



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
September 10, 2015

Members in Attendance:

Marcus E. Sernel	Chairman
Randy Buddemeyer	Treasurer, Board Member
Matthew Blumenthal	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

David Axelrod, MD	Board Member
Catharine Lynne Ritter	Board Member
Florence Mannes	Board Member

Invited Guests:

Shelley Bowen, Director, Family Services & Awareness
Lynda Sedefian, Executive Assistant
Matthew J. Toth, PhD, Science Director
Kate McCurdy, SMAB, *Emerita*

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

Agenda Items:

1. Ratification of Minutes
2. Financials
3. Fundraising
4. Science & Medicine
5. Volunteer Workshop
6. Board Development
7. Other

The meeting, held via teleconference, was called to order by the Chairman on Thursday, September 10, 2015 at 8:00 pm ET.

1. Ratification of Minutes

The board approved the May 26, 2015 Board minutes, as amended on this date.
The board approved the July 29, 2015 Board minutes, as amended on this date.

2. Financials

Lindsay Groff provided an overview of the 2015 year-to-date comparison financial statements, which reflected the following:

*Items placed on the November 13-15, 2015 Board meeting agenda

**Items needing follow-up

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2015 – 08/31/2015

Total Revenues of \$2,523,414; including unrestricted donations of \$182,099, and the balance of \$2,341,315 is temporarily restricted (SciMed, Varner, and Will McCurdy Funds).

Total Expenses of \$1,020,482; and an Excess of Revenue over Expenditures of \$1,502,932.

Total Current Assets	\$ 3,710,295
Total Current Liabilities	\$ 474,284
Total Fund Balance	\$ 3,236,011

Note: BSF is finalizing the extensive paperwork to move funds from our current banking institution to US Trust for investing. Once complete, BSF will continue with the plan agreed upon during the July 29, 2015 board meeting.

3. Fundraising

Lindsay provided an overview of year-to-date fundraising activities. To date, two appeals have been sent which have yielded a positive return. There will be two more appeals sent (November and December). We will also engage our donors in #GivingTuesday, an online campaign (December 1). Lindsay also reported there are various grassroots fundraisers scheduled.

Vote - Gift Acceptance Policy

Lindsay presented a Gift Acceptance Policy which defines (1) the types of assets that are acceptable gifts; (2) the forms of gifts that are acceptable; and (3) BSF's role in gift administration.

VOTED: To adopt the Gift Acceptance Policy as of this date.

4. Science & Medicine

2015 Research Grant Cycle

Matt Toth reported that the revised 2015 BSF Research Grant Guidelines have been provided on the website. To date, 15 Letters of Intent have been submitted for the 2015 Research Grant cycle. These letters will be distributed to the SMAB for input to provide back to the applicants by September 15th.

Note: The Board approved the revised 2015 Research Grant Application Guidelines and Requirements via email prior to this meeting.

Bezafibrate Clinical Trial

Matt provided an update on how to best proceed with a US bezafibrate clinical trial. Matt will continue his efforts and will keep the board apprised.**

Barth Syndrome Clinic at Kennedy Krieger Institute (KKI)

Dr. Vernon is expanding the scope of her involvement in the KKI clinic to include general mitochondrial disease individuals in addition to BTHS individuals.

Advisory Group for Clinical/Translational Research

Matt reported that he is in the process of forming a Clinical Studies Advisory Group to seek input as clinical studies mature to the point where volunteers from the BSF community will be asked to participate. So far, Drs. Arnie Strauss, John Jefferies, and Michael Schlame have agreed to serve. More members will be added.

*Items placed on the November 13-15, 2015 Board meeting agenda

**Items needing follow-up

The purpose of this small group is to quickly provide advice as clinical studies come to BSF's immediate attention, especially when the number of volunteers may be limiting among the potential studies. The group will interact primarily through email exchanges and have a broad knowledge of the various technologies and therapeutic ideas involved with BTHS.

After a discussion, the board authorized Matt Toth to extend an invitation to the additional proposed candidates discussed during this meeting.**

Scientific & Medical Advisory Board Roster (SMAB)

Matt reported that he has discussed with Dr. Schlame and Cathy Ritter the fact that one member of the SMAB in 2015, and six members in 2016 are scheduled to have their terms expire. The board discussed the cultivation of prospective SMAB members and Matt Toth proposed a number of candidates for the Board's consideration. Following this discussion, it was agreed upon to authorize Matt Toth to extend an invitation to the proposed candidates to serve on the SMAB for a 4-year term. Matt will keep the board apprised.**

VOTE: To authorize Matt Toth to extend an invitation to the proposed candidates to serve on the SMAB for a 4-year term.

VOTE: To authorize Matt Toth to extend an invitation to Grazia Isaya, MD, PhD (Professor of Biochemistry/Molecular Biology; Professor of Pediatrics, Mayo Clinic) to attend BSF's 2016 Conference as a guest, offering to fund the cost of travel/accommodations.

2016 Conference

Matt proposed a list of prospective names for the keynote speaker at BSF's 2016 Conference. The board discussed additional ideas. After a discussion, the board tasked Matt Toth to start a dialogue with the prospective speakers to gauge their interest.

NIH R01 Grant

Matt reported that Dr. Bill Pu has received an R01 grant from the NIH, which is estimated to provide for over \$500K per year for four years. Seven R01 awards have been funded from the NIH for BTHS-related research to date. To date, over \$20.2 million have been awarded for BTHS-related research including \$3.6 million from BSF.

5. Volunteer Workshop

Shelley provided an update on the logistics of the Volunteer Workshop scheduled for November 12-15, 2015 in Newberry, SC. Shelley and Lindsay will work together to develop the agenda for this meeting along with anticipated outcomes which will be provided to the board in the near future.**

6. Board Development

Susan Osnos provided an update on proposed candidates for board membership. After a discussion, board members were assigned the task of engaging in a preliminary conversation with the proposed candidates to assess their interest in BSF and its mission.**

7. Other

Administration

Lindsay reported that Sandra Stevens (Fundraising Project Manager) has resigned as of September 4, 2015. The board would like to recognize Sandra for all of her efforts during her employment with BSF. The board will now consider the best approach in filling this role going forward.**

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**Items needing follow-up

Lindsay reported that the new insurance plan with Aetna has resulted in a lower cost overall to BSF and its employees.

Adjournment

The Board of Directors adjourned the meeting at 10:40 pm ET.

The next Board meeting is scheduled for November 13-15, 2015 in Lake Murray, SC. The next Executive Committee meeting is scheduled for Tuesday, October 27, 2015.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Susan A. McCormack". The signature is fluid and cursive, with the first name "Susan" and last name "McCormack" clearly distinguishable.

Susan A. McCormack
Secretary