



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
April 14, 2016

Members in Attendance:

Marcus E. Sernel	Chairman
David Axelrod, MD	Board Member
Matthew Blumenthal	Board Member
Randy Buddemeyer	Treasurer, 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:

Valerie (Shelley) Bowen, Director, Family Services & Awareness
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 & Discussion – Financials
3. Review & Discussion – Fundraising
4. Update & Discussion – Science & Medicine
5. Update & Discussion – 2016 Conference
6. Discussion – Leadership Development

The meeting, held via teleconference, was called to order by the Chairman on Thursday, April 14, 2016 at 8:00 pm ET.

1. Ratification of Minutes

The board approved the January 19, 2016 Board minutes, as submitted on this date.

The board approved the February 20, 2016 Board minutes, as submitted on this date.

The board approved the March 22, 2016 Executive Committee 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 – 3/31/2016

Total Revenues of \$125,021, including unrestricted donations of \$80,303; the balance of \$44,718 is temporarily restricted (SciMed, Varner, and Will McCurdy Funds).

Total Expenses of \$521,996; and a Deficiency of Revenue over Expenditures of \$396,975.

Total Current Assets	\$ 3,762,364
Total Current Liabilities	\$ 509,313
Total Fund Balance	\$ 3,253,051

2015 Audit

Lindsay reported that the 2015 audit with Gray, Gray, & Gray is underway and should be completed within the next 14 days.

3. Review & Discussion - Fundraising

Lindsay provided a review of the 2016 strategic plan for fundraising created by contractor, Felicia Ganote.

Strategic Development Plan

Lindsay reported that Felicia Ganote has submitted several grants in support of the 2016 Conference. Lindsay reported that Felicia's agreement will expire at the end of April. Lindsay proposed, and the Board agreed, to extend this agreement through 2016 to allow Felicia to continue executing the Strategic Development Plan.

4. Update & Discussion - Science & Medicine

Matt Toth provided an update on Science and Medicine initiatives.

5. Update & Discussion - 2016 Conference

Shelley Bowen provided an update regarding the 2016 Conference. The theme of this year's Conference is Team Barth. Preparations are well underway. Shelley expressed her gratitude for the volunteers who are helping with Conference planning. Matt Toth also provided an update on the Science and Medicine sessions of the Conference.

6. Discussion – Leadership Development

Susan Osnos informed the Board of the current status of Board development.

Adjournment

The Board of Directors adjourned the meeting at 10:00 pm ET. The next Board meeting is scheduled for Wednesday, July 20, 2016 at 9:00 pm ET. The next Executive Committee meeting is scheduled for Tuesday, May 10, 2016 at 8:00 pm ET.

Respectfully submitted,



Susan A. McCormack
Secretary
