



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
May 26, 2015

Members in Attendance:

Marcus E. Sernel	Chairman
David Axelrod, MD	Board Member
Matthew Blumenthal	Board Member
Randy Buddemeyer	Treasurer, Board Member
Florence Mannes	Board Member
Susan A. McCormack	Secretary, Board Member
Catharine Lynne Ritter	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/Partial Attendance

Susan Osnos	Board Member
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Invited Guests:

Shelley Bowen, Director, Family Services & Awareness
Lynda Sedefian, Executive Assistant
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. Vote - Ratification of Minutes
2. Vote – Board Terms
3. Annual Conflict of Interest and Confidentiality Agreement
4. Discussion – Employee Health Insurance
5. Review – 2015 Year-to-Date Financials
6. 2015 Budget
7. Update – 2014 Audit
8. Discussion – Investment Options
9. Update – Fundraising
10. Update – Science & Medicine
11. Discussion – Volunteer Workshop

The meeting, held via teleconference, was called to order by the Chairman on Tuesday, May 26, 2015 at 8:00pm ET. Marc welcomed Matthew Blumenthal who was elected to serve on BSF's Board of Directors commencing May 26, 2015 for a three-year term. Marc also expressed his appreciation for the detailed Executive Update provided.

1. Vote – Ratification of Minutes

The board approved the February 28-March 1, 2015 Board minutes, as amended on this date.
The board approved the April 14, 2015 Executive Committee minutes, as submitted on this date.

2. Vote – Board Terms

Marc Sernel reviewed the term limits of the current Board of Directors.

David Axelrod, Susan Osnos and Marc Sernel’s 3-year terms ended as of April 2015. The board voted unanimously to re-elect all three members for an additional 3-year term.

VOTED: To re-elect David Axelrod to serve an additional 3-year term. Said term will run through April 2018.

VOTED: To re-elect Susan Osnos to serve an additional 3-year term. Said term will run through April 2018.

VOTED: To re-elect Marc Sernel to serve an additional 3-year term as Chairman. Said term will run through April 2018.

3. Annual Conflict of Interest and Confidentiality Agreement

Marc reminded the board members to review and sign the annual Conflict of Interest, Confidentiality Acknowledgement Agreement and Policy Gift Disclosure forms and return to Lynda Sedefian to keep on file.

4. Discussion – Employee Health Insurance

Lindsay Groff notified the board that she has recently been alerted about a new IRS ruling which states that BSF can no longer reimburse employees for their individual health plans, in whole or in part. Lindsay Groff and Ellen Bruno explored two group health care plans that provide coverage to employees in multiple states. (Before the ACA, this was not possible.) The deadline to comply is June 30, 2015. Following a discussion, it was:

VOTED: To authorize Lindsay and Marc to move forward with finalizing the selection of a group healthcare plan for BSF employees with enrollment prior to the June 30, 2015 deadline.

5. Review - 2015 Year-to-Date Financials

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

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2015 – 04/30/2015

Total Revenues of \$1,556,651; including unrestricted donations of \$72,676, and the balance of \$1,483,975 is temporarily restricted (SciMed, Varner, and Will McCurdy Funds).

Total Expenses of \$808,793; and an Excess of Revenue over Expenditures of \$747,858.

Total Current Assets	\$ 3,035,917
Total Current Liabilities	\$ 554,980
Total Fund Balance	\$ 2,480,937

6. 2015 Budget

Lindsay presented a revised 2015 consolidated budget based upon the discussion held at the February 28-March 1, 2015 board meeting.

7. Update – 2014 Audit

Lindsay reported that Gray, Gray, & Gray delivered a clean audit of BSF’s 2014 financial statements. The audited financial statements and Form 990 were circulated via email for the Board of Directors’ review and approval. They have also been uploaded to BSF’s website.

The Barth Syndrome Foundation will register with all fifteen (15) states where BSF solicits funds concurrently with the filing of its 2013 Auditor’s Report and IRS Form 990.

8. Discussion – Investment Options

Lindsay provided an overview of the Finance Committee’s meeting held on Friday, May 22, 2015 to discuss investment options. Following a discussion, the board authorized Lindsay to pursue the next steps in contacting US Trust to create a customized Investment Policy Statement, which serves as a blueprint for BSF’s portfolio by documenting objectives, risk tolerance, cash flow needs, tax situation, and wealth aspirations.

Lindsay will also request a conference call with US Trust and the BSF Board of Directors to discuss possible investment options.

It was noted that BSF needs to adopt a policy with clear direction on where money sits in operating fund and what is invested.*

9. Update - Fundraising

Lindsay provide a summary of year-to-date fundraising activities including donor appeals, planned giving, grassroots fundraising, progress on restricted funds, and donations/sponsorships from for-profit corporations.

Vote – New Fund - Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome

Lindsay and Steve McCurdy provided a description of a newly created fund in honor of Steve’s son, Will McCurdy. Contributions to this new fund, initially funded by a one-time \$2 million donation from the McCurdy, Russell and Malkin families in memory of Will, will be used by BSF for the development of therapies designed to prevent, alleviate, or eliminate the symptoms of Barth syndrome.

Initially, donations in Will’s memory were collected under the “Until Barth is Cured” campaign. Now that a formal fund has been established, donations made late in 2014 under “Until Barth is Cured” were moved into the new fund. After a discussion, it was:

VOTED: To approve the transfer of funds received in memory of Will McCurdy from the “Until Barth is Cured” campaign to the newly created Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome.

10. Update – Science & Medicine

Research Grant Program

Dr. Matt Toth reported that all ten 2014 BSF Research Grant awardees that were decided at the BSF Board Meeting in February have been announced, and the first checks have gone out for eight of them. The Cade and the Goncalves first checks will be delayed until June due to Dr. Cade’s request and due to Dr. Goncalves move in May to a position at the Harvard T. H. Chan School of Public Health. The 2014 cycle had the largest number of awards and committed the largest amount of funds ever in the history of the Program (\$ increase of 52% from 2013). Notably, BSF was able to fund 100% of the applications recommended for funding by the SMAB this year. That percentage had dropped as low as 58% during the 2013 grant cycle.

*Items placed on the September 10, 2015 Board meeting agenda

Bezafibrate initiative

Matt reported on the promising findings regarding bezafibrate's effect on dilated cardiomyopathy in a young mouse model. These data have been incorporated into a revised US clinical plan for a US bezafibrate trial which may ultimately be filed with the FDA.

Matt reported that efforts to coordinate with Dr. Colin Steward's NHS grant to test bezafibrate with BTHS individuals are progressing. The UK effort is planning on an October start date for the trial using a tablet formulation and pill-training for the volunteers. The US effort with the FDA will seek to coordinate with the UK effort as much as possible.

Matt reminded the BSF Board that Dr. Hilary Vernon is very interested in performing a natural history study on BTHS which is a natural outgrowth of the KKI clinic. At the February BSF Board meeting her application to do something similar as part of a BSF Research Grant was denied. Nevertheless, Matt was told to encourage Dr. Vernon to submit a plan with a budget for studying the natural history of BTHS that would not be part of the Research Grant Program, but that would contribute to ongoing clinical trials like the bezafibrate initiative.

World Orphan Drug Congress

Lindsay reported that, in April, she attended the World Orphan Drug Congress in Washington, DC. Representatives from the National Institutes of Health (e.g., Steve Groft and Yaffa Rubenstein), the Food and Drug Administration, big pharma, biotech firms, and patient advocacy groups all joined together to talk about how to get treatments to those suffering in the fastest, safest way possible. Important contacts were made, relationships were formed, and connections were rekindled.

Biotechnology Industry Organization (BIO) International Convention

Lindsay reported that, in June, she will join approximately 15,000 attendees at the Biotechnology Industry Organization (BIO) International Convention in Philadelphia, PA. As a patient advocacy group, BSF is granted a free (shared) booth in the exhibit hall, as well as complimentary attendance at all educational sessions. She hopes to gain further insight into developing treatments for ultra-rare diseases with small patient populations. There are specific educational tracks that will cover these (and other) topics.

Cardiolipin as Key Lipid of Mitochondria in Health and Disease (Mini-meeting, second edition 2015)

Dr. Matt Toth proposed that BSF sponsor the Cardiolipin as Key Lipid of Mitochondria in Health and Disease Mini-meeting which is being co-hosted by Drs. Angela Corcelli and Michael Schlame. This meeting is scheduled for September 30-October 1, 2015 in Florence, Italy. A number of our members of the Scientific & Medical Advisory Board will also be attending this meeting. After a discussion, it was:

VOTED: To authorize a budget of US \$2,000 as sponsorship in support of this meeting.

For-Profit Sponsorship and Other Topics

Lindsay proposed that the board consider how to treat the donation/sponsorship from for-profit organizations and ways in which we can offer advertisements, perhaps on the website or in our newsletter.

A discussion about future clinical trials, interest from for-profit companies, and increased requests for open access to published articles ensued. Given the newness of possible therapies for Barth syndrome, a task force was formed (Lindsay Groff, Marc Sernel, Steve McCurdy, John Wilkins and David Axelrod) and has been tasked with benchmarking other similar organizations on best practices in encouraging participation in clinical trials. In addition, the group will benchmark other similar organization's best practices in supporting open-access to peer-reviewed journal articles.

11. Discussion – Volunteer Workshop

Shelley Bowen provided an overview of the volunteer workshop scheduled for November 13-15, 2015 in South Carolina. The purpose of this workshop is to broaden and increase volunteer participation in order to help BSF accomplish its mission.

It was recommended that Shelley and Lindsay draft a preliminary agenda along with a detailed set of tasks and anticipated outcomes for this meeting to be presented to the board at its next meeting.*

Adjournment

The Board of Directors convened the meeting at 10:20pm ET. The next Board meeting is scheduled for Thursday, September 10, 2015. The next Executive Committee meeting is scheduled for Thursday, July 23, 2015.

Respectfully submitted,



Susan A. McCormack
Secretary