



Barth Syndrome Foundation, Inc.
Board of Directors Meeting
August 21, 2020

Members in Attendance:

Kate McCurdy	Chair, Board Member
David Axelrod, MD	Board Member
Jamie Baffa	Board Member
Matthew Blumenthal	Board Member
Megan Branagh	Board Member
Brandi Dague	Board Member
B.J. Develle	Board Member
Michelle Florez	Board Member
Emily Milligan	Board Member, <i>ex-officio</i>
Nina Russell MD	Board Member
Peter van Loo	Board Member
Kevin Woodward	Treasurer, Board Member

Members Not in Attendance

Nicole Derusha-Mackey	Secretary, Board Member
Florence Mannes	Board Member

Invited Guests

Shelley Bowen	Director of Family Services, BSF
Natalie Cohn	BSF Controller
Erik Lontok	Director of Research, BSF
Susan McCormack	Chair, Policies and Agreements Committee
Brett Smith	Operations & Communications Lead, BSF
Stacey Woodward	Chair, Fundraising Committee

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

Agenda Items:

1. **Welcome**
2. **Vote on approval of June 2020 Board minutes**
3. **Discussion: Committee Initiatives**
4. **Vote: Committee Members**
5. **Discussion: Treasurer Report**
6. **Discussion: Family Services Program Strategic Guidance**
7. **Presentation: 2020-2021 Research Grant Cycle**
8. **Vote: SMAB Nominations**
9. **Update: Pulse Infrane Discovery Project of BSF Registry**
10. **Update: Strategic Planning Meeting in October 2020**
11. **Other Business**
12. **Adjournment**

The meeting, held via Zoom, was called to order by Kate McCurdy, on Friday August 21, 2020 at 1pm ET.

1. **Welcome**
 - a. Kate McCurdy welcomed everyone and called the meeting to order at 1:05pm
2. **Vote on approval of June 2020 Board minutes and ratification of email vote since last Board meeting**
 - a. **Approved** June 2020 Board meeting minutes with slight amendments
 - b. **Ratified** Board email vote taken since last board meeting to **approve** the revised contract with Hyatt Regency Coconut Point for July 2023 International Barth conference
3. **Discussion: Committee Initiatives**
 - a. Executive Committee (Kate McCurdy)
 - i. Hope to hire a Development Director at some point in the future but not during Covid time
 - ii. In the future we want to review our website but we do not have the resources to do it now
 - b. Finance & Investments Committee (Kevin Woodward)
 - i. We are revamping the format of our financial reports (to be discussed more later in this meeting)
 - c. Policies & Agreements Committee (Susan McCormack)
 - i. Hardworking committee and Brett Smith has joined as *ad hoc* member
 - ii. Have been looking into creation of an Inclusion Committee – have passed draft document onto Kate McCurdy to take to the Board
 - iii. Make sure all the governing policies and procedures are necessary, well-written and up to date every year or two; addressing 9 policies currently
 - d. Fundraising Committee (Stacey Woodward)
 - i. Committee working really well
 - ii. They are producing 30 second video re: even though we are in a pandemic and have had to change our conference to be virtual, BSF is still doing good work and please donate
 - iii. Encourage people to get involved in various year-end fundraising campaigns
 - iv. Major donor program under development; mostly focused on retention of former donors but want to reach new donors as well; ultimately a new Development Director could really help with this
 - v. Kate McCurdy asked that, regardless of amount, we are asking that all Board members please to donate to BSF; very important that there is 100% participation
 - e. Board Development Committee (Kate McCurdy)
 - i. Terrific committee
 - ii. Instituted “Buddy system” for new board members for first few meetings; new members also will have phone calls with various constituents as introductions
 - f. Council of Affected Individuals (Peter van Loo)
 - i. Brand new
 - ii. Purpose is to furnish insight into what affected individuals need and want
 - iii. Don’t have any minutes yet (still working on a name) but thinking about what projects they might do and how they might help BSF
4. **Vote on Committee Members** (Kate McCurdy)
 - a. Nomination, discussion about and **approval** of Palmer Lummis as Audit Committee member
5. **Discussion: Family Services Program Strategic Guidance** (Emily Milligan and Shelley Bowen)
 - a. Purpose of Family Services program: foster caring global community that offers each affected family and his/her family knowledge, resources, guidance and emotional support
 - b. Objectives
 - i. Advance collaboration amongst clinicians to improve health outcomes for people affected by BTHS

- ii. Educate individuals and their families to help them understand the various symptoms of this complex disease and help them navigate its management
 - iii. Grow and nurture a caring and supportive community to help empower affected individuals and their families
 - iv. Integrate healthcare providers into BSF family programs and global community so there is a two-way benefit of increasing knowledge
 - v. Support individuals, families and physicians in their quest to obtain a diagnosis and throughout the Barth syndrome journey
 - c. Productive strategic discussion of what we should be aspiring to achieve in Family Services in the next 1-3 years globally; ideas will be incorporated into the BSF Strategic plan by end of the year
6. **Discussion: Treasurer Update** (Kevin Woodward)
- a. Have revised and clarified BSF's monthly financial reporting format so that it is more easily digestible by the Board and more appropriate for management and strategic decision making
 - b. Overall full-year forecast is essentially at break even, a favorable situation vs. what was budgeted
 - c. Donations now forecast to be above budget
 - d. BSF has benefitted from quick pivoting of the staff to deal with Covid pandemic
 - e. Investment account is with US Trust in conservative portfolio and is doing well
7. **Presentation: 2020-2021 Research Grant Cycle** (Erik Lontok)
- a. Announced 2021 research grant cycle yesterday; applications due Nov. 2, 2020; then peer reviewed; final awards voted on by Board in March 2021
 - b. No specific RFAs this cycle; we will discuss our priorities at strategic planning meeting later this year; also will consider idea of strategic research agreements and contracts in addition to seed grant program
8. **Vote on SMAB Nominations** (Erik Lontok)
- a. Five SMAB members discussed, proposed and **approved** to have their 4-year SMAB terms renewed:
 - i. Michael Schlame MD - also Chair
 - ii. Todd Cade PT, PhD
 - iii. William Pu MD
 - iv. Mindong Ren PhD
 - v. Arnold Strauss MD (wanted us to know that he will be retiring soon)
 - b. Discussed, proposed and **approved** the nomination of Riekelt Houtkoper PhD from the Amsterdam Medical Center as a new SMAB member
9. **Update on Pulse Inframe Discovery Project of BSF Registry** (Erik Lontok)
- a. All their interviews have been completed
 - b. They are delving into the details of existing data
 - c. Goal is to have report done for the Board's review in October
10. **Update on Strategic Planning Meeting in October 2020** (Kate McCurdy)
- a. Will focus on the scientific and medical priorities of BSF
 - b. October 3-4, 2020 (Day 1 - review landscape with our Board and several outside advisors; Day 2 – Board discussion of BSF's science and medical priorities)
 - c. Will be virtual meeting
11. **Other Business** (Kate McCurdy)
- a. Elamipretide trial update
 - b. BSF considering our own advocacy efforts (BSF direct interactions with the FDA and perhaps a petition to them as well)
12. **Adjournment**
- a. With no further business, Kate McCurdy adjourned the meeting at 3:08pm ET. The next Board of Directors' meeting is scheduled for Saturday, October 3, 2020 from 11am – 3pm ET.

Respectfully submitted,
Kate McCurdy
Notetaker