

## MINUTES

Barth Syndrome Foundation, Inc.

Board of Directors Meeting

August 18, 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
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**

Shelley Bowen	Director of Family Services, BSF
Brett Smith	Operations and Communications, BSF
Erik Lontok	Director of Research, BSF
Bill Belscher	Audit Committee, Chair

### **Members in Not Attendance:**

Peter van Loo	Board Member
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## **AGENDA**

1. *Discussion on Committee Initiatives*
  - a. *Executive*
  - b. *Audit*
  - c. *Board Development*
  - d. *Finance & Investments*
  - e. *Fundraising*
  - f. *Inclusion*
  - g. *Policies & Agreements*
2. *Focus Topic: BSF Family Services*
3. *Discussion: 2022 Conference*
4. *Discussion: Treasurer Update on 2021 Financials*
5. *Vote: BSF TAFAZZIN Database*

## 6. *Update: FDA Interaction*

The meeting, held via Zoom, was called to order by Kate McCurdy on Wednesday, August 18 at 12:04 p.m. ET.

1. Welcome
  - a. Kate McCurdy welcomed everyone and called the meeting to order at 12:04 p.m. ET
  - b. Next Kate moved to vote to approve minutes from previous meetings, with several minor revisions—no other board members suggested any revisions to meeting minutes,
  - c. **APPROVED:** Minutes from June2021 board meeting, pending discussed revisions
2. Committee Updates
  - a. Executive Committee (Kate McCurdy)
    - i. *No update from the Executive Committee*
  - b. Audit Committee
    - i. Bill Belscher walked through BSF’s Form 990 and explained its purpose to the board
    - ii. Kate made several suggested changes to BSF’s form 990 and clarified that the board is required to review and have the opportunity to comment
  - c. Fundraising Committee
    - i. Emily provided an update on Fundraising Committee activities
      1. BSF launched a new sweepstakes for a trip to Cabo with the goal of expanding our reach outside of our immediate community
      2. BSF preparing to launch the swag shop in September under Megan’s leadership
      3. Preparation for Giving Tuesday is underway—theme will be “This Is Barth Syndrome” to celebrate our people and their life milestones
  - d. Inclusion
    - i. BJ recapped our plan to host a forum focused on inclusion
    - ii. Two individuals raised their hands to participate and share their perspective
      1. Decision made to interview these two individuals to get their input rather than hosting a forum
      2. Iyar and Jon to conduct the interviews
    - iii. Board reiterated its commitment to making BSF more inclusive
    - iv. Expectation was set that we would revisit the idea of a forum next year to see if there is more interest within the community
    - v. Kate suggested we include an article in the next BSF Beat to highlight what we have done
    - vi. Bill offered to share resources that he can access through his work at PWC
  - e. Policy and Agreements
    - i. *No new updates at this time*
3. Family Services
  - a. Shelley Bowen provided an overview of Family Services as a refresher for the board

- i. Goal of Family Services is to meet the needs of our families
  - ii. We engage in advocacy work, specifically working with our families to share their stories
- b. Then reviewed major highlights of what Family Services has accomplished, including
  - i. Updating and expanding our fact sheet library to educate families about Barth Syndrome, all of which are available on our website
  - ii. Hosting the first global, virtual meetup in June of 2020
  - iii. Growing our social media presence and making our virtual resources more inclusive by introducing Wordly to provide live translations
    - 1. BSF has received positive feedback on Wordly when it was used during a recent webinar focused on the effect of COVID-19 on transplant patients
  - iv. Creating social connection by bringing members of our community together through virtual gatherings, including roundtables for affected individuals, parents of young children, siblings, etc.
- c. BSF Cares
  - i. Family Services is introducing a new program with the goal of being there for our families in tough times and celebrating together in good times
  - ii. This is a harmonious initiative with our international affiliates
  - iii. What we plan to do includes:
    - 1. Using QR codes to make it easier to access and share important resources
    - 2. Creating a bereavement program
      - a. BSF has engaged an artist in Asheville, NC to create a custom inventory of ornaments for families of those who lost their lives to Barth syndrome
    - 3. Implementing a system where people can easily send e-cards of encouragement in difficult times
    - 4. Organizing volunteers to mail cards for birthdays, anniversaries, etc.
      - a. This includes working with someone in South Carolina to create custom teddy bears for those dealing with long-term illness
    - 5. Sharing “Cups of Care” mugs for parents
      - a. Families will also received a branded tin of cookies
  - iv. Family Services is creating an inventory of who has received what to make sure we are being fair and equitable
  - v. Estimated budget impact
    - 1. \$1,715 to build and execute for the remainder of the year
    - 2. \$3,100 estimated annual costs
    - 3. Largely volunteer-driven, which helps from a budgeting perspective
  - vi. Board engaged in discussion regarding BSF Cares
  - vii. **APPROVED:** \$1,715 investment for BSF Cares
- d. Family Services and Research

- i. Shelley shared the difficulty of recruiting for ongoing BSF “Barth tired” research study
    - ii. Discussion ensued about communications and persistent challenges within our community
- 4. 2022 Conference
  - a. Emily raised the question if BSF can stay the course or if we should change directions given current COVID trends
  - b. Planning the Conference takes a huge amount of staff’s attention / resources, and we also rely heavily on volunteers who have expressed apprehension about moving forward
  - c. Board discussed Conference and potential outcomes
- 5. Financial Update
  - a. Kevin Woodward shared an updated on our investment policy
    - i. BSF started with a very conservative position
    - ii. Six months ago, BSF decided we needed to update our investment policy to reflect an increased appetite for risk
    - iii. Thus, we worked with US Trust to make the following changes
      - 1. Lowered our cash limit from 15% to 10%
      - 2. Raised equities limit from 22% to 32%
      - 3. Lowered fixed income from 63% to 58%
      - 4. Other small changes not noted during the Board meeting
    - iv. Kate shared how US Trust asked BSF to look at operational and strategic cash flow to inform further changes
      - 1. Finance and Investments committee is working on this and will discuss with US Trust
  - b. Emily shared current financial position for BSF
    - i. BSF is trending less than one percent behind forecast, but no noted concerns
- 6. Tafazzin Database Proposal
  - a. Erik Lontok shared the history of the Tafazzin database run by Iris Gonzalez and the process for identifying others to take over management of the database
  - b. Emphasized that the search process has been thorough and highlighted Iris’ involvement in making sure BSF makes the right decision
  - c. Erik presented a proposal from Prasoon Agarwal, PhD, that will require an initial investment of \$9,500 to set up and migrate the database with a recurring annual investment of \$3,000 to manage
  - d. Both Erik and Iris endorse this proposal
  - e. **APPROVED:** Acceptance of Prasoon Agarwal’s, PhD, proposal and the required investment
- 7. FDA Update
  - a. Kate provided an update on interactions with Stealth and FDA
  - b. Stealth announced it will submit a New Drug Application (NDA) for Elamipitride by the end of August
  - c. BSF is planning for all possible outcomes

- d. Discussion amongst the Board
- 8. Adjournment
  - a. Kate McCurdy adjourned the meeting at 2:06 p.m. ET with no other business pending

Respectfully submitted,

Jamie Baffa – Secretary