



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
January 19, 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
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

Florence Mannes	Board Member
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Invited Guests:

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

The meeting, held via teleconference, was called to order by the Chairman on Tuesday, January 19, 2016 at 8:00 pm ET.

1. Ratification of Minutes

The board approved the November 15, 2015 Board minutes, as submitted on this date.

2. Review & Discussion - Financials

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

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2015 – 12/31/2015

Total Revenues of \$3,148,600, including unrestricted donations of \$591,448; the balance of \$2,557,152 is temporarily restricted (SciMed, Varner, and Will McCurdy Funds).

Total Expenses of \$1,229,250; and an Excess of Revenue over Expenditures of \$1,919,350.

Total Current Assets	\$ 3,913,698
Total Current Liabilities	\$ 261,269
Total Fund Balance	\$ 3,652,429

The board indicated its gratitude to Lindsay Groff, the rest of the staff, and all board members for their commitment to reach our 2015 goal of ending the year with a net surplus. This goal was achieved as a result of both increased fundraising efforts and reduced expenses.

2016 Consolidated Budget

Lindsay presented a review of the preliminary proposed 2016 consolidated budget. The Board engaged in a discussion. This item has been placed on the February 20, 2016 board meeting agenda for final approval.*

2015 Audit

Lindsay reported that the 2015 audit with Gray, Gray, & Gray is underway.

3. Review & Discussion - Fundraising

Lindsay provided a review of 2015 year-end fundraising activities, metrics, and the impact on revenue. The November direct mail appeal performed quite well, as did the December direct mail appeal. Several families sent an appeal directly to their friends and family via mail.

Strategic Development Plan

Felicia Ganote started her contracted work in late November and has quickly jumped in by writing a grant. In addition, she has begun her work on other parts of the strategic development plan. Lindsay reported that Felicia's three month agreement will expire at the end of February. Lindsay proposed, and the Board agreed, to extend this agreement through April to allow Felicia to continue finalizing and executing the Strategic Development Plan.

4. Update & Discussion - Science & Medicine

2015 Research Grant Program

Matt Toth reported the Scientific & Medical Advisory Board (SMAB) will meet on January 27, 2016 to review the 16 grant applications that have been submitted for the 2015 research grant cycle. The Board of Directors will meet on February 20, 2016 to vote on funding.

5. Update – Family Services & Awareness

Pediatric Heart Failure Meeting

David Axelrod reported on Shelley Bowen's presentation at the Pediatric Heart Failure Meeting held in San Diego, CA on December 4, 2015. There were a total of 256 pediatric heart failure healthcare professionals in attendance. Shelley had the opportunity to hold meetings with numerous transplant and heart failure experts from around the US. The board thanked Shelley for a job well done by increasing awareness of BTHS.

Barth Syndrome Registry & Repository (BRR 2.0)

Shelley Bowen provided an update on enrollment activity of the BRR 2.0. Matt Toth reported that the Western Institutional Review Board (WIRB) has approved the BRR2.0 for another year.

*Items placed on February 20, 2016 Board meeting agenda

6. Update & Discussion - 2016 Conference

Lindsay reported that the 2016 Conference Steering Committee continues to meet on a regular basis for the planning of the conference. Registration and sleeping room reservations for the conference went “live” on January 19th. A keynote speaker was selected, and planning for the educational sessions is underway.

7. Other

Board of Directors Meeting

Marc Sernel proposed that the Board of Directors meeting in July will be held on Wednesday, July 20, 2016 from 6:00 – 8:00 pm ET in Clearwater, FL.

2015 Staff Evaluations

Marc reported that the Organizational Development Committee has begun 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 evaluation. Marc reported that we expected to be able to complete this process so that the review and proposed compensation changes could be discussed at the next Board meeting.*

Adjournment

The Board of Directors adjourned the meeting at 9:55 pm ET. The next Board meeting is scheduled for Saturday, February 20, 2016 at 9:00 am ET. The next Executive Committee meeting is scheduled for Tuesday, March 22, 2016 at 8:00 pm ET.

Respectfully submitted,



Susan A. McCormack
Secretary