



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
April 24, 2019

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

Invited Guest

Mr. Baltazar (Dorfman Abrams Music LLC)

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

Agenda Items:

1. Review & Vote: 2018 Audit Report
2. Discussion & Vote: Proposed amendments to BSF By-Laws and Policies
3. Discussion & Vote: BSF Organizational Objectives
4. Review & Discussion: 2019 YTD Financials
5. Discussion: Update on Clinical Trials and Portfolio Review Meeting
6. Discussion: Staffing Update

The meeting, held via GoToMeeting, was called to order by Ms. McCormack, on Wednesday, April 24, 2019, at 12:00 pm ET. Ms. McCormack acknowledged that Cathy Ritter's term as a Director has ended and the Board formally thanked Cathy for her many years of dedicated service on BSF's Board.

1. **Review & Vote - 2018 Audit**

Mr. Baltazar presented BSF's 2018 audit. He pointed out that this year's audit presentation is slightly different from past years because of a new Accounting Standards Update (ASU) for all nonprofit organizations. He stated that in the opinion of Dorfman Abrams Music, BSF's financial statements:

"...present fairly, in all material respects, the financial position of The Barth Syndrome Foundation, Inc. as of December 31, 2018 and 2017, and the changes in net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America."

VOTED: To accept the 2018 Audit Report from Dorfman Abrams Music LLC as presented on this date.

The Board thanked Mr. Baltazar for presenting to the Board and Dorfman Abrams Music LLC for their diligence in preparing BSF's 2018 audit.

2. **Discussion & Vote – Proposed Amendments to BSF By-Laws and Policies**

Ms. McCormack presented a proposed change to BSF's By-Laws to align re-election of Directors with their initial election dates as opposed to holding all re-elections in April of any given year.

VOTED: To approve the changes to BSF's By-Laws as proposed on this date.

On behalf of the Governance Committee, Ms. Branagh presented recommended updates to certain BSF policies in keeping with the standards of various regulatory and oversight bodies.

The Board discussed various policies and

VOTED: To approve the proposed policy updates as presented on this date.

The Board thanked the Governance Committee for their work reviewing the Foundation's policies and procedures.

3. **Discussion & Vote: BSF Organizational Objectives**

Ms. Milligan presented an update on BSF's organizational objectives for the remainder of FY 2019. She noted that the Foundation's organizational objectives will change over time as new opportunities present themselves.

VOTED: To approve the updated Organizational Objectives as presented on this date.

4. **Review & Discussion – 2019 YTD Financials**

Ms. McCormack and Ms. Milligan presented the YTD financial position as of 3/31/2019 for BSF which showed:

- Total Revenues of \$394,007
- Total Expenses of \$529,301; and a Deficiency of Revenue over Expenditures of \$135,294
- Total Net Assets of \$4,905,188

5. Discussion – Update on Clinical Trials and Portfolio Review Meeting

Ms. Milligan presented to the Board an update regarding the status of current and prospective clinical trials for Barth syndrome. Specifically:

- TAZPOWER is currently in Open Label Extension
- CARDIOMAN has begun in the UK
- BSF is still hopeful about future prospects for a gene therapy trial

Ms. Milligan then led the Board in a discussion about the planned Portfolio Review meeting scheduled for June 2019. She noted that a date and venue have been identified, external reviewers have been confirmed, and a moderator has been engaged. Work will continue on finalizing the schedule.

6. Discussion – Staffing Update

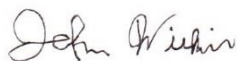
Ms. Milligan informed the Board that:

- Per the Board's prior direction and funding approval, BSF has engaged a Communications Consultant
- An unpaid intern has been identified to perform quality control on BSF's contact database
- A temporary Data Migration Consultant has been hired to standardize BSF's contact data prior to migration into Blackbaud
- A Search Committee has been formed for the Science Director position. This Committee has held its initial meeting and is currently finalizing a job description document. The Committee will inform the Board and the BSF community periodically of its progress.

Adjournment

The meeting was adjourned at 3:00 pm ET. The next Board of Directors meeting is scheduled for Wednesday, July 10, 2019 @ 12:00 pm ET. The next Executive Committee meeting is scheduled for Thursday, June 13, 2019 @ 12:00 pm ET.

Respectfully submitted,



John Wilkins
Secretary