

MINUTES

Barth Syndrome Foundation, Inc.

Board of Directors Meeting

December 14, 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
Nina Russell, MD	Board Member
Brandi Dague	Board Member
B.J. Develle	Board Member
Megan Branagh	Board Member
Andrew Buddemeyer	Board Member
Peter van Loo	Board Member

Invited Guests

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

Members in Not Attendance:

Maryanne Chrisant, MD	Board Member
-----------------------	--------------

AGENDA

1. *Discussion on Committee Initiatives*
 - a. *Fundraising*
 - b. *Inclusion*
2. *Vote: Updated BSF Policies and Procedures*
3. *Discussion: Treasurer Update on 2021 Financials*
4. *Discussion: 2021 BSF Accomplishments*
5. *Discussion: 2022 BSF Goals*
6. *Discussion: Preliminary 2022 Operating Budget*
7. *Amended 2022 BSF Board Meeting Schedule*

8. Executive Session

The meeting, held via Zoom, was called to order by Kate McCurdy on Tuesday, December 14 at 12:01 p.m. ET.

1. Welcome
 - a. Kate McCurdy welcomed everyone and called the meeting to order at 12:01 p.m. ET
 - b. Given that the board did not receive the October minutes until shortly before this meeting, Kate asked that board members send any requested edits and their approval of the minutes via email following the meeting
2. Committee Updates
 - a. Fundraising Committee (Stacey Woodward)
 - i. Giving Tuesday update
 1. BSF hit its goal of \$100,000 with a similar number of donors to last year[KM1]
 2. Encouraged by the participation of newer families to our community
 3. Stacey acknowledged Christy Balcells' contribution to make sure Giving Tuesday was a success
 - ii. Development and Stewardship Manager hiring
 1. Emily shared that she has interviewed 10 people for the role and hopes to have a short list in December
 2. Stacey also raised that the committee is looking for additional volunteers
 - b. Diversity (BJ Develle)
 - i. Started with a reminder that we decided to start with a focus group instead of committee
 - ii. There was low interest, but Jon and Iyar conducted several interviews
 - iii. Feedback from these conversations included
 1. Some of the forms that we use are fit around a "mom" and "dad" structure and we should update these documents to be more inclusive
 2. Concern about cliques within our community, specifically newer families versus older families
 3. We share private information in groups with greater public access and there's a need for community members to be sensitive to others' privacy
 4. The larger our community gets, the more segmented we become by health issues, family structure, and other factors
 5. End of life care is a challenging topic—we have historically avoided this and we may consider revisiting how we approach this topic
 - iv. BJ recommended that we take this feedback and act on it, and revisit the need for a committee a year from now
 - v. **APPROVED:** We defer on creating a Diversity Committee for the time being as we act on the feedback gathered
3. Updated Policies and Procedures (Susan McCormack)

- a. Susan started with a recap on our approach to policies
- b. Reinforced that the expectation is that the committee policies should be reviewed on an annual basis
- c. Susan then moved to review updated policies
 - i. Diversity and nondiscrimination policy
 - 1. Changes were minor, largely focused on updating language to current expectations and usage
 - 2. Kate suggested minor edits to clarify that BSF's policy promotes diversity
 - 3. **APPROVED:** With Kate's edits
 - ii. Gift Acceptance Policy
 - 1. Streamlined some of the language
 - 2. Updated for today's technology
 - 3. Kate suggested updating the language around the responsibility for paying associated expenses
 - 4. Discussion followed regarding gifts of securities
 - 5. **APPROVED:** With Kate's edits
 - iii. Evaluating Organization Effectiveness
 - 1. Minor edits made and suggested
 - 2. **APPROVED**
 - iv. Operating Reserve Policy
 - 1. Policy was previously written with "hard" numbers
 - 2. Susan reviewed what we mean by "Operating Reserve"
 - 3. Kate suggested clarifying "Operating Budget" within the policy so that it doesn't include grant agreements and research contracts not paid from the general fund
 - 4. Kate asked to table this policy until we can understand where we stand right now
 - 5. Emily will follow up with Natalie to get the necessary information so we can reevaluate in January
 - v. Animal Use Policy
 - 1. Erik has reviewed and has been using the language in research contracts
 - 2. If we change this language, we would need to change language in other places as well
 - 3. **APPROVED**
 - vi. Board of Directors Attendance Policy
 - 1. Used to have a hard number that we have changed to 75% of planned meetings
 - 2. Added language to account for virtual board meetings
 - 3. Discussion followed about language regarding virtual meetings and required number of meetings
 - 4. **APPROVED:** With discussed edits
 - vii. Committee policies
 - 1. Susan shared that there were no material edits to the committee agreements that were distributed to board members
 - 2. Finance and Investments committee to update their policy in January
 - 3. **APPROVED:** Audit, Board Development, Fundraising, Policies and Agreements, and Executive Committees

4. Update on 2021 Financials (Kevin Woodward)
 - a. Overall, the foundation is in an excellent position
 - b. We had originally planned to run a deficit this year, based on our strategic plan, but that is no longer the case
 - c. Currently we are projecting to be \$500,000 above forecast (\$300,000 surplus versus \$200,000 deficit)
 - d. There were a few factors driving this
 - i. Fundraising exceeded expectations, especially with major donors
 1. However, we do not expect the major donor increases to be recurring
 - ii. Research agreement costs came in lower than expected, in part because the Arrhythmia Project has been pushed to next year
 1. BSF France's contribution toward the Arrhythmia Project will also be pushed to next year
 - iii. Solid year from an investment performance perspective
 - e. Discussion followed
 - f. Forecasted that we will be able to review final numbers in January
5. 2021 Organizational Achievements
 - a. Emily reinforced that we set a number of goals for 2021 and we want to reflect on what we've achieved over the past year
 - b. Emily invited board members to comments and share feedback
 - c. Desire is to discuss 2022 goals before we approve a budget in February
 - d. Emily asked staff to share their achievements from 2021
 - e. Erik reviewed R&D achievements in 2021
 - i. Implement solutions to optimize grant program post-award management
 - ii. Use platforms to create GDPR/HIPAA compliant community surveys and merge existing BSF data assets
 - iii. Strengthened relationships by bringing affiliates into co-funded grantee progress reports
 - iv. Research policy updates and revisions
 - v. Connecting with additional industry partners and non-profit / academic institutions
 - vi. Realizing past collaboration with co-funded awards and public-private research efforts such as "What Is Barth Tired?"
 - vii. Eric emphasized there is still a lot more that BSF wants to do
 - viii. Beyond the grant program, we are pursuing strategic efforts such as the Gene Therapy Roadmap with Clive Spiegler and hiring Prasoan Agarwal PhD to manage the Variants Database with Iris Gonzalez retiring
 - ix. Emily emphasized how BSF is much more active in designing the protocols for human subjects, helping with study recruitment
 - x. Arrhythmia Project
 1. Emily is hopeful that we'll have feedback from NYU Langone on BSF's agreements with them
 2. Represents a shift from being a passive funder toward being a more active partner
 - f. Shelley reviewed Family Services achievements in 2021
 - i. Major accomplishment was launching the "We Care" initiative to support our families going through hardship, and we had a wonderful response

- ii. Created opportunities for newer families to hear from older individuals with Barth syndrome
 - iii. Christy Balcells launched virtual yoga and has offered to continue this as long as it's helpful
 - iv. We also wanted to strengthen the bond with our younger affected individuals given how hard it's been over the past two years, and we received the suggestion to do a talent show for the end of the year
 - v. Brought together families and it was incredibly fun and well-received
 - g. Emily touched on 2021 Advocacy Achievements
 - i. We had hoped for some better outcomes in terms of potential therapy approvals, but incredibly proud of the work we did and what we were able to achieve
 - ii. Shelley shared work BSF has done with Project Sunshine to develop Rare Teleplay
 - 1. We were able to serve as a test group with the goal of expanding to other rare diseases similar to Barth syndrome
 - h. Brett reviewed communications achievements in 2021
 - i. Doubled the frequency of the newsletter, now quarterly
 - 1. Distribution of about 4,000
 - ii. Refreshed our email strategy and platform
 - 1. Open rate has increased from 18% to 29%
 - iii. Social media presence has been strong this year
 - iv. Creating a plugin for Barthcares.org
 - v. Improving our donor acknowledgement
 - i. Emily reviewed fundraising achievements in 2021
 - i. We wanted to broaden our audience beyond our immediate community
 - ii. Cabo fundraiser didn't quite meet aspirations, but hopeful that hiring a Development and Stewardship Manager can move us more in this direction
 - iii. Swag shop opened
 - iv. Acknowledged volunteers' contributions to making Giving Tuesday a success
 - v. We had great success with major donors this year, and Emily acknowledged Steve McCurdy's work in making this happen
 - j. Members voiced their appreciation for all that staff has accomplished
- 6. 2022 Operating Budget (Kate McCurdy)
 - a. We'll spend most of our time discussing this during the February meeting, especially when it comes to strategic initiatives
 - b. Only includes expenses at the moment—what we are targeting to spend next year as an organization
 - c. Does not include strategic investments and research grants above our baseline
 - d. Kevin reviewed the estimated expenses for 2022
 - i. Highlighted that additional spending on two new hires is driving up our expenses
 - ii. Forecasted a conservative estimate on Conference expenses--we are hoping to reduce these further
 - iii. Additional expenses planned for improved medical insurance and introduction of 401k for staff
- 7. FDA Update

- a. Kate attended another meeting with Stealth and FDA and believes the door is not closed—but cannot say more than that
- 8. Board Schedule
 - a. Kate reminded the board that the 2022 meeting schedule has been updated
- 9. Gene Therapy Session
 - a. Invited board to meeting with Clive Spiegler on 1/6 during which he will present his Gene Therapy Roadmap to the board
- 10. Executive Sessions
 - a. Asked staff and committee members not on the board to leave the conversation
 - i. Kate asked the board to either share feedback on Emily or email directly to Kate by the end of the year.
 - ii. Discussion and vote regarding cost-of-living increase and bonus pools for staff
- 11. Adjournment
 - a. Kate McCurdy adjourned the meeting at 2:13 p.m. ET with the understanding the board would schedule an ad hoc meeting to discuss the 2022 conference

Respectfully submitted,

Jamie Baffa – Secretary