



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
Lake Murray, SC
November 15, 2015

Members in Attendance:

Marcus E. Sernel	Chairman
Florence Mannes	Board Member
Susan A. McCormack	Secretary, Board Member
Susan Osnos	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

David Axelrod, MD	Board Member
Matthew Blumenthal	Board Member
Randy Buddemeyer	Treasurer, Board Member

Invited Guests:

Lynda Sedefian, Executive Assistant
Matthew J. Toth, PhD, 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 – Financials
3. Review & Discussion – Fundraising
4. Update & Discussion – Science & Medicine
5. Update – Board Development
6. Update – 2016 Conference

The meeting, held face-to-face in Lake Murray, SC, was called to order by the Chairman on Sunday, November 15, 2015 at 8:15 am ET.

1. Ratification of Minutes

The board approved the September 10, 2015 Board minutes, as amended on this date.
The board approved the October 27, 2015 Executive Committee minutes, as submitted on this date.

2. Review - 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 – 10/31/2015

Total Revenues of \$2,580,778, including unrestricted donations of \$203,050; the balance of \$2,377,728 is temporarily restricted (SciMed, Varner, and Will McCurdy Funds).

Total Expenses of \$1,117,789; and an Excess of Revenue over Expenditures of \$1,462,989.

Total Current Assets	\$ 3,518,955
Total Current Liabilities	\$ 322,887
Total Fund Balance	\$ 3,196,068

The October financials show that BSF remains financially stable. In addition, Lindsay provided a statement from US Trust that outlines the performance of our investments.

3. Review & Discussion - Fundraising

Lindsay provided an estimated forecast of year-end fundraising activities. The November appeal will hit mailboxes following Thanksgiving. Another appeal will be sent in December. The McCurdy family will send their year-end appeal. We will also engage our donors in #GivingTuesday, an online campaign (December 1).

Strategic Development Plan

Lindsay reported that she, Shelley Bowen, and Randy Buddemeyer had an opportunity to meet with Felicia Ganote on November 2-3, 2015. Lindsay presented a preliminary Strategic Development Plan created by Felicia which provides a high-level outline of a three-year strategic fundraising plan for BSF. Following a detailed discussion, the Board authorized Lindsay to hire Felicia Ganote as a contractor for a three-month period to allow her to begin executing the Strategic Development Plan.

VOTED: To authorize Lindsay to hire Felicia Ganote as a contractor for a three-month time period to develop a detailed Strategic Development Plan.

4. Update & Discussion - Science & Medicine

2015 Research Grant Program

Matt Toth reported that 16 grant applications have been submitted for the 2015 Research Grant Program (8 from USA, 2 from Canada, 2 from Italy, and 1 each from France, Germany, Brazil, and Scotland). The SMAB meeting to review all grants is scheduled for the end of January, 2016.

Bezafibrate Clinical Trial - UK

Matt provided an update on preparation for a bezafibrate clinical trial that would take place in the UK. After a detailed discussion about challenges associated with manufacture of the compound, it was proposed that BSF potentially make funds available to assist Barth Syndrome Trust (BST) and BST clinical investigators to overcome these challenges. Matt will work with Dr. Colin Steward and BST clinical investigators to determine what additional funding is needed to overcome the challenges and allow this clinical trial to move forward.

VOTED: To authorize a budget of up to \$60,000, from the Will McCurdy Fund for the Advancement of Therapies for Barth Syndrome, to help facilitate the bezafibrate clinical trial.

Scientific & Medical Advisory Board (SMAB) Roster

Matt reported that John Lynn Jefferies, MD, MPH, FAAP, FACC and Hilary Vernon, MD, PhD have accepted BSF's invitation to serve on the SMAB for 4-year terms.

Dr. Jefferies' current research interests include heritable causes of vascular disease, novel drug therapies for advanced heart failure, novel gene discovery in cardiomyopathy, characterization and management of left ventricular noncompaction, and early diagnosis and management of chemotherapy induced cardiotoxicity.

Dr. Vernon's research interests include understanding intermediary metabolism in Barth syndrome and in disorders of branch chain amino acid metabolism. Dr. Vernon is the director of the Barth Syndrome Interdisciplinary Clinic at the Kennedy Krieger Institute. She serves on the Maryland State Advisory Council on Hereditary and Congenital Disorders and the NIH Working Group for Mitochondrial Models, and is on the faculty of the North American Metabolic Academy of the Society for Inherited Metabolic Disorders.

Clinical Trials

Matt reported that advertisements for Dr. John Jefferies clinical study, which is supported by his 2014 BSF Research Grant, have appeared on the BSF website, Facebook page, Family Listserv, and will be in the Fall newsletter.

13th EuroFedLipid Congress

Lindsay reported that the satellite meeting of the 13th EuroFedLipid Congress, entitled Cardioplin as a Key Lipid of Mitochondria in Health and Disease, 2nd ed., was successful and coincided with a meeting of the BSF Italian affiliate. It was held in Florence, Italy on September 30 to October 1, 2015. BSF gave financial aid to this meeting which was co-chaired by Drs. Michael Schlame and Angela Corcelli. The meeting was attended by several researchers well-known to BSF.

5. Update – Board Development

Suze Osnos provided an update on, and the Board discussed, proposed candidates for future board membership.

6. Update - 2016 Conference

R13 Grant

Matt Toth reported that he has filed to apply for a R13 grant from the National Heart, Lung, and Blood Institute, and he has received permission to do so. The SciMed Organizing committee that oversees the SciMed sessions is now composed of Drs. Cade, Towbin, Strauss, and Wanders, with Matt as PI of the R13 application. Deadline for the R13 application is December 12, 2015.

Adjournment

The Board of Directors adjourned the meeting at 10:25 am ET.

Respectfully submitted,



Susan A. McCormack
Secretary