



Barth Syndrome Foundation, Inc.
Board of Directors Meeting
January 25, 2017

Members in Attendance:

Marcus E. Sernel	Chairman
David Axelrod, MD	Board Member
Matthew Blumenthal	Board Member
Randy Buddemeyer	Treasurer, Board Member
Nicole Derusha-Mackey	Board Member
B.J. Develle	Board Member
Susan A. McCormack	Secretary, Board Member
Susan Osnos	Board Member
John Wilkins	Board Member
Kevin Woodward	Board Member
Lindsay Groff, Executive Director	Board Member, <i>ex-officio</i>
Stephen B. McCurdy	Chairman <i>Emeritus</i>

Members Not in Attendance

Florence Mannes	Board Member
Catharine Lynne Ritter	Board Member

Invited Guests

Matthew J. Toth, PhD, BSF Science Director

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 – 2018 Conference
5. Update & Discussion – Science & Medicine
6. Staff Evaluations

The meeting, held via teleconference, was called to order by the Chairman on Wednesday, January 25, 2017, at 8:00 pm ET.

1. Ratification of Minutes

The Board approved the November 1, 2016 Board minutes, as submitted on this date.

2. Review & Discussion – Financials

Lindsay Groff provided an overview of the 2016 year-end comparison financial statements, which reflected the following:

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2016 – 12/31/2016

Total Revenues of \$1,130,733, including unrestricted donations of \$827,583; the balance of \$303,150 is temporarily restricted (Science/Medicine, Varner, and Will McCurdy Funds).

Total Expenses of \$1,228,893; and a Deficiency of Revenue over Expenditures of \$98,160.

Total Current Assets	\$3,781,680
Total Current Liabilities	\$ 229,819
Total Fund Balance	\$3,551,861

2017 Preliminary Budget

Lindsay Groff provided a review of the draft 2017 consolidated budget. The Board engaged in a discussion. This item has been placed on the February 15, 2017 Board meeting agenda.

3. Review & Discussion – Fundraising

Lindsay provided a review of 2016 year-end fundraising activities. BSF-led activities included: the 2016 conference, the Boston event, the NY Islanders game, #GivingTuesday, numerous direct mail appeals, and e-appeals. Our community also helped through personal appeals and grassroots events. Lindsay noted that, with the exception of the conference and the Boston event, these are recurring efforts that will continue in 2017. She will also seek new opportunities to raise money for BSF.

4. Update & Discussion – 2018 Conference

Lindsay provided a review of the results received from an RFP sent to St. Petersburg/Clearwater, Orlando, Daytona, and Ft. Lauderdale venues for BSF’s 2018 conference. Lindsay will provide an updated summary along with a final recommendation to the Board once a full evaluation is completed.*

5. Update & Discussion – Science & Medicine

Matt Toth provided an update on science and medicine initiatives, as follows:

Research Grant Program

Matt reported that BSF received 14 grant applications for the 2016 research grant cycle. The SMAB teleconference to discuss the grants was held on January 25, 2017 at 12:00 pm ET. The BSF Board of Directors will meet on February 15, 2017 to vote on grant awards for the 2016 grant cycle.*

Bezafibrate Initiative

Matt reported that Dr. Colin Steward has conferred with the NIHR (the UK institution providing the funding) about the UK bezafibrate trial. The NIHR has agreed to increase the amount originally budgeted for drug manufacture which was underfunded. However, due to other restrictions that deal with personnel costs to run the trial, the UK bezafibrate trial will need to find additional funding on the order of 33,000 British Pounds (~ \$41,000 USD) to perform the study.

VOTED: To allow a budget of 33,000 British Pounds to support this bezafibrate trial.

SMAB

Matt reported that the SMAB has agreed to have an off-year meeting coinciding with the June 29, 2017 afternoon session of the UMDF (United Mitochondrial Disease Foundation) conference (Alexandria, Virginia) which will be focused on Barth syndrome research as a mitochondrial disease. BSF has donated \$7,000 to UMDF to cover the cost of the five speakers at this afternoon session (three of whom are SMAB members), and Matt will coordinate the SMAB meeting for the evening of June 29th. So far, over 10 SMAB members have indicated they would like to attend and several have expressed interest in attending the full UMDF conference schedule.

*Items needing follow-up

Stealth

Stealth held a face-to-face meeting with several BSF members on December 12, 2016, in New York to discuss the upcoming elamipretide clinical trial. Also in attendance were members of the Adelphi Consulting group who presented their conclusions about the extensive interviews they conducted at the BSF Conference in July 2016.

Healx

The Healx and Bill Pu collaboration for discovering the mRNA signature of BTHS cells continues its progress. The Pu-Healx collaboration has reached the stage where mRNA signatures are being sequenced from high-expressed genes down to low-expressed genes. The quality of the sequence is good, and Dr. Pu is asking to spend ~ \$1,300 more than what was originally budgeted for these expenses in 2016. Dr. Pu's expenses (which are just cost expenses with no overhead) are increasing from ~ \$13,000 in the original budget to ~ \$15,000. As the collaboration continues, BSF still has a commitment of 18,000 British Pounds for the second of the two parts of the contract with Healx.

BRR

Stealth BioTherapeutics provided a summary of the BRR data which BSF had provided them on September 21, 2016. Matt, Shelley, and Lindsay teleconferenced with Stealth about using the results of the BRR analysis and potential publication(s). On December 12, 2016, Stealth met with several BSF members to discuss the elamipretide clinical trial and the ways the BRR data could be used more effectively. IRB approval for BRR was renewed on December 29, 2016, for another year with WIRB. Patient Crossroads, the company which hosts the website for the BRR, has changed its name to AltaVoice. Matt intends to file an update with WIRB to clarify certain phrases of the consent document originally approved in December, 2013.

6. Staff Evaluations

Marc reported that the Organizational Development Committee will begin the process of employee performance evaluations. Marc and the Organizational Development Committee, headed by Suze Osnos, will work together to engage in staff interviews and review employee performance evaluations. Marc reported that we expect to be able to complete this process so that the review and proposed compensation changes could be discussed at the next Board meeting scheduled for February 15, 2017.*

Adjournment

The Board of Directors adjourned the meeting at 9:50 pm ET. The next Board of Directors meeting is scheduled for February 15, 2017 @ 12:00 pm ET.

Respectfully submitted,



Susan A. McCormack
Secretary