



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
July 17, 2018

Members in Attendance:

Susan A. McCormack	Chair, Board Member
Megan Branagh	Board Member
Nicole Derusha-Mackey	Board Member
B.J. Develle	Board Member
Florence Mannes	Board Member
John Wilkins	Board Member
Kevin Woodward	Treasurer, Board Member
Stephen B. McCurdy	Chairman <i>Emeritus</i>

Members Not in Attendance

David Axelrod, MD	Board Member
Matthew Blumenthal	Board Member
Catharine Lynne Ritter	Board Member

Invited Guests:

Paola Cazzaniga, President, Barth Italia Onlus
Michaela Damin, Board of Directors, Barth Syndrome Trust (UK)
Susan Hone, President, Barth Syndrome Foundation of Canada
Professor Amelia Morrone, Translator, Barth Italia Onlus
Lynda Sedefian, Executive Assistant, BSF

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

Agenda Items:

1. Ratification of Minutes
2. Discussion & Vote – Stealth’s use of BSF Logo
3. Discussion & Vote – Proposed Executive Committee Policy
4. Discussion & Vote – Customer Relation Management (CRM) System
5. Discussion – BSF Board Candidate Conference Target List
6. Discussion – Proposed By-Laws Change
7. Discussion – BSF Strategic Plan

The meeting, held via face-to-face in Clearwater Beach, Florida, was called to order by Susan McCormack, on Tuesday, July 17, 2018, at 6:50 pm ET. Susan welcomed members of BSF’s affiliates who were invited to join the meeting to provide updates.

Susan thanked the affiliate leads for their very informative updates. At this time the affiliate leads adjourned.

1. Ratification of Minutes

The Board approved the April 9, 2018 Board minutes, as submitted on this date.

2. Discussion & Vote – Stealth BioTherapeutic’s Use of BSF Logo

Susan McCormack reported that Stealth BioTherapeutics has requested permission to use BSF’s logo on their “Fact Sheet” about Barth syndrome. After discussion, it was

VOTED: To allow Stealth BioTherapeutics to use BSF’s logo on the “Fact Sheet” on Barth syndrome contingent upon the recommendations discussed at today’s meeting.

3. Discussion & Vote – Proposed Executive Committee Policy

Susan McCormack reported that the Executive Committee has drafted a proposed Executive Committee Policy for review. After discussion, it was

VOTED: To approve the Executive Committee Policy contingent upon the discussion at today’s meeting.

4. Discussion & Vote – Customer Relation Management (CRM) System

Emily Milligan reported that BSF acquired Bloomerang in 2013 as a fundraising and donor relationship management tool. To date, Bloomerang has solely been implemented as a transaction repository with minimal donor data. In order to achieve BSF’s fundraising goals and diversity revenue sources, BSF must consider whether to proceed with a full implementation of Bloomerang, understanding that there are significant limitations to the platform; or procure an alternative comprehensive solution such as the non-profit version of Salesforce. After discussion, it was decided to table this issue for a future Board meeting.*

5. Discussion – BSF Board Candidate Conference Target List

Susan McCormack provided an update on proposed candidates for board membership. After a discussion, board members were assigned the task of engaging in a preliminary conversation with the proposed candidates to assess their interest in BSF and its mission.

6. Discussion – Proposed By-Laws Change

Susan McCormack proposed a change to BSF’s By-Laws to change the name of the Nominating Committee to Governance committee.*

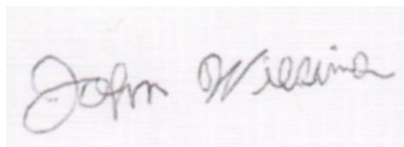
7. Discussion – BSF Strategic Plan

Emily Milligan provided a template of BSF’s strategic plan including strategic goals, deliverables, metrics and current impact. Emily, along with BSF’s staff, will work to update BSF’s strategic plan to prioritize aligning staff inputs with strategic plan outputs, as prioritized by the Board. If required, a plan will be proposed to adequately resource efforts and infrastructure to support BSF’s strategic priorities.*

Adjournment

The Board of Directors adjourned the meeting at 9:15 pm EDT. The next Board meeting will be held via teleconference on Tuesday, August 28, 2018 @ 12:00 pm EDT. The next Executive Committee meeting is scheduled for Tuesday, September 18, 2018 @ 12:00 pm EDT.

Respectfully submitted,



John Wilkins
Secretary