



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
June 28, 2017

Members in Attendance:

Marcus E. Sernel	Chairman
B.J. Develle	Board Member
Nicole Derusha-Mackey	Board Member
Florence Mannes	Board Member
Susan Osnos	Board Member
John Wilkins	Board Member
Kevin Woodward	Treasurer, Board Member
Stephen B. McCurdy	Chairman <i>Emeritus</i>

Members Not in Attendance/Partial Attendance

David Axelrod, MD	Board Member
Matthew Blumenthal	Board Member
Susan A. McCormack	Secretary, Board Member
Catharine Lynne Ritter	Board Member
Lindsay Groff, Executive Director	Board Member, <i>ex-officio</i>

Invited Guests:

Lynda Sedefian, Executive Assistant

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

Agenda Items:

1. Ratification of Minutes
2. Review & Discussion - Financials
3. Review & Discussion – Fundraising
4. Update & Discussion – Board Leadership Development
5. Discussion – BSF Website
6. Update & Discussion – Science/Medicine
7. Executive Session – Health Insurance

The meeting, held via teleconference, was called to order by the Chairman on Wednesday, June 28, 2017, at 12:00 pm ET.

1. Ratification of Minutes

The April 8, 2017 Board minutes and May 31, 2017 Executive Committee minutes will be distributed to the Board via email for final approval.

2. Review & Discussion - Financials

Kevin Woodward provided an overview of the 2017 year-to-date financial statements, which reflected the following:

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2017 – 05/31/2017

Total Revenues of \$307,661, including unrestricted donations of \$269,255; the balance of \$38,406 is temporarily restricted (Science/Medicine, Varner, and Will McCurdy Funds).

Total Expenses of \$454,817; and a Deficiency of Revenue over Expenditures of \$147,156.

Total Current Assets	\$3,760,900
Total Current Liabilities	\$ 330,502
Total Fund Balance	\$3,430,398

3. Review & Discussion – Fundraising

Steve McCurdy provided a review of 2017 fundraising activities, metrics, and the impact on revenue.

4. Update & Discussion – Board Leadership Discussion

Susan Osnos provided an update on proposed candidates for Board membership.*

5. Discussion – BSF Website

Marc Sernel reported that BSF has been informed by Pixelera (current host of BSF’s website) that they are phasing out website support. As such, we will need to find a new provider. Lynda Sedefian will put together a project team to define the overall goals for the website, including specific questions regarding content, “look and feel,” functionality, and integration of third party tools (like linking donations to the database). This project, already underway, will take a significant amount of time for staff this summer/early fall.

6. Update & Discussion – Science/Medicine

Marc Sernel provided an update on science and medicine initiatives, including an update on Stealth/Elamipretide, gene therapy, the Bezafibrate trial (UK), and the Healx-Pu collaboration.

Marc reported that Dr. Matt Toth and several SMAB members (along with Steve and Kate McCurdy) will be attending the United Mitochondrial Disease Foundation (UMDF) symposium on June 28-July 1, 2017, in Alexandria, VA. On Thursday, June 29th, the afternoon session will focus on Barth syndrome as a mitochondrial disease with three SMAB members presenting (Drs. Schlame, Vernon, and Pu). BSF has donated to support this afternoon session. The BSF SMAB meeting will be held on June 29, 2017.

Marc also reported that Stealth will present detailed results from the MMPOWER-2 trial evaluating safety, tolerability and efficacy of treatment with elamipretide for primary mitochondrial myopathy at the UMDF symposium.

7. Executive Session – Health Insurance

The Board of Directors adjourned the meeting at 1:00 pm ET, at which time Lynda Sedefian left the meeting and an Executive Session was held.

Adjournment

The Board of Directors adjourned the Executive Session at 1:20 pm ET. The next Board meeting will be held via GoToMeeting and is scheduled for Wednesday, October 18, 2017 @ 12:00 pm ET. The next Executive Committee meeting is scheduled for Wednesday, September 27, 2017 @ 8:00 pm ET.

Respectfully submitted,



Susan A. McCormack
Secretary

*Items needing follow-up