



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
July 10, 2019

Members in Attendance:

Susan A. McCormack	Chair, Board Member
David Axelrod, MD	Board Member
Megan Branagh	Board Member
Nicole Derusha-Mackey	Board Member
B.J. Develle	Board Member
Michelle Florez	Board Member
Florence Mannes	Board Member
Stephen B. McCurdy	Chairman <i>Emeritus</i>
Emily Milligan	Board Member, <i>ex-officio</i>
John Wilkins	Secretary, Board Member
Kevin Woodward	Treasurer, Board Member

Members Not in Attendance

Matthew Blumenthal	Board Member
Brandi Dague	Board Member

Invited Guest

Lynda Sedefian, Executive Assistant

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

Agenda Items:

1. Discussion: Financial Update
2. Discussion: BSF Registry Update
3. Discussion & Vote: Governance Committee Chair
4. Discussion & Vote: Proposed By-Law Change
5. Discussion & Vote: Proposed Policy for Creation of Fundraising Committee
6. Discussion & Vote: Election of Fundraising Committee Chair
7. Discussion: Portfolio Review Summary and Next Steps
8. Review: Summary of Action Steps
9. Board Executive Session

The meeting, held via GoToMeeting, was called to order by Ms. McCormack, on Wednesday, July 10, 2019, at 12:00 pm ET.

1. **Discussion – Financial Update**

Mr. Woodward presented the YTD financial position as of 6/30/2019 for BSF which showed:

- Total Revenues of \$640,382
- Total Expenses of \$795,599; and a Deficiency of Revenue over Expenditures of \$155,217
- Total Net Assets of \$4,757,147

The Board recommended that Mr. Woodward schedule a meeting with BSF's Finance Committee and US Trust to review BSF's investment portfolio. Following this meeting, Mr. Woodward will report back to the Board on its findings.*

Ms. Milligan informed the Board that BSF's 2018 Annual Report will be distributed via email on July 11, 2019, as well as via ground mail the week of July 15th to constituents in the US. Also, a "Breakthroughs for Barth" \$10,000 challenge will be distributed on July 11th via email and social media.

2. **Discussion – BSF Registry Update**

Ms. Milligan presented a top-level overview of BSF's registry outlining analysis and efforts to date. As a result of the Portfolio Review meeting that was held on June 19, 2019, it was recommended that BSF seek input to identify specific ways BSF should prioritize the registry. A meeting will be scheduled in early August to continue this discussion.*

3. **Discussion & Vote: Governance Committee Chair**

Ms. McCormack notified the Board that Ms. Branagh has resigned from the role of Chair of the Governance Committee. Ms. Michelle Florez has accepted the offer from the Board to serve as Chair of this Committee.

VOTED: To elect Ms. Florez as Chair of the Governance Committee

The Board thanked Ms. Branagh and the Governance Committee for their work reviewing the Foundation's policies and procedures to ensure compliance with the National Health Council, Better Business Bureau and other regulatory bodies.

4. **Discussion & Vote – Proposed Change to By-Laws**

Ms. McCormack proposed the following change to BSF's By-Laws:

"Section 17. Additional Standing Committees. The following four committees shall be governed by their respective Board-approved policy documents:

- a) Finance and Investments Committee
- b) Audit Committee
- c) Governance Committee
- d) Fundraising Committee

Each Committee's policy document will be reviewed annually by the Governance Committee. Any proposed changes to such policy documents must be approved by a majority vote of the Board of Directors."

VOTED: To adopt the proposed change to BSF's By-Laws, as stated above.

5. Discussion & Vote – Proposed Policy for Creation of Fundraising Committee

Ms. McCormack submitted a proposed policy for the creation of the Fundraising Committee, outlining the roles and responsibilities of this Committee.

VOTED: To adopt the proposed Policy Regarding Fundraising Committee, as submitted on this date.

6. Discussion & Vote – Election of Fundraising Committee Chair

Ms. McCormack informed the Board that Ms. Nicole Derusha-Mackey has offered to serve as Chair of the Fundraising Committee.

VOTED: To elect Ms. Derusha-Mackey as Chair of the Fundraising Committee.

7. Discussion & Vote – Proposed Collaboration with Anavex Life Sciences Corporation

Ms. Milligan presented to the Board a proposed collaboration with Anavex Life Sciences Corporation to fund testing of the ANAVEX2-73 in the Barth KO mouse at Boston Children's Hospital (BCH) (PI: Bill Pu). BSF's grant to BCH is an off-cycle award to explore the potential therapeutic benefit of investigational drug ANAVEX2-73 in Barth syndrome.

VOTED: To allow Ms. Milligan to move forward with contracting to fund up to \$60,000 for BCH grant proposal: The effect of Anavex 2-73 on mouse models of Barth syndrome (PI: Bill Pu). Approval contingent on Anavex agreeing to contribute up \$70,000 to support the tri-party collaboration.

8. Discussion: Portfolio Review Summary and Next Steps

Ms. Milligan provided a detailed summary of the Portfolio Review meeting that was held on June 19, 2019, including recommendations/suggestions and proposed next steps. Following an in-depth discussion, it was recommended that the Board form a committee to prioritize next steps going forward. Mr. McCurdy has offered to reside on this committee, along with Ms. Kate McCurdy, Ms. Milligan and Ms. McCormack. *

9. Review – Summary of Action Steps:

Ms. McCormack summarized the actions steps:

- Mr. Woodward will schedule a meeting with the Finance Committee and US Trust to review BSF's investment portfolio. Following the meeting, he will report back to the Board.
- The Board has been asked if they would be willing to match a portion of the \$10,000 Breakthroughs for Barth Campaign. Board members have been asked to contact Ms. Milligan if they are willing to provide a matching gift.
- Ms. Sedefian is in the process of scheduling a meeting in early August to seek input to identify specific ways BSF should prioritize the registry.
- Ms. Sedefian will update the By-Laws and upload to the website

- Ms. Sedefian will update the Governance Committee roster on the website to include Ms. Florez as Chair
- Ms. Sedefian will upload the Policy for the Fundraising Committee to the website
- Once the Fundraising Committee members have been elected, Ms. Sedefian will update the website to include the Fundraising Committee roster
- Ms. Milligan will form a committee to prioritize next steps from the Portfolio Review meeting recommendations and will call a meeting of this committee.

At this time, Ms. Sedefian left the meeting and a Board Executive Session commenced.

Adjournment

The meeting was adjourned at 1:45 pm ET. The next Board of Directors meeting is scheduled for Saturday, October 19, 2019 @ 11:00 am ET. The next Executive Committee meeting is scheduled for Thursday, September 12, 2019 @ 12:00 pm ET.

Respectfully submitted,

John Wilkins
Secretary