



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
December 2nd, 2019

Members in Attendance:

Susan A. McCormack	Chair, Board Member
David Axelrod, MD	Board Member
Megan Branagh	Board Member
Brandi Dague	Board Member
Nicole Derusha-Mackey	Board Member
B.J. Develle	Board Member
Michelle Florez	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
Kevin Woodward	Treasurer, Board Member
Matthew Blumenthal	Board Member
Peter van Loo	Board Member

Members Not in Attendance

Florence Mannes	Board Member
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Invited Guests

Femida Gwadry-Sridhar, Bsc Pharm, MSc (Epi), Phd – CEO and Founder, Pulse Inframe
Michael Bowen- Governance and Conference Steering Committee Member

Staff in Attendance

Shelley Bowen, Director, Family Services & Advocacy
Erik Lontok, PhD, Director of Research

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

Follow-up items from prior board meetings:

1. Bank of America Update
2. Posting of Board Nomination Procedures

Agenda Items:

1. Discussion: Year-To-Date Financials
2. Discussion: Research Update
3. Discussion & Vote: Policy changes per NHC requirements
4. Discussion & Vote: 2022 Conference Venue

5. Presentation by Guest Speaker re: Registry Platforms
6. Discussion & Vote: Registry platform

The meeting, held via GoToMeeting, was called to order by Ms. McCormack, on Monday, December 2nd at 7:00 pm ET.

Follow-up Items from prior board meetings

1. Bank of America Update

Mr. Woodward has scheduled a meeting of the Finance & Investments Committee with Bank of America for December 11, 2019, pursuant to the September meeting held between these parties. Bank of America will present BSF's new investments manager as well as her proposed investment strategy for BSF's portfolio for 2020.*

2. Board Nomination Procedures

Ms. Florez informed the Board that the Governance Committee posted BSF's new Board Nomination Procedures to BSF's main list serve. Ms. Florez will work with Ms. Milligan to post them to BSF's website.

Agenda Items:

1. Discussion: Year-To-Date Financials (01/01/2019 – 11/29/19)

Mr. Woodward provided an overview of year-to-date financials.

- Total Revenues of \$842,000
- Total Expenses of \$1,125,000;
- and a Deficiency of Revenue over Expenditures of \$283,000
- Total Net Assets of \$4,488,000

2. Discussion: Research Update

Dr. Lontok presented the current status of BSF's annual grant program. This year, BSF received a total of 15 grant applications. Dr. Lontok expressed his view that this year's applications were very high quality. He plans to meet with the SMAB to review and discuss the grant proposals in January, 2020.

Dr. Lontok is working on a potential collaboration with the American Heart Association (AHA) whereby BSF and AHA could potentially co-fund a predoctoral and/or postdoctoral fellow performing research relevant to both organizations.

BSF staff is working to assemble a Gene Therapy Advisory Group, to help guide BSF through the complicated process of working toward a gene therapy treatment for Barth syndrome. Dr. Lontok presented his ideas for the makeup of this group.

3. Discussion & Vote: Policy changes per NHC requirements

Ms. Florez presented various changes to BSF's policies recommended by the Governance Committee per NHC guidelines. Ms. Florez thanked Michael Bowen and the rest of the Governance Committee for their efforts on this critical policy work.

VOTED: To approve the policies as revised.

Ms. Florez and Ms. Milligan will ensure that all changes are communicated to NHC and that the revised policies are posted to BSF's web site.*

4. Discussion & Vote: 2022 Conference Venue

Ms. Bowen presented the proposed conference venue for 2022 as recommended by the Conference Committee – the Hyatt Regency Coconut Point Resort in Bonita Springs, Florida. The Board discussed various aspects of the recommendation, including location, amenities, access to nearby medical care and cost to attendees..

VOTED: To execute a contract with the Hyatt Regency Coconut Point for BSF's 2022 Conference.

5. Presentation by Guest Speaker re: Registry Platforms:

Ms. Gwadry-Sridhar presented on the Pulse Infoframe registry platform and answered numerous questions from BSF's Board. Ms. Gwadry-Sridhar then departed the call

6. Discussion & Vote: Registry Platform

The Board discussed whether to contract with Pulse Infoframe to perform exploratory work on migrating all of BSF's registry data – currently held in various locations – onto one platform.

VOTED: To execute a \$30,000 contract with Pulse Infoframe for exploratory registry work.

Adjournment

The meeting was adjourned at 10:00 pm ET. The next Board of Directors meeting is scheduled for Wednesday , January 29, 2020 @ 11:00 am ET. The previously scheduled Executive Committee meeting for Thursday, December 12, 2019 @ 12:00 pm ET has been cancelled.

Respectfully submitted,

John Wilkins
Secretary