



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
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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

Miriam Greenberg	SMAB
Grant Hatch	SMAB
Michio Hirano	SMAB
John Jefferies	SMAB
Bill Pu	SMAB
Mindong Ren	SMAB
Colin Steward	SMAB
Arnie Strauss	SMAB
Hilary Vernon	SMAB
Ron Wanders	SMAB

Former Chairpersons:

Susan McCormack	Former BSF Chairperson
Steve McCurdy	Former BSF Chairperson
Marc Sernel	Former BSF Chairperson

Presenters:

Brian Blakey	CBO, Stealth BioTherapeutics
Jen Farmer	CEO, FARA
Femida Gwadry-Sridhar	CEO and Founder, Pulse InfoFrame
Reenie McCarthy	CEO, Stealth BioTherapeutics

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

