



# MINUTES

Barth Syndrome Foundation, Inc.  
Board of Directors Meeting  
October 23, 2018

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**Members in Attendance:**

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

**Members Not in Attendance**

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

**Invited Guests:**

Lynda Sedefian, Executive Assistant  
Kate McCurdy, *Ex-officio*, SMAB  
Matthew J. Toth, PhD, Science Director

***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 – Science/Medicine Strategy
3. Discussion & Vote – Barth Registry & Repository (BRR)
4. Discussion & Vote – Election of Members & Chairs for New Committees
5. Discussion & Vote – Approval of Contract for 2020 Conference Venue
6. Discussion – Year-to-Date Financials
7. Discussion – Communications Plan Update

The meeting, held via GoToMeeting, was called to order by Susan McCormack, on Tuesday, October 23, 2018, at 12:00 pm ET. Susan welcomed Brandi Dague and Michelle Florez to the meeting and thanked them for their willingness to serve on the Board for a three-year term, commencing on this date.

**1. Ratification of Minutes**

The Board approved the August 28, 2018 Board minutes, as submitted on this date.

**2. Science/Medicine Strategy**

Matthew Toth provided an overview on science/medicine strategies and therapeutic areas relevant to Barth syndrome. After a detailed discussion, it was agreed upon that BSF would encourage and support specific therapeutic areas to maximize BSF’s impact on the BTHS landscape. A meeting will be held in Spring 2019 to discuss these therapeutic areas. External experts in industry, together with members of BSF’s Scientific and Medical Advisory Board and Board of Directors, will be invited to participate. This meeting will be funded by the Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome.\*

**VOTED:** This motion was unanimously approved by the Board to allow a budget of up to \$45,000 to host this off-conference-year meeting in Spring 2019.

*At this time, Matthew Toth and Kate McCurdy exited the meeting.*

**3. Barth Registry & Repository (BRR)**

Emily Milligan reported that as a result of the August 28<sup>th</sup> Board meeting, it was agreed upon that BSF continue diligence and determine whether BSF should maintain a full-scale registry & repository (or just a registry or just a repository). As such, BSF staff was tasked with answering the Board’s questions to facilitate an informed decision. After a detailed discussion, it was

**VOTED:** To provide a budget of up to \$10,000 for Emily Milligan to hire a consultant to advise BSF on its role in resourcing a full scale BRR; an unlinked registry; and/or an unlinked repository.

**VOTED:** To allow Emily to finalize the contract with University of Florida for the current BRR 2.0.

This item has been placed on the next Board meeting’s agenda for follow-up discussion.\*

**4. Election of Members & Chairs for New Committees**

Susan McCormack provided an update on the election of Chairs and Members of new Board Committees, as follows:

<b>Audit Committee</b>	<b>Finance &amp; Investments Committee</b>	<b>Governance Committee</b>
Stephen McCurdy, Chair Bill Belscher, Member John Wilkins, Member	Kevin Woodward, Chair Rosemary Baffa, Member Kelsey Bastian, Member Susan McCormack, Member	Megan Branagh, Chair Michaela Damin, Member Nicole Derusha-Mackey, Member Chris Hope, Member Florence Mannes, Member Tracy Torbert, Member

**VOTED:** To accept the election of new Committee Members and Chairs.

**5. Approval of Contract for 2020 Conference Venue**

Emily Milligan advised the Board that due diligence has been served for securing a venue for BSF’s 2020 conference. Emily provided an overview of venue comparisons. Following a detailed discussion, it was

**VOTED:** To approve the contract with Hilton Clearwater Beach for BSF’s 2020 conference.

\*Items needing follow-up

6. **Discussion – Year-to-Date Financials**

Kevin Woodward provided an overview of year-to-date financials, as follows:

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2018 – 09/30/2018

Total Revenues of \$1,639,311.

Total Expenses of \$950,422; and an Excess of Revenue over Expenditures of \$688,889

Total Net Assets of \$4,401,558

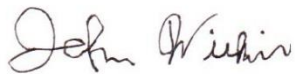
7. **Discussion – Communications Plan Update**

Emily Milligan reported that Cristy Balcells has completed Phase 1 of BSF’s Communications Plan which she will provide to the Board for review.

**Adjournment**

The Board of Directors adjourned the meeting at 2:10 pm EDT. The next Board meeting will be held via teleconference in January 2019 (TBD). The next Executive Committee meeting is scheduled for Tuesday, December 11, 2018 @ 12:00 pm EDT.

Respectfully submitted,



John Wilkins  
Secretary