



Barth Syndrome
Foundation

Barth Syndrome Foundation, Inc. Board of Directors Meeting

December 8, 2020

Members in Attendance:

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

Members Not in Attendance

Florence Mannes	Board Member
Nina Russell MD	Board Member

Invited Guests

Bill Belscher	Chair, Audit
Shelley Bowen	Director of Family Services, BSF
Natalie Cohn	BSF Controller
Erik Lontok	Director of Research, BSF
Susan McCormack	Chair, Policies and Agreements Committee
Brett Smith	Operations & Communications Lead, BSF
Stacey Woodward	Chair, Fundraising Committee

Our Mission – Saving lives through education, advances in treatment, and finding a cure for Barth syndrome.

Agenda Items:

1. **Welcome**
2. **Update: BOD Member Resignation**
3. **Vote: Approval of October 2020 Board Meeting Minutes**
4. **Discussion: Committee Initiatives**
5. **Discussion: Treasurer Report**
6. **Vote: Grant Transfer (PI: Cade)**
7. **Discussion: 2021 Operating Budget and Timeline**
8. **Vote: Go/No-Go Decision In-Person Conference 2021**
9. **Discussion: FDA Update**
10. **Update: 2020 Organizational Goals**
11. **Other Business**

12. Adjournment

The meeting, held via Zoom, was called to order by Kate McCurdy, on Friday December 8, 2020 at 12pm ET.

1. **Welcome**
2. **Update: BOD Member Resignation**
 - a. Nicole Derusha-Mackey resigned from the Board and Committee. A replacement to the open Board seat will coincide with Board appointments in April. Board Development committee meeting on Dec 9th to discuss candidates. Goal is to install an acting secretary to be voted on at next Board meeting on Dec 12th. We look forward to continue to working with Nicole on our mission and thank her for her 4 years of service on the Board.
3. **Vote on approval of October 2020 Board minutes**
 - a. **Approved** October 2020 Board meeting minutes.
 - b. August Board Minutes will be voted on next time Board convenes.
4. **Discussion: Committee Initiatives**
 - a. Executive Committee (Kate McCurdy)
 - i. Most items are subject of today's Board meeting
 - b. Finance & Investments Committee (Kevin Woodward)
 - i. 2020 was a good year for BSF despite the challenges of COVID
 - ii. Finance Committee is putting together a proposed budget early in 2021
 - iii. Committee met with US Trust last week to make adjustments to cash and equities, rebalancing investment portfolio slightly and lowering BSF's fees
 - c. Policies & Agreements Committee (Susan McCormack)
 - i. Committee has been working hard reviewing policies
 - ii. 5 have been forwarded to the Board for approval, which will be voted on at the February Board meeting
 - iii. 6 remain under review, some requiring more thorough legal review
 - iv. Schedule going forward will be looked at every 2 to 3 years, as recommended by our auditors
 - d. Fundraising Committee (Stacey Woodward)
 - i. Committee still celebrating Giving Tuesday success
 - ii. Giving Tuesday required more effort to get people enthusiastic and engaged around fundraising
 - iii. T-shirt sale in the Fall, made about \$600
 - iv. Turning towards end of year letter appeal
 - v. BSF also added an end of year letter appeal
 - vi. 12-Days of Giving to drive engagement during virtual time to bring community together
 - vii. Improved process for acknowledgment letters as well as providing reports to solicitors for personalized appreciation
 - viii. Focus on corporate matches going forward
 - e. Board Development Committee (Kate McCurdy)
 - i. Not applicable
 - f. Audit Committee (Bill Belscher)
 - i. Dorfman has provided their fees for 2021
 - ii. Proposal is \$12,900 (audit as well as state filings) which is an 8% (or \$1k) increase over 2020 and consistent with industry standards
 - iii. Discussed, proposed, and **approved** to rehire Dorfman for 2021
 - iv. Bill to inform Dorfman we will proceed with their services
5. **Discussion: Treasurer Update** (Kevin Woodward)
 - a. As of October 30, team forecasts full-year net positive significantly above budget.
 - b. BSF's government PPP loan has also helped, assumed to be forgiven before audit in Q1 2021

- c. Donations forecasted to outperform budget across all areas of fundraising efforts
 - d. Organization has done our best to mitigate financial exposure due to cancellation of the 2020 Conference
 - e. BSF is going to experience a strong year financially in 2020
6. **Vote: Grant Transfer (PI: Cade)**
- a. Proposed and **approved** to transfer \$13k from Washington University to Duke University for same scope of work.
7. **Discussion: 2021 Operating Budget and Timeline**
- a. Goal is to finalize budget in January, but will not get voted on until February
 - b. Finance Committee will continue to work on budget
 - c. Coordinate with affiliates around distribution of reports and collateral
8. **Vote: Go/No-Go Decision In-Person Conference 2021**
- a. BSF sought input from families on listserv and social media to make decision a community-informed process
 - b. Overwhelmingly, people voiced that they did not think it was feasible to travel to/attend the in-person meeting, although many families remained hopeful that vaccines would be available by July
 - c. Physicians on the Board shared their perspective that it would be the safest and smartest approach to make a great virtual experience. Individuals would need to have access to vaccines and respond to the therapy in order for an indoor event to be safe. Presently, there is no pediatric vaccine on the horizon.
 - d. If international participants could not travel, that would also detract from the perceived value of the Conference and BSF's focus to be globally inclusive.
 - e. Discussed, proposed, and **approved** to:
 - i. Not host an in-person conference;
 - ii. Authorized to convert the conference into a virtual experience, doing our best to accommodate international participants; and
 - iii. Re-negotiate the contract with the Hilton, to mitigate BSF's financial exposure.
 - f. BSF will communicate to stakeholders as soon as the Hilton has been informed of the impossibility to hold an in-person conference
9. **Discussion: FDA Update**
- a. In November, BSF delivered the community petition, issued a press release, and coordinated a key opinion letter to FDA.
 - b. BSF has had representation at FDA/sponsor meetings to ensure they consider the patient voice in their decision-making process.
 - c. BSF is working with Division of Cardiology and Nephrology as well as the Rare Disease group to schedule a meeting and hear from BSF patients and caregivers early in 2021.
 - d. Further efforts may need to be coordinated by BSF to provide additional data to FDA.
10. **Update: 2020 Organizational Goals**
- a. 2020 was a year of pivoting.
 - b. The success of BSF's Virtual Scientific Symposium was a great testament to how BSF pivoted scientifically in 2020, absent examples to draw from at the time when BSF executed this event.
 - c. Financial performance was exemplar. BSF scaled back on expense line, overperformed on revenue.
 - d. BSF fostered a virtual community through the roundtable series, bringing together various constituents to create space for community and shared experiences and clinical guidance.
 - e. The strategic planning initiative shifted to a virtual setting. While not ideal, we progressed how we think about our research portfolio construction.
 - f. In the area of Advocacy, BSF secured more than 4200 signatures in support of our community petition and assisted with the key opinion leader letter to FDA.
 - g. BSF demonstrated that we were nimble and responsive to the changing environment to continue to advance our mission.

h. Volunteers were critical to all of these efforts and remain hugely important going forward.

11. Other Business

- a. Due to Brexit, Kirkland, LLP, can no longer represent BSF in mainland Europe beginning in 2021. Proposed and **approved** that Kilburn & Strode will take over pro bono trademark representation of BSF in mainland Europe.
- b. 2021 Board meetings to be scheduled in coming weeks.
- c. The Board went into executive session at 1:37pm EST to discuss staff compensation.

12. Adjournment

With no further business, Kate McCurdy adjourned the meeting at 1:55pm ET. The next Board of Directors' meeting is scheduled for Saturday, December 12, 2020 from 12 – 2pm ET.

Respectfully submitted,
Emily Milligan
Notetaker