

MINUTES

Barth Syndrome Foundation, Inc.

Board of Directors Meeting

June 16, 2021

Members in Attendance:

Kate McCurdy	Board Member, Chair
Emily Milligan	Board Member <i>ex officio</i> , Executive Director
Jamie Baffa	Board Member, Secretary
Florence Mannes	Board Member
Michelle Florez	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

Cristy Balcells	Fundraising Consultant
Michael Bowen	Policies & Agreements Committee
Shelley Bowen	Director of Family Services, BSF
Natalie Cohn	Controller
Erik Lontok	Director of Research, BSF
Susan McCormack	Policies & Agreements Committee, Chair
Steve McCurdy	Finance & Investment Committee
Brett Smith	Operations and Communications, BSF
Stacey Woodward	Fundraising Committee, Chair

Members in Not Attendance:

Kevin Woodward	Board Member, Treasurer
Peter van Loo	Board Member

AGENDA

1. *Discussion on Committee Initiatives*
 - a. *Executive*
 - b. *Audit*
 - c. *Board Development*
 - d. *Finance & Investments*
 - e. *Fundraising*
 - f. *Inclusion*

- g. *Policies & Agreements*
- 2. *Vote: Modified BSF Policies*
- 3. *Vote: Employee Benefits (Health Insurance)*
- 4. *Discussion: Treasurer Update on 2020 Financials*
- 5. *Focus Topic: BSF Communications*
- 6. *Discussions and Vote: 2022 Conference*
- 7. *Update: FDA Interaction*

The meeting, held via Zoom, was called to order by Kate McCurdy on Wednesday, June 16 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. Next Kate moved to vote to approve minutes from previous meetings, with two recommended revisions—no other board members suggested any revisions to meeting minutes,
 - c. **APPROVED:** Minutes from April 2021 board meeting, pending discussed revisions
- 2. Committee Updates
 - a. Executive Committee (Kate McCurdy)
 - i. Since the April board meeting, the Executive Committee has approved two investments for the foundation:
 - 1. \$6,750 per year for Wordly, a service that offers live translation services for 15 supported languages. BSF will use to make webinars and other events more accessible to Barth families from around the world.
 - 2. Up to \$600 to sponsor a June 18th social event for Barth siblings.
 - b. Audit Committee
 - i. *No update from the Audit Committee*
 - c. Board Development Committee
 - i. *No update from the Board Development Committee*
 - d. Finance & Investments Committee (Steve McCurdy)
 - i. Determined that 401k for staff is likely feasible from an economic and operationally perspective for the first time. Expect to bring a recommendation to the board at the August meeting.
 - ii. Scott Konrad and Hub were recommended by Mark Greene to conduct a risk assessment—this assessment has been completed and shared with the board.
 - iii. Recommendation for BSF to retain Scott and Hub as our broker, at no cost to BSF.
 - iv. **APPROVED:** BSF to retain Scott Konrad and Hub as our broker to help BSF determine additional insurance needs.
 - e. Fundraising Committee (Stacey Woodward)
 - i. Fundraising from the Islanders game went better than expected.

- ii. Happy Heart Week was a huge success—raised more than \$90,000 which included donations from first-time donors.
 - iii. Florence Mannes facilitated an auction for a BSF bottle of Miraval wine.
 - iv. Targeting a raffle fundraiser for late summer and a gaming related fundraiser during Q1 2022.
 - v. Christy is pursuing corporate sponsorship for the BSF webinar series.
 - f. Policies and Agreements (Susan McCormack)
 - i. Working on schedule to review policies every two to three years.
 - ii. One policy related to clinical studies and trials is outstanding —Erik is working on this with input from the SMAB and others. Committee will meet in July to review.
 - iii. Document retention policy has been revised but is with legal counsel to ensure it aligns with other work, including GDPR.
 - iv. Lobbying policy and guidelines has been updated.
 - 1. Non-profits are limited in how much they can spend on lobbying.
 - 2. This policy clarifies the difference between lobbying and advocacy to ensure we always maintain our non-profit status.
 - v. **APPROVED:** Updated lobbying policy and guidelines.
 - g. Inclusion (B.J. Develle)
 - i. BJ reiterated the plan to facilitate an inclusion forum with members of the BSF community.
 - ii. We have worked with partners to draft language that we will share with the community and ask for participants.
 - iii. Goal is to share with the community before the end of the summer.
 - iv. Kate asked if individuals can nominate other members of our community to participate.
 - 1. Yes, they can.
 - v. Jon Stokes and Iyar Mazar will help facilitate the conversation.
 - vi. We will provide Jon and Iyar additional context as they prepare for the conversation.
 - h. *Kate thanked the committees for their continued efforts and expressed confidence that the committee system is working as intended.*
- 3. Employee Benefits (Steve McCurdy)
 - a. BSF needs to renew its medical, vision, and dental insurance policies.
 - b. BSF's size and the fact that we are a New York based organization with no employees living in New York complicates this process.
 - c. Finance & Investments committee explored other options, including a Professional Employment Organizations (PEO).
 - d. PEOs provide outsourced HR, health insurance, payroll, and more.
 - i. They can purchase and execute these services at more competitive costs because of scale.

- e. Most PEOs require a minimum of five employees—but the PEO we have chosen (Insperity) would allow us to join with four and will give us a beneficial rate under the presumption that our long-term ambition is to hire a fifth employee.
 - f. Steve reviewed the two options available to BSF, renewing with United Healthcare or joining Insperity, in detail.
 - g. Insperity offers employees greater options, adds an HSA, and out of network coverage.
 - h. Regardless of which plan an employee chooses, BSF would fund 50% of the premiums for a “base” plan.
 - i. Even after \$11,000 PEO fee, BSF would come in under our current budget, while giving staff better health insurance options and significant savings.
 - j. Discussion about PEO and health insurance options took place.
 - k. **APPROVED:** Working with Insperity to provide health insurance for BSF staff.
 - l. Kate acknowledged the importance of a healthcare advocacy organization like BSF offering its employees great health insurance.
 - m. Steve acknowledged Natalie’s efforts in developing and analyzing the proposal.
4. Treasurer Update on 2020 Financials (Natalie Cohn)
- a. 990 is currently in progress and we expect a draft shortly—we are working on the state registrations that will follow.
 - b. We expressed appreciation for the partnership with Dorfman.
 - c. We have increased our donation forecast based on the success of Happy Heart Week and other efforts.
 - d. Cashing in on credit card rewards has helped us, too.
 - e. Investment income of \$100,000 (currently unrealized).
 - f. We may need to pay some research expenses in Q1 2022 instead of 2021, which will affect timing of forecasts but not the projects overall.
 - g. Overall, our budget is on track and everything is as expected.
5. BSF Communications (Emily Milligan and Brett Smith)
- a. Emily kicked off the discussion and shared that the goal is to start small by reconsidering our website needs.
 - b. Brett Smith provided an overview of how BSF communicates and the current state of the BSF website.
 - c. Offered three options for the path forward with the website:
 - i. Refine the content for search engine optimization (SEO) purposes.
 - ii. Simplify and refine the structure of the website.
 - iii. Pursue a complete overhaul of the website.
 - d. Emily shared how the website is foundational to how BSF communicates and how we can reach new people.
 - e. Discussion followed among board members and staff.
 - f. Staff to come back with a formal recommendation at a future board meeting based on input from board conversation.
6. 2022 Conference (Emily Milligan)

- a. Emily reviewed the decisions and discussions to date, as well as the cost considerations for hosting the conference at the Hilton Clearwater in 2022.
 - i. For the 2020 conference, BSF's contracted costs were \$93,800.
 - ii. For the 2022 conference, BSF's contracted costs are expected to be \$99,000.
 - iii. The biggest cost increase is due to room rates rising from \$159 to \$185 per night.
 - 1. This is because the market price for these rooms has increased as well.
 - b. With assistance from the American Bar Association, we were able to secure favorable cancellation terms and flexibility on the room requirements.
 - c. For 2024, the Hyatt contract terms did not change at all.
 - d. Discussion followed among board members and staff.
 - e. **APPROVED:** Staff to move forward with signing the Hilton contract for 2022
 - f. **APPROVED:** Staff to move forward with signing the Hyatt contract for 2024
7. FDA Interactions
- a. FDA remains very engaged with BSF and with Stealth.
 - b. BSF's project manager at the FDA has been changed to a more senior person.
8. Adjournment
- a. Kate McCurdy adjourned the meeting at 2:04 p.m. ET with no other business pending.

Respectfully submitted,

Jamie Baffa – Secretary