



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
August 28, 2018

Members in Attendance:

Susan A. McCormack	Chair, Board Member
David Axelrod, MD	Board Member
Matthew Blumenthal	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>
Emily Milligan	Board Member, <i>ex-officio</i>

Members Not in Attendance

Catharine Lynne Ritter	Board Member
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Invited Guests:

Lynda Sedefian, Executive Assistant

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 – Addition of New Board Member(s)
3. Discussion & Vote – Proposed Committee/By-Law Changes
4. Discussion – Barth Syndrome Registry & Repository (BRR)

The meeting, held via GoToMeeting, was called to order by Susan McCormack, on Tuesday, August 28, 2018, at 12:00 pm ET.

1. Ratification of Minutes

The Board approved the July 17, 2018 Board minutes, as submitted on this date.

2. Discussion & Vote – Addition of New Board Member(s)

Susan McCormack, Kevin Woodward and John Wilkins provided an update on proposed candidates for board membership. This item will be placed on the agenda for further discussion/vote at the October 23, 2018 Board of Directors' meeting, if not before via email.*

3. **Discussion & Vote – Proposed Committee / By-Law Changes**

Susan McCormack reported that BSF's By-Laws were originally written when the Foundation was incorporated. Since that time, the organization has grown substantially, and we now need Board Committees structured differently that was originally envisioned.

The current By-Laws require only an "Executive Committee" and a "Finance and Audit Committee." The Board has already adopted a new policy for the Executive Committee this past July.

Susan proposed the following changes:

1. Split the finance and audit functions, as is typical for similar organizations
2. Add an investments overview function to the finance function
3. Add a separate committee responsible for auditing BSF's financials annually
4. Reconfigure the "Nominating Committee" mentioned in Article III, Section 18 into a "Governance Committee," with broader responsibilities.

All proposed changes are to Article III, Sections 17 and 18 of the By-Laws, as shown below.

Section 17. Additional Standing Committees. The following three committees shall be governed by their respective policy documents:

- a) *Finance and Investments Committee*
- b) *Audit Committee*
- c) *Governance 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.

Section 18. Other Committees. The Board of Directors may, by resolution passed by a majority of the Board of Directors then in office, designate committees. Such committees may include, without limitation, an Executive Committee, a Finance and Investments Committee, an Audit Committee, a Governance Committee, and a Fundraising Committee. Each such committee will be governed by a policy document. All such policy documents will be drafted by the Governance Committee and must be approved by a majority vote of the Board of Directors before a committee can be formed. 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. Any such committee shall have and may exercise all the powers and authority which may be delegated by the Board of Directors in the management of the business and the affairs of the Corporation and may authorize the seal of the Corporation, if any, to be affixed to all papers which may require it; but such committee shall not have any power of authority in reference to: (a) amending the Certificate of Incorporation or amending the By-Laws, (b) adopting an agreement of merger or consolidation, (c) selling, leasing or exchanging all or substantially all of the Corporation's property or assets, or (d) adopting a resolution to dissolve the Corporation.

The Executive Committee will review, amend and approve the new committee policies and proposed by-law changes at its September 18, 2018 meeting and then present them to the Board of Directors.*

VOTED: That the Board of Directors approve the structure of three new committees mentioned above.

VOTED: That the Board of Directors amend the By-Laws to reflect the structure of three new committees.

VOTED: That the Executive Committee be empowered to review, amend and approve the new committee policies and proposed by-law changes.

4. **Discussion – Barth Syndrome Registry & Repository (BRR)**

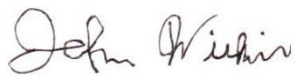
Emily Milligan provided an overview of BSF’s original vision of the BRR along with a timeline. The purpose of the BRR was to amass medical records and pair this information with biological specimens from individuals with Barth syndrome (BTHS) into a single resource to be utilized by researchers.

Emily sought the Board’s input on questions and diligence staff should pursue to facilitate further discussion at the Board of Directors’ October 23, 2018 meeting.*

Adjournment

The Board of Directors adjourned the meeting at 2:00 pm EDT. The next Board meeting will be held via teleconference on Tuesday, October 23, 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