Barth Syndrome Foundation, Inc.
Board of Directors Meeting
3 & 4 Oct 2020

Our Mission – Saving lives through education, advances in treatment, and finding a cure for Barth syndrome

DIRECTORS
Members in Attendance:
Kate McCurdy Chair, Board Member
David Axelrod Board Member
Jamie Baffa Board Member
Matthew Blumenthal Board Member
Megan Branagh Board Member
Brandi Dague Board Member
Nicole Derusha-Mackey Secretary, Board Member
B.J. Develle Board Member
Michelle Florez Board Member
Florence Mannes Board Member
Emily Milligan Board Member, ex-officio
Nina Russell Board Member
Peter van Loo Board Member

Members Not in Attendance:
Kevin Woodward Treasurer, Board Member

INVITED GUESTS

Staff/Consultants:
Shelley Bowen Director of Family Services, BSF
Julia Greenstein Moderator
Erik Lontok Director of Research, BSF
Brett Smith Operations & Communications Lead, BSF

Advisors:
Michael Schlame SMAB Chair
Todd Cade SMAB
Gerry Cox Gene Therapy Advisory Group Member, BSF
Brain Feingold SMAB
The meeting, held via Zoom, was called to order by Kate McCurdy, on Saturday, October 3, 2020, at 12pm EST. This meeting, being a discussion with scientific experts as well as members of BSF’s governing bodies, consisted of the following purpose, goals, and agenda.

**Purpose:**
The Research Strategic Planning process will set BSF’s research priorities, and focus energy and resources to support those priorities over the next 3-5 years. The purpose is to ensure that employees and other stakeholders work toward common goals and establish agreement around intended outcomes/results. Ultimately, the process will produce fundamental decisions that will shape and guide what BSF does, why we do it, and how we will know if we’ve achieved our goals.

**Goals:**
1. Provide sufficient background information about research and development for the Board to be able to use a data-informed approach to strategic planning of BSF’s research efforts
2. Establish a baseline understanding of BSF’s historical experience in advancing treatments and finding a potential cure through various research mechanisms
3. Identify key research gaps with input from expert advisors and discuss opportunities for BSF to address these gaps in specific focus areas
4. Understand current trends in the roles of rare disease nonprofits and the life science ecosystem
5. Take an organizational inventory of BSF’s strengths, weaknesses, opportunities, and threats as they pertain to advancing research and therapies to end suffering and loss of life from Barth syndrome
**Agenda:**

**October 3**

Participants: BOD, Former Chairpersons, & Staff Only

11:00 Welcome, Introductions and Goals of Meeting - Kate and Emily (20 min)
11:20 Review of Research and Development – Julia Greenstein (30 min/10 min Q&A)
12:00 Break

Participants: BOD, Former Chairpersons, SMAB, External Advisors, & Staff

12:15 What We Know about BTHS: Focus Area Review - Erik (45 min/15 min Q&A)
1:15 Research Tools
   Registry outlook and rationale - Erik (5 min)
   Pulse program review - Femida Gwadry-Sridhar (30 min/20 min Q&A)
2:10 Future Opportunities Discussion - All Participants (35 min)
2:45 Wrap-up - Kate and Emily (15 min)
3:00 Day 1 Concludes

**October 4**

Participants: BOD, Former Chairpersons, & Staff Only

11:00 Reflections on yesterday’s meeting - All Participants (35 min)
11:35 Role of cutting-edge non-profits in therapy dev. - Jen Farmer (30 min/10 Q&A)
12:15 Break
12:40 Attracting downstream partners - Emily (5 min)
   Stealth and TAZPOWER learnings - Reenie McCarthy (20 min/10 min Q&A)
1:15 Strategic Collaborations - Erik (30 min)
1:45 Guided discussion: Strategy and BSF SWOT analysis - Julia and Kate (60 min)
2:45 Wrap-up and next steps - Kate and Emily (15 min)
3:00 Day 2 Concludes

Board input and recommendations regarding strategic priorities emerging from this meeting will be discussed and decided at a subsequent meeting. A full recording of this meeting is available on Vimeo. Contact Brett Smith (brett.smith@barthsyndrome.org) for access to the recordings of these meet