

MINUTES



Barth Syndrome Foundation, Inc.
Board of Directors ANNUAL Meeting
14 April 2020

Members in Attendance:

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

Invited Guest

Ed Baltzar	Dorfman Abrams Music, LLC
Bill Belscher	BSF Audit Committee Member
Natalie Cohn	BSF Comptroller
Susan McCormack	BSF Board Chair (until this meeting)
Steve McCurdy	BSF Board Member <i>Emeritus</i> (until this meeting)
Michael Minion	Dorfman Abrams Music LLC
John Wilkins	BSF Board Member (until this meeting)

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

Agenda Items:

1. **Welcome**
2. **Vote on Board/Officer: Kevin Woodward**
3. **2019 Audit Report**
4. **Acknowledgment of Service: Susan McCormack, John Wilkins and Steve McCurdy**
5. **Vote: Revision to Committee Policy Documents and By-Laws**
6. **Vote on Committee Members & Committee Chairs**
7. **Discussion: Treasurer Update**
8. **Vote: 2020 Revised Organizational Goals**
9. **Vote: 2020 Revised Budget Proposal**
10. **Vote: AHA-BSF Grant**
11. **Discussion: 2021 Conference**
12. **Discussion: BSF-led Efforts to Advance a Gene Therapy Program in BTHS**
13. **Announcements**

The meeting, held via GotoMeeting, was called to order by Susan McCormack, on Tuesday April 14th 2020 at 10am ET.

1. Welcome

Susan McCormack thanked the Board and staff for all of their efforts during her term. She also welcomed Kate McCurdy as the incoming Board Chair.

2. Vote on Board/Officer: Kevin Woodward

VOTED: to renew Kevin Woodward for a 3-year Board term on the Board and for a similar term as Treasurer.

3. 2019 Audit Report

Ed Baltzar from Dorfman Abrams Music LLC presented the clean 2019 audit.

VOTED: to approve audit once the term “affiliate” is better defined and the wording in footnote #10 is confirmed.

4. Acknowledgment of Service: Susan McCormack, John Wilkins and Steve McCurdy

Kate McCurdy thanked Susan McCormack, John Wilkins and Steve McCurdy for all their efforts and good service to BSF over the years and gave Susan and John gifts of appreciation from BSF (Steve was given one previously when he stepped down as Board Chair).

5. Vote: Revision to one Committee’s Structure, several Policy Documents and By-Laws

VOTED: to split the responsibilities of the Governance Committee into two Committees – The Board Development Committee and the Policies & Agreements Committee.

VOTED: to approve the policy documents for the new Board Development Committee and the new Policies & Agreements Committee

VOTED: to approve modifications to the policy documents for the Executive Committee, the Finance & Investments Committee, the Audit Committee, and the Fundraising Committee as proposed. Substantive changes include:

- 3-year terms
- Requirement of one instead of two Board members on each Committee except the Executive Committee (which is comprised completely of Board officers)
- Allowance that except for the Executive and Finance & Investments Committees, all other Committees may have non-Board Chairs
- Various clauses to make each document consistent with the others.

VOTED: to approve changes to the Bylaws to:

- Reflect current practicalities (e.g., being able to use email to notify members of a Board meeting)
- Update the definition of who is a Barth syndrome family member of the Board
- Modernize the title of Chairman to Chair
- Reflect the new Committee structure that was just approved.

6. Vote on Committee Members and Chairs

VOTED: to approve Committee membership and Chairs for 3-year terms each as presented so that the full roster of each committee is as follows:

Executive Committee

As already approved

Board Development Committee:

Kate McCurdy, BOD Chair, Acting Chair

Brandi Dague, BOD
Nicole Derusha-Mackey, BOD
B.J. Develle, BOD
Susan Osnos
Steve McCurdy

Policies & Agreements Committee

Susan McCormack, Chair
Matt Blumenthal, BOD
Michael Bowen
Andrew Buddemeyer
Christiane Hope

Finance & Investments Committee

Kevin Woodward, BOD, Treasurer, Chair
Natalie Cohn, BSF Comptroller, *ex officio*
Emily Milligan, Executive Director, BOD, *ex officio*
Susan McCormack
Kate McCurdy, BOD Chair
Steve McCurdy

Audit Committee

Bill Belscher, Chair
Michelle Florez, BOD

Fundraising Committee

To be determined at the next Board meeting

7. Discussion: Treasurer Update

Natalie Cohn, BSF Comptroller, presented the 2020 Year-to-date (YTD) financial report
VOTED: to acknowledge the 2020 YTD financials.

8. Vote: 2020 Revised Organizational Goals

Emily Milligan presented revised organizational goals, given the current Covid-19 pandemic, as they map to the 2017-2020 Strategic Plan.

1. *Research and Development of Therapies:* Become a strategic funder to advance research priorities and high-impact therapeutic opportunities
2. *Community Engagement:* Expand and strengthen worldwide support of BSF's mission
3. *Leadership and Advocacy:* BSF grows its global influence in the rare disease sector as a standout organization advocating for therapies, policies, and treatments that positively impact affected individuals

VOTED: to accept amended organizational goals.

9. Vote: 2020 Revised Budget Proposal

Emily Milligan presented a revised 2020 budget proposal, given the current Covid-19 pandemic.
VOTED: to approve a 2020 revised budget, showing in a full-year deficit of \$160,793.

10. Vote: AHA-BSF Grant

BSF executed a co-funding agreement with AHA in 2020 to support junior investigators' career development specifically relevant to Barth syndrome. For the 2020 AHA grant cycle, Erik Lontok led a discussion about a specific application at hand for BSF to consider co-funding. To improve the visibility and quality of applications in the future, Erik will approach AHA to align on criteria for competitive applications.

VOTED: not to co-fund the AHA-BSF Fellowship application that was presented but to follow up with AHA for further discussions.

11. Discussion: BSF-led Efforts to Advance a Gene Therapy Program in BTHS

Erik Lontok provided an update on BSF's gene therapy efforts.

12. Discussion: 2021 Conference

The in-person 2020 International Scientific, Medical and Family Barth Syndrome Conference, originally scheduled to be held in Florida in July 2020, has had to be postponed until July 19-24, 2021, due to the Covid-19 pandemic. BSF considered alternative venues but the Hilton Clearwater Beach Resort provided the most competitive contract. As a result of postponing the 2020 conference, BSF is exploring switching to odd years going forward. A new venue had been secured for 2022 Conference and is being renegotiated for 2023. Erik Lontok will organize a virtual scientific and medical symposium for two days in July 2020. A virtual commemoration of BSF's 20th Anniversary is also being planned for this year.

13. Announcements

Kate McCurdy suggested and everyone agreed that the Board should meet every other month (6 times/year) plus one extra time early in the year for a dedicated research grant review and awarding session, starting now. There may also be some *ad hoc* meetings if urgent issues requiring Board attention arise between scheduled Board meetings.

Also, this year, the October Board meeting will be a two-day strategic planning retreat that will include the Board, our SMAB and some outside advisors. We will see if the pandemic will allow us to hold this meeting in person or whether it has to become a virtual meeting.

Doodle surveys will be sent out in order to find the best dates for Board meetings for the balance of 2020.

Adjournment

With no further business, the meeting was adjourned at 12:15 pm ET. The next Board of Directors meeting is scheduled for Tuesday, June 23, 2020 @ 12:00 noon ET.

Respectfully submitted,
Nicole Derusha-Mackey
Secretary