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

Minutes

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
Nicolle 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, ex-officio
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 Emeritus (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

*Items needing follow-up
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

*Items needing follow-up*
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**

*Items needing follow-up*
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