

**MINUTES**  
**Barth Syndrome Foundation, Inc.**  
**Board of Directors Meeting**  
**April 25, 2022**

**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
Andrew Buddemeyer	Board Member
Florence Mannes	Board Member
Mark Greene	Board Member
Megan Branagh	Board Member
Michelle Florez	Board Member
Miriam Greenberg, PhD	Board Member
Peter van Loo	Board Member
B.J. Develle	Board Member

**Invited Guests**

Bill Belscher	Audit Committee, Chair
Brett Smith	Operations and Communications, BSF
Edward Baltazar	Dorfman, Abrams, Music
Erik Lontok, PhD	Director of Research, BSF
Loree Tillman	Development and Stewardship Manager, BSF
Melissa Huang	Clinical Research Coordinator, BSF
Natalie Cohn	Controller
Stacey Woodward	Fundraising Committee, Chair
Steve McCurdy	Finance & Investments Committee
Melissa Huang	Clinical Research Coordinator

**Members in Not Attendance:**

Brandi Dague	Board Member
Maryanne Chrisant, MD	Board Member
Nina Russell, MD	Board Member

**AGENDA**

1. *Welcome*
2. *Vote: Board Minutes and Record Offline Votes*
3. *Discussion: Committee Updates*
4. *2021 Financials & Audit Report*

5. *Discussion and Votes: SciMed Update*
6. *Update: #StrongerTogether World Tour*
7. *Report and Discussion: Update on 2022 Q1 Financials*

The meeting, held via Zoom, was called to order by Kate McCurdy on Monday, April 25 at 12:03 p.m. ET.

1. Welcome
  - a. Kate McCurdy welcomed our two new board members – Miriam Greenberg, PhD and Marc Greene
  - b. Kate shared the board resource handbook and reiterated her ask that board members share any feedback
2. Vote: Board Minutes and Record Offline Votes
  - a. Jamie Baffa asked for a vote on the February minutes with no edits having been suggested over email
  - b. **APPROVED:** February minutes
  - c. Jamie reviewed offline votes taken since the last board meeting, including:
    - i. Approval of the December minutes
    - ii. Approval of the following members of the SMAB for an additional term:
      1. Brian Feingold, MD MS – 4-year term
      2. Colin Steward, PhD FRCP FRCPC – 1-year term
      3. Grant Hatch, PhD – 1-year term
      4. Michio Hirano, MD – 4-year term
      5. Miriam Greenberg, PhD – 4-year term
      6. Ronald Wanders, PhD – 4-year term
3. Discussion: Committee Updates
  - a. Kate shared that in the interest of preserving time, committees shared written updates as a pre-read to this meeting
  - b. There were no questions about the updates provided by the committees
4. 2021 Financials & Audit Report
  - a. Edward Baltazar, BSF's auditor, walked through both the 2021 Financials with Audit Report and the 2021 Governance Report produced by Dorfman, Abrams, Music
  - b. There were no significant concerns in either document
  - c. Ed clarified that the foundation needs to provide or point to the full audit report when we refer to information in the report as audited financial results
  - d. Ed offered a closed session for the board alone if desired; none was requested
  - e. **ACCEPTED:** 2021 Financials with Audit Report and 2021 Governance Report

## 5. Discussion and Votes: SciMed Update

- a. Erik Lontok reviewed the current state of SciMed and the foundation's approach to research and development
- b. IRB protocol
  - i. Erik reinforced the importance of a consistent and broad IRB protocol that aligns with the work outlined in the foundation's strategic investments
  - ii. Erik proposed that the foundation work with E&I to develop an IRB protocol for the foundation and end its agreement with WCG
  - iii. Emily Milligan shared there would be an incremental investment between \$4,000 and \$10,000 to wind down the relationship with WCG and to begin working with E&I, however, there would be no net effect on this year's budget as we no longer anticipate spending funds on biosamples this year
  - iv. The ongoing maintenance cost to work with E&I is less than it would be to continue with WCG
  - v. **APPROVED:** BSF to partner with E&I to develop IRB protocol
- c. Arrhythmia project update
  - i. Erik shared an update on the arrhythmia project, including a revised, four-year timeline
  - ii. Emily noted that contract negotiations, specifically the language regarding the sharing of data across institutions, has proved challenging
  - iii. Emily shared that this is difficult work that few organizations are willing to do, but that the foundation's goal is to build the infrastructure needed for a natural history of Barth syndrome
  - iv. Erik clarified that the IRB protocol for BSF and the arrhythmia project, while distinct, will be similar
  - v. Additional discussion followed
- d. TCT Investment
  - i. Erik summarized the funding history of enzyme replacement therapy and what it's taken to get to where it is today
  - ii. Dr. Michael Chin began his research at the University of Washington and has since moved to Tufts University
  - iii. University of Washington owns the patents related to Dr. Chin's research and his company, Transcellular Therapeutics (TCT), has been paying licensing fees since he moved to Tufts
  - iv. Erik proposed that the foundation invest in TCT via a convertible note of \$25,000 to support the patent and license costs related to Barth syndrome enzyme replacement therapy
  - v. This amount will cover patent costs through the end of 2023

- vi. Steve McCurdy explained what a convertible note is and shared that this investment will give the foundation greater influence in the business operations of TCT as it hopefully grows
    - vii. Steve reinforced that while \$25,000 will not show on our financial reports as an expense given that it is an investment, the foundation should view this as a grant (a cost) given the high level of risk
    - viii. **APPROVED:** BSF to invest \$25,000 in TCT via a convertible note
  - e. Gene Therapy Update
    - i. Erik shared an update on the foundation's gene therapy roadmap
    - ii. Discussion followed
- 6. Update: #StrongerTogether World Tour
  - a. Emily provided an update on the planning for the Stronger Together World Tour
  - b. Emily noted that the foundation has contacted the National Organization for Rare Disorders (NORD) and confirmed that BSF families can leverage their Rare Disease Educational Support Program to help fund their travel costs
  - c. Staff is also exploring the idea of a staff retreat connected to one of the tour stops, though no budget has been set at this time
- 7. Report and Discussion: 2022 Q1 Financials
  - a. Kevin Woodward shared an update on current financials, noting that both spending and revenue are on target
  - b. The foundation did not update its financial forecasts at the end of Q1 as financials are on target
  - c. Kevin noted that we have not yet spent funds allocated toward strategic investments
  - d. Our investment portfolio is down but is in line with the market
- 8. FDA Update
  - a. Kate shared that she and Emily are in the process of scheduling another meeting with the FDA
- 9. Adjournment
  - a. Kate McCurdy adjourned the meeting at 2:05 p.m. ET

Respectfully submitted,

Jamie Baffa – Secretary