



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
January 29th 2020

Members in Attendance:

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

Staff in Attendance

Shelley Bowen, Director, Family Services & Advocacy
Natalie Cohn, Controller

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

Executive Session

Follow-up items from prior board meetings :

1. Bank of America Investment Strategy
2. Policy Updates / NHC

Agenda Items:

1. 2019 Mission Impact & Organizational Goals
2. 2019 Financial Results (Unaudited)
3. Governance Issues
4. 2020 Organizational Goals
5. 2020 Budget, including Conference

The meeting, held via GoToMeeting, was called to order by Ms. McCormack, on Wednesday, January 29th at Noon ET.

The Board entered an executive session.

Follow-up Items from prior board meetings

1. Bank of America Investment Strategy

Ms. McCormack and Mr. Woodward updated the Board regarding various proposals for BSF's equity investment strategy. The Finance Committee will meet to determine which proposal is most prudent. *

2. Policy Updates / NHC

Mr. Wilkins, filling in for Ms. Florez, presented that the policy changes which the Board approved at its December meeting have been submitted to the NHC and approved by them and posted to BSF's website. BSF remains a member in good standing of the NHC. The Board thanked the Governance Committee for its efforts.

Agenda Items:

1. 2019 Mission Impact & Organizational Goals – review

Ms. Milligan presented a review of the Foundation's impact and reviewed goals from 2019.

Drawing from the 2017-2020 Strategic Plan, the team targeted specific deliverables mapped to BSF's overarching organizational goals in 2019:

Research and Therapeutic Strategy: Develop and promote BSF's therapeutic strategy and research priorities

Communication and Engagement: Successfully implement adopted communication tools to broaden and deepen engagement in BSF's mission

Advocacy: Establish BSF as the premier organization advocating for therapies and policies that positively impact individuals affected by Barth syndrome

Noteworthy deliverables included BSF hosting a listening session with FDA in Spring 2019, executing BSF's first-ever portfolio review in June 2019, adopting new communication strategies to meet the diverse preferences of BSF's constituency, netting the highest performing Giving Tuesday fundraiser in BSF's history, and opening the 2020 conference registration months ahead of schedule.

The Board expressed its thanks to both staff, volunteers and donors who have contributed to a great 2019.

2. 2019 Financial Results (Unaudited)

Mr. Woodward presented a review of the pre audit 2019 financials

- Total Revenues of \$843,973
- Total Expenses of \$1,209,058;
- Thus, a deficiency of Revenue vs. Expenditures of \$365,085
- As of 12/31/19, our US Trust investment account had a balance of \$4,474,091

3. Governance Issues

Mr. Wilkins, filling in for Ms. Florez, presented the recommendation of the Governance Committee for the role of Board Chair for BSF, beginning April 2020.

VOTED: Katherine McCurdy was elected to fill the position of Board Chair, starting on April 1, 2020.

4. 2020 Organizational Goals

Ms. Milligan led a discussion of staff's proposed 2020 organizational goals for BSF. Specific objectives were grouped into three distinct categories:

- Research and Development of Therapies
- Community Engagement

- Leadership and Advocacy

5. **2020 Budget, including Conference**

Ms. Milligan presented the proposed 2020 Conference budget. After much discussion, the Board recommended various revisions to the budget and remitted it back to the Conference Committee for reconsideration.

Adjournment

The meeting was adjourned at 2:30 pm ET. The next Board of Directors meeting is scheduled for Saturday, February 29th, 2020 @ 11:00 am ET. The next Executive Committee meeting is pending.

Respectfully submitted,

John Wilkins
Secretary