



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
October 18, 2017

Members in Attendance:

Marcus E. Sernel	Chairman
David Axelrod, MD	Board Member
Matthew Blumenthal	Board Member
B.J. Develle	Board Member
Nicole Derusha-Mackey	Board Member
Florence Mannes	Board Member
Susan A. McCormack	Secretary, Board Member
Susan Osnos	Board Member
John Wilkins	Board Member
Kevin Woodward	Treasurer, Board Member
Stephen B. McCurdy	Chairman <i>Emeritus</i>
Lindsay Groff, Executive Director	Board Member, <i>ex-officio</i>

Members Not in Attendance/Partial Attendance

Catharine Lynne Ritter	Board Member
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Invited Guests:

Lynda Sedefian, Executive Assistant
Kate McCurdy, *Emerita*, SMAB

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 - Operations
4. Review & Discussion – Fundraising
5. Update – 2018 Conference
6. Update & Discussion – Board Development
7. Update & Discussion – Science/Medicine
8. Other

The meeting, held via GoToMeeting, was called to order by the Chairman on Wednesday, October 18, 2017, at 12:00 pm ET.

1. Ratification of Minutes

- The April 8, 2017 Board minutes, as submitted on this date.
- The May 31, 2017 Executive Committee minutes, as submitted on this date.
- The June 28, 2017 Board minutes, as submitted on this date.
- The September 27, 2017 Executive Committee minutes, as submitted on this date.

2. Review & Discussion - Financials

Lindsay Groff provided an overview of the August 2017 financial statements, which reflected the following:

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2017 – 08/31/2017

Total Revenues of \$403,293, including unrestricted donations of \$339,343; the balance of \$63,950 is temporarily restricted (Science/Medicine, Varner, and Will McCurdy Funds).

Total Expenses of \$679,394; and a Deficiency of Revenue over Expenditures of \$276,101.

Total Current Assets	\$3,582,130
Total Current Liabilities	\$ 280,696
Total Fund Balance	\$3,301,434

3. Review & Discussion – Operations

Executive Director Position

On September 27, 2017, Lindsay Groff informed the Executive Committee that she will resign her full-time position as Executive Director, on November 3, 2017.

Marc Sernel informed the board that Lindsay has offered to continue to work with BSF in a consultant role through February 9, 2018. After discussion, the board agreed to accept this offer and retain Lindsay in a consultant role beginning November 4, 2017 thru February 9, 2018, to allow for a seamless transition.

VOTE: The board agreed to retain Lindsay Groff in a consulting role starting November 3, 2017 thru February 9, 2018.

Marc Sernel provided an overview of next steps in the process of filling this position. A search committee has been formed, consisting of Marc Sernel, Susan McCormack, Susan Osnos, Kevin Woodward, Kate McCurdy, and Lindsay Groff.*

Felicia Ganote

Lindsay updated the Board that Felicia Ganote, who has consulted with BSF on fundraising strategies the past two years, has resigned from her consulting position due to personal reasons.

4. Review & Discussion - Fundraising

Lindsay Groff provided an overview of fundraising activities, metrics, and the impact on revenue, as well as plans for year-end fundraising activities (i.e., mailed appeals, e-appeals, #GivingTuesday, events, phone calls, etc.). Lindsay informed the board that the NY Islanders will host a Barth Syndrome Night on February 9, 2018.

5. Update – 2018 Conference

Lindsay Groff provided an update on conference planning for BSF’s 2018 conference. The Conference Steering Committee consists of all staff members, along with Kevin Woodward, Lois Galbraith, Susan Hone, and Jack Higgins. Preliminary planning is underway (footprint of conference, keynote speaker, theme, etc.). The next meeting is scheduled for November 2, 2017.

6. Update & Discussion – Board Development

Marc Sernel provided an update on proposed candidates for Board membership. A decision was made to invite Megan Branagh to serve on the board for a 3-year term, commencing January 2018.

VOTED: To invite Megan Branagh to serve on the board for a 3-year term, commencing January 2018.

*Items needing follow-up

7. Update & Discussion – Science/Medicine

Stealth/Elamipretide

Marc Sernel provided an update on science and medicine initiatives, including an update on the Stealth/Elamipretide clinical trial. Marc informed the board that a meeting was held on October 11, 2017, with members of Stealth and BSF, wherein BSF was provided an update on the progress of this clinical trial.

Bezafibrate

Marc Sernel provided an update on the bezafibrate initiative in the UK. This clinical trial is estimated to start in mid-2018.

Research Grant Program

Marc Sernel provided an overview of the revised grant application process for the grant program.

Request from Dr. Robin Duncan for KO Mice

Marc Sernel informed the board that BSF has received a request from Dr. Robin Duncan for financial assistance to obtain the KO mice from Dr. Strathdee's lab in Glasgow, Scotland. The total cost, which is mainly shipping costs to Canada, is approximately \$2,000. Dr. Duncan has a 2015 BSF Research Grant, but this request for the knock-out (KO) mouse model is beyond the scope of her grant.

VOTED: To allow a budget of up to \$2,000 to assist in the distribution of the KO mouse to Dr. Robin Duncan.

United Mitochondrial Disease Foundation (UMDF) Meeting

Marc Sernel informed the board that ten members of the SMAB, as well Steve McCurdy and Dr. Colin Phoon, attended an off-year SMAB meeting at the UMDF conference in Alexandria, Virginia on June 29, 2017. In addition, an afternoon session of the UMDF meeting was devoted to BTHS research and CL, and this session was well-received. Please see the attached report of that off-year meeting for more details. One recommendation was to have off-year SMAB meetings on a regular basis.

The board will discuss potential new candidates to serve on the Scientific & Medical Advisory Board (SMAB) at the next board meeting in 2018.*

8. Other

Global Genes Meeting

Lindsay Groff informed the board that she and Shelley Bowen attended the Global Genes Meeting held on September 14-16, 2017, where Dr. Colin Steward was awarded the 2017 International RARE Champion of Hope Award. Dr. Steward has dedicated a large portion of his career to helping families with Barth syndrome lead better quality lives.

Website

Lindsay Groff informed the board of the progress of Lynda Sedefian and Shelley Bowen bringing over content to the new website, which is scheduled to go live mid-November.

Adjournment

The Board of Directors adjourned the meeting at 1:40 pm ET. The next Executive Committee meeting is scheduled for Tuesday, December 19, 2017 @ 8:00 pm ET.

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