

MINUTES

Barth Syndrome Foundation, Inc.

Board of Directors Meeting

June 23, 2022

Members in Attendance:

Andrew Buddemeyer	Board Member
Brandi Dague	Board Member
Emily Milligan	Board Member <i>ex officio</i> , Executive Director
Florence Mannes	Board Member
Jamie Baffa	Board Member, Secretary
Kate McCurdy	Board Member, Chair
Kevin Woodward	Board Member, Treasurer
Mark Greene	Board Member
Megan Branagh	Board Member
Michelle Florez	Board Member
Miriam Greenberg	Board Member

Invited Guests

Barbara Tucciarone	National Organization for Rare Disorders (NORD)
Bill Belscher	Audit Committee, Chair
Brett Smith	Operations and Communications, BSF
Erik Lontok	Director of Research, BSF
Melissa Huang	Clinical Research Coordinator, BSF
Shelley Bowen	Director of Family Services, BSF

Members in Not Attendance:

B.J. Develle	Board Member
Maryanne Chrisant, MD	Board Member
Nina Russell, MD	Board Member
Peter van Loo	Board Member

AGENDA

1. *Welcome*
2. *Vote: Board Minutes*
3. *Update: #Stronger Together World Tour*
4. *Update: Treasurer Report*
5. *Update: 2022 SciMed Symposium*
6. *Discussion and Vote: Conference 2023 v 2024*
7. *Discussion and Vote: "Barth Cares" Emergency Relief Program*
8. *Update: Gene Therapy Roadmap*
9. *Discussion: BSF FDA KOL Workshop*
10. *Other Business: Fundraising FTE*

The meeting, held via Zoom, was called to order by Kate McCurdy on Thursday, June 23 at 12:05 p.m. ET.

1. Welcome
 - a. Kate McCurdy welcomed board members and invited guests
2. Vote: Board Minutes and Record Offline Votes
 - a. Jamie Baffa asked for a vote on the February board meeting, March research grant meeting, and April board meeting minutes with no edits having been suggested over email
 - b. **APPROVED:** February board meeting, March research grant meeting, and April board meeting minutes as written
 - c. Mark Greene and Miriam Greenberg abstained from voting on the February board meeting minutes and March research grant meeting minutes due to not being on the board at that time
 - d. **APPROVED:** On May 23, 2022, the Board approved an offline vote for BSF staff to work with the Mayo Clinic to develop a US-based MLCL/CL ratio diagnostic for Barth syndrome. The initiative is at no financial cost to BSF.
3. Update: #Stronger Together World Tour
 - a. Summaries of locations, dates, registration numbers and agendas were presented.
 - b. Shelley Bowen highlighted the foundation's work with local EMS organizations and guidance shared with attendees to prepare for possible medical emergencies
 - c. Five families applied for funding through NORD and all five were approved for funding
 - d. Florence Mannes shared that the Paris stop will need to move to a different date to accommodate their desired speaker
 - e. The foundation had budgeted \$100,000 for the Stronger Together World Tour, but expenses are currently tracking closer to \$50,000
 - f. The foundation negotiated significant discounts for families attending tour stops in the US, with rooms discounted from nearly \$400 down to close to \$200 per night
 - g. Melissa Huang reviewed onsite research process for tour stops, including that registration will allow the foundation to gather information to create Global Unique Identifiers (GUIDs) for research participants
 - h. Kate and Emily Milligan reinforced the importance of creating GUIDs, or global unique research IDs, to make sure that each patient has a secure and de-identified ID number that enables data to be linked across research studies, (including the arrhythmia project), without breaching a patient's privacy
 - i. Discussion followed
 - j. Emily reviewed proposed COVID safety protocols for the Stronger Together World Tour stops in the US, which include:

- i. Any individuals who are feeling ill are asked to stay home
 - ii. No vaccine or booster will be required, unless specified by the venue or local public health protocols
 - iii. No COVID-19 negative test will be required
 - iv. BSF will provide KN95 masks, hand sanitizer, and rapid tests for all attendees, though their use will not be required
 - v. BSF will provide color-coded wrist bands to allow attendees to indicate their social distancing preferences, and these wrist bands can be swapped during the tour stop if comfort levels change
 - vi. All registrants must sign a waiver that specifically addresses COVID
 - k. **APPROVED:** COVID safety protocols as proposed for July tour stops, understanding they may evolve for future stops
4. Update: Treasurer's Report
- a. Kevin Woodward shared the foundation's investment portfolio is down, but less than the overall market given our conservative investment strategy
 - b. In the budget summary moving forward, unrealized gains and losses within our portfolio will be accounted for as a separate line item, to differentiate operating results from unrealized investment figures
 - c. Reframed "revenue" to "operating revenue" in the report based on this change
 - d. The foundation remains on target to meet operating revenue projections for the year
 - e. Kevin forecasted a meeting with Bank of America to review the investment portfolio, but is not expecting major changes to the foundation's approach
5. Update: 2022 SciMed Virtual Symposium
- a. Erik Lontok shared a detailed review of the agenda for the SciMed Virtual Symposium
 - b. Emily encouraged board members to attend the Symposium as their calendars allow
6. Discussion and Vote: Conference 2023 v 2024
- a. Emily recapped recent decisions related to the conference and feedback from SciMed participants
 - b. Hilton Clearwater is unavailable during the dates the foundation would prefer in 2023, and prices are increasing substantially
 - c. The foundation currently has a \$5,000 deposit with the Hilton that we would need to work to recoup if we were to cancel our contract with the Hilton for 2023
 - d. Emily proposed that the foundation cancel with the Hilton in 2023 and that the foundation proceed with the current agreement to host the next conference at the Hyatt Clearwater in 2024
 - e. **APPROVED:** The foundation will cancel its 2023 contract with the Hilton and commit to hosting a full international conference at the Hyatt in 2024, with the intention to host additional smaller gatherings in the US and Europe in 2023 as we are this year

- f. The foundation's contract with CVENT has been postponed multiple times and they are asking for an additional commitment to them for 2026 (in addition to 2024) if the foundation postpones again; \$13,000 has been paid so far and might be at risk if we decide not to sign contract
 - g. **APPROVED:** The foundation will amend its contract with CVENT for 2024 and agree to the request for a contract for 2026 at the same rate
7. Discussion and Vote: "Barth Cares" Emergency Relief Program
- a. Emily introduced Barbara Tucciarone from NORD and the work they are doing to establish and manage an emergency relief program for Barth syndrome
 - b. Barbara shared a video introducing NORD, the work they do, and information about the proposed "Barth Cares" emergency relief program
 - c. Barbara then shared greater detailed regarding how the program would work and what it would cover for families
 - i. Only U.S. citizens and permanent residents of at least six months will be eligible for the program, based on NORD's ability to administer
 - ii. Program will assist those affected by Barth syndrome and their families who have experienced hospitalization or death due to Barth syndrome in the past 12 months
 - iii. Maximum award will be \$750 per individual with Barth syndrome per year, to assist with non-medical expenses
 - iv. Up to 20 patients per year can benefit from the program
 - d. The foundation will pay NORD a fee of 10% to administer this program
 - e. Overall budget impact will be \$17,000 per year, against \$20,000 we have budgeted for such a program in 2022
 - f. Shelley shared the perspective of the Family Services Working Group and their support for the program
 - g. Emily forecasted a conversation with the Finance & Investments committee on how the foundation will manage the program from a financial perspective
 - h. **APPROVED:** The foundation to contract with NORD to establish and manage an emergency relief program for Barth syndrome, with the parameters listed above
8. Update: Gene Therapy Roadmap
- a. Erik shared an update on the various Gene Therapy efforts, including the signing of a three-way CDA between Provention Bio, the University of Florida, and the foundation
 - b. Expect an initial response to the BGTC applications for Barth syndrome by the end of July
9. Discussion: BSF FDA KOL Workshop
- a. Kate shared that Stealth has been granted a pre-NDA meeting with the FDA to review new data
 - b. Expect this meeting to happen in Q3 of 2022

- c. The foundation is helping Stealth on a KOL letter
- d. The foundation will also have its own meeting with the Department of Cardiology and Nephrology at the FDA to discuss possible drug development pathways for Barth syndrome as well as clinical endpoints and trial design

10. Other Business: Fundraising FTE

- a. Emily shared that the foundation did not renew Loree Tillman's contract and that Emily is working with the fundraising committee on next steps
- b. There will likely be an offline vote regarding E&I (our possible new IRB) as they have recently been acquired, so we need to do some more due diligence but may need a vote before our next board meeting

11. Adjournment

- a. Kate McCurdy adjourned the meeting at 2:05 p.m. ET

Respectfully submitted,

Jamie Baffa – Secretary