
 - d. **APPROVED:** The board voted to approve Jamie as Board Secretary
- 10. Adjournment
 - a. Kate McCurdy adjourned the meeting at 2:06 p.m. ET with no other business pending

Respectfully submitted,

Jamie Baffa – Secretary