



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
October 19, 2019

Members in Attendance:

Susan A. McCormack	Chair, Board Member
David Axelrod, MD	Board Member
Brandi Dague	Board Member
Nicole Derusha-Mackey	Board Member
B.J. Develle	Board Member
Michelle Florez	Board Member
Florence Mannes	Board Member
Kate McCurdy	Board Member
Stephen B. McCurdy	Chairman <i>Emeritus</i>
Emily Milligan	Board Member, <i>ex-officio</i>
John Wilkins	Secretary, Board Member

Members Not in Attendance

Matthew Blumenthal	Board Member
Megan Branagh	Board Member
Peter van Loo	Board Member
Kevin Woodward	Treasurer, Board Member

Invited Guest

Shelley Bowen, Director, Family Services & Advocacy
Matt Klein, MD, MS, FACS, Chief Executive Officer, BioElectron
Erik Lontok, PhD, Director of Research
Lynda Sedefian, Executive Assistant
Members of the Governance Committee (Michael Bowen; Chris Hope)

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

Agenda Items:

1. Discussion: Bank of America Update
2. Discussion & Vote: Board Nomination Procedures
3. Discussion & Vote: Re-Election of SMAB members
4. Discussion: Year-To-Date Financials
5. Discussion: 2020 Conference Family Scholarship Program
6. Guest Speaker: Matt Klein, MD, MS, FACS, Chief Executive Officer, BioElectron
7. Discussion: Research Collaborations Update

The meeting, held via GoToMeeting, was called to order by Ms. McCormack, on Saturday, October 19, 2019, at 11:00 am ET. Ms. McCormack welcomed Kate McCurdy and Peter van Loo to the Board and thanked them for their commitment to serve for a 3-year term. Ms. McCormack also reported that the Board has re-elected Nicole Derusha-Mackey and B.J. Develle to serve an additional 3-year term, commencing on this date.

1. Discussion: Bank of America Update

Ms. McCormack provided an overview of the meeting that was held with members of BSF's Finance and Investments Committee and Bank of America on October 15, 2019, to review BSF's investment portfolio. Members of Bank of America provided an overview assessment of BSF's existing investment strategy and reported that BSF's portfolio is in good standing. A follow-up meeting is planned and Ms. McCormack will provide feedback to the Board.*

2. Discussion & Vote: Board Nomination Procedures

Ms. Florez informed the Board that the Governance Committee developed Board Nomination Procedures which will be placed on BSF's website. The Board reviewed these procedures and recommended that the document reference the [Board of Directors and Officer Descriptions](#) and [Written Statement of Duties of Board Members](#), which are provided on BSF's website.*

VOTED: To approve the Board Nomination Procedures with the above-mentioned amendment.

Ms. Florez will include the recommended changes to the Board Nomination Procedures and publish them to BSF's web site.*

3. Discussion & Vote: Re-Election of SMAB Members

Dr. Lontok informed the Board that the terms of SMAB members Drs. John Lynn Jefferies and Hilary Vernon are up for re-election.

Dr. Jefferies is the Chief of Cardiology at the University of Tennessee Health Science Center and given this leadership role now has a limited role in seeing patients. In his previous position as Director of the Advanced Heart Failure and Cardiomyopathy Services in the Heart Institute at Cincinnati Children's Hospital Medical Center, he played a primary role in Barth syndrome patient heart transplantation cases.

Dr. Vernon is an Associate Professor of Genetic Medicine McKusick-Nathans Institute of Genetic Medicine Johns Hopkins University, head of the Barth Syndrome Clinic at the Kennedy Krieger Institute, and lead investigator of the ongoing TAZPOWER clinical trial.

Drs. Jefferies and Vernon have expressed their eagerness to continue SMAB membership. After a discussion, the Board

VOTED: To re-elect Drs. John Lynn Jefferies and Hilary Vernon to serve an additional 4-year term on BSF's SMAB.

Dr. Lontok will notify Drs. John Lynn Jefferies and Hilary Vernon of their re-election to serve on BSF's SMAB.*

4. Discussion: Year-To-Date Financials (01/01/2019 – 09/30/2019)

Ms. McCormack provided an overview of year-to-date financials.

- Total Revenues of \$761,000
- Total Expenses of \$998,000;
- and a Deficiency of Revenue over Expenditures of \$236,000
- Total Net Assets of \$4,652,000

5. Discussion: 2020 Conference Family Scholarship Program

Ms. McCormack reported that Ms. Milligan, Ms. Bowen, and members of the Conference Steering Committee propose that BSF adopt a Family Scholarship Program to assist families in attending BSF's 2020 Conference. Scholarships will be based on financial need to allow individuals to attend who would otherwise be unable. Priority will be given to applicants who (1) are attending the conference for the first time; (2) are an affected individual or a parent/primary caregiver of an individual with a diagnosis of BTHS - living or deceased; and/or (3) have been actively engaged in BSF's mission to advance research (e.g., clinical trials, surveys, registry, conference clinics, etc.). BSF intends on awarding up to 10 scholarships. To maintain independence and anonymity, scholarships will be reviewed by an undisclosed committee external to the BSF community.

VOTED: To adopt the Family Scholarship Program to assist families in attending BSF's 2020 Conference, up to a total amount of \$10,000 for all scholarships awarded.

At this time, Ms. Milligan introduced Dr. Matt Klein who was invited to join this meeting to provide insights on Board construction. Michael Bowen and Chris Hope, members of BSF's Governance Committee, also joined this portion of the meeting.

6. Guest Speaker: Matt Klein, MD, MS, FACS, Chief Executive Officer, BioElectron

Dr. Klein provided insights from the perspective of a potential industry collaborator to help educate BSF about key criteria to consider when seeking out and evaluating new directors for the Board. His guidance will help mold BSF's Governance Committee's strategic vision around Board composition and inform best practices for procurement of new leadership talent.

After an in-depth discussion, the Board thanked Dr. Klein for sharing his perspective on Board construction.

At this time, Dr. Klein, Michael Bowen and Chris Hope left the meeting.

7. Discussion: Research Collaborations Update

Dr. Lontok provided an update on research collaborations with the American Heart Association, Anavex, and the University of Florida.

Adjournment

The meeting was adjourned at 1:20 pm ET. The next Board of Directors meeting is scheduled for Monday, December 2, 2019 @ 7:00 pm ET. The next Executive Committee meeting is scheduled for Thursday, December 12, 2019 @ 12:00 pm ET.

Respectfully submitted,

John Wilkins
Secretary