

MINUTES

Barth Syndrome Foundation, Inc.

Board of Directors Meeting

February 26, 2021

Members in Attendance:

Kate McCurdy	Board Member, Chair
Jamie Baffa	Board Member, Acting Secretary
Michelle Florez	Board Member
Florence Mannes	Board Member
Emily Milligan	Board Member <i>ex officio</i> , Executive Director
Nina Russell, MD	Board Member
Peter van Loo	Board Member
Kevin Woodward	Board Member, Treasurer

Invited Guests

Shelley Bowen	Director of Family Services, BSF
Erik Lontok	Director of Research, BSF
Brett Smith	Operations & Communications Lead, BSF

Members NOT in Attendance:

David Axelrod, MD	Board Member
Matthew Blumenthal	Board Member
Megan Branagh	Board Member
Brandi Dague	Board Member
B.J. Develle	Board Member

AGENDA

1. *Discussion & Approval: 2021 Strategic Priorities*
2. *Discussion & Approval: 2021 Operating Budget*
3. *Update: FDA Interaction*
4. *Other Business*
5. *VOTE: Additional Term for Board of Directors Members*
6. *Adjournment*

The meeting, held via Zoom, was called to order by Kate McCurdy on Friday, February 26 at 12 p.m. ET.

1. Welcome
 - a. Kate McCurdy welcomed everyone and called the meeting to order at 12:02 p.m. ET; this is a continuation of the February 23, 2021 Board meeting agenda
2. Discussion & Approval: 2021 Strategic Priorities

- a. Emily provided a quick recap of our strategic priorities discussion from our previous meeting on February 23, 2021
3. Discussion & Approval: 2021 Operating Budget Priorities
- a. Over the past three years BSF has run a surplus of over \$1.5mm
 - b. The proposed operating budget purposefully reflects a deficit of ~\$200k as we intend to use the surplus from previous years to fund important investments
 - c. This includes ~\$355k worth of investments into specific strategic priorities
 - d. When looking at our revenue projections for 2021 ...
 - i. We are projecting less income from contributions compared to 2020 (projecting \$886k in 2021 against \$970 in actual contributions for 2020)
 - ii. BSF is not eligible for another PPP loan
 - iii. Our projections do not factor in unrealized gains in our investment portfolio
 - e. Risks to our budget in 2021 ...
 - i. One of the biggest was the cancellation of the Hilton contract for 2021
 - ii. Recently received word that Hilton will cancel the contract without penalty and return our \$15k deposit—this mitigates a substantial risk
 - f. Research investments for 2021 ...
 - i. We have allocated \$200k for baseline research
 - 1. May have found an additional study worth funding at an additional \$50k and will discuss during our grant meeting
 - ii. \$125k for a natural history study
 - iii. \$75k for drug repurposing and disease management
 - g. We are anticipating 84% of our expenses be dedicated to programming (~\$1.1mm)
 - i. 80% of expenses is a strong baseline that non-profits target
 - h. Not broken out in the budget is \$7.5k in legal fees for a GDPR review
 - i. No questions
 - j. **APPROVED:** 2021 Strategic Priorities
 - k. **APPROVED:** 2021 Operating Budget
 - l. Staff will work with Natalie every other month to update forecasts so we can get ahead of any issues
4. UPDATE: FDA Interaction
- a. On March 3, the FDA will host a listening session with members of the BSF community to better understand our willingness to accept uncertainty of benefit in potential treatments
 - b. Five members of our community will give personal testimonies
 - c. An additional five members of our community will participate in the discussion and answer questions
 - d. BSF is not allowed to record the meeting, and it is uncertain if FDA will produce minutes that can be shared
 - e. This meeting is not focused on a specific drug
5. Discussion and Approval: Board Expectations and Guidelines

- a. Kate reviewed the Board Expectations and Guidelines and shared that while some of these may be assumed, it is helpful to have them documented
 - b. Nina suggested adding “to attend and contribute to meetings” to the second bullet
 - c. Michelle suggested adding being flexible as an additional item, and Kate agreed to add
 - d. **APPROVED:** Board Expectations and Guidelines pending the addition of edits proposed by Nina and Michelle
6. VOTE: Additional Terms for Board Members
- a. Kate asked Florence to leave the call
 - b. Discussion amongst those present regarding the nominations of Florence Mannes and Megan Branagh to additional terms on the board
 - c. **APPROVED:** Megan Branagh to a second term on the board beginning April 2021
 - d. **APPROVED:** Florence Mannes to a third term on the board beginning April 2021
7. Adjournment
- a. Kate McCurdy adjourned the meeting at 12:52 p.m. ET with no other business pending

Respectfully submitted,

Jamie Baffa – Secretary