



Barth Syndrome Foundation, Inc.  
Board of Directors Meeting  
September 27, 2016

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**Members in Attendance:**

Marcus E. Sernel	Chairman
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>

**Members Not in Attendance**

David Axelrod, MD	Board Member
Florence Mannes	Board Member
Stephen B. McCurdy	Chairman <i>Emeritus</i>
Catharine Lynne Ritter	Board Member

**Our Mission - *Saving lives through education, advances in treatment, and finding a cure for Barth syndrome.***

**Agenda Items:**

1. Update – Board Development
2. Update – Financials
3. Update – Fundraising
4. Post-Conference
5. Other

The meeting, held via teleconference, was called to order by the Chairman on Tuesday, September 27, 2016 at 8:00 pm ET.

**1. Update – Board Development**

Susan Osnos reviewed the term lines of the current Board of Directors. Cathy Ritter's 3-year term ended in April 2016. The board voted unanimously to re-elect Cathy Ritter for an additional 3-year term.

**VOTED:** To re-elect Cathy Ritter to serve an additional 3-year term. Said term will run through April 2019.

Susan provided an update on board recruitment. Following a discussion, the board voted unanimously to elect the following members for a 3-year term as of this date.

**VOTED:** To invite Nicole Derusha-Mackey to serve a 3-year term. Said term will run through April 2019.

**VOTED:** To invite BJ Develle to serve a 3-year term. Said term will run through April 2019.

Marc Sernel noted that Susan McCormack has accepted the role of Vice Chair and will then assume the role of Chair in April 2018.

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\*Items placed on the November 1, 2016 board meeting.

Note: The board needs to elect a new Secretary and Treasurer for 2017.\*

**2. Update – Financials**

Lindsay Groff provided an overview of the August 2016 comparison financial statements, which reflected the following:

**Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2016 – 08/31/2016**

Total Revenues of \$481,638, including unrestricted donations of \$391,851; the balance of \$89,788 is temporarily restricted (Science/Medicine, Varner, and Will McCurdy Funds).

Total Expenses of \$981,878; and a Deficiency of Revenue over Expenditures of \$500,240.

Total Current Assets	\$3,537,211
Total Current Liabilities	\$ 387,431
<b>Total Fund Balance</b>	<b>\$3,149,780</b>

**3. Update – Fundraising**

Lindsay Groff provided a review of year-end fundraising activities, metrics, and the impact on revenue.

Lindsay provided an update on the October 24th event in Boston. It will be an opportunity to: thank major donors in this region, leverage existing donors to find new donors, and increase awareness. Doug Melton and Bill Pu will be the featured speakers.

Lindsay also provided an update on a unique opportunity to have a “Barth Night” at the November 18th New York Islanders game. A PSA (Public Service Announcement) will be shown to the fans on the jumbotron about Barth syndrome. BSF will also receive the proceeds from the game’s 50/50 raffle. Other fundraising activities will occur during the night, including inviting top donors to the owner’s box. A huge thanks to Kate and Steve McCurdy for this incredible opportunity!

Three direct mail appeals will be sent in the fall/winter, including e-appeals.

**4. Update – Post-Conference**

Lindsay provided a post-conference update including feedback from the attendees at the SciMed and Family sessions of BSF’s 2016 Conference which was very positive.

**5. Other**

**United Mitochondrial Disease Foundation Conference**

The United Mitochondrial Disease Foundation (UMDF) is interested in devoting an afternoon session of the UMDF 2017 Annual Meeting to Barth syndrome (BTHS). UMDF has been a valuable peer in the patient advocacy area, and it has provided several grants to our researchers over the years to work on BTHS-specific projects. The 2017 UMDF Meeting will be held June 28 to July 1, 2017 at the Hilton in Alexandria, VA. This would be a unique opportunity for BTHS researchers to display their progress, and it would provide an even greater exposure of our cause to the researchers and physicians we want to attract. Dr. Michael Schlame has agreed to organize this afternoon session. UMDF requests that BSF cover the travel and room expenses of the speakers for this BTHS session. The estimate for five speakers should be ~ \$5,000. This could also serve as an off-year SMAB meeting that was promoted at the July BSF SMAB meeting.

**VOTED:** To allow a budget of up to \$5,000 to support the UMDF Meeting.

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\*Items placed on the November 1, 2016 board meeting.

Global Genes Summit

Lindsay reported that she attended the Global Genes RARE Patient Advocacy Summit which was held on September 22-24, 2016 in Huntington Beach, California.

Better Business Bureau Wise Giving Alliance

Lindsay reported that she was recently interviewed by the BBB's Wise Giving Alliance with the goal to increase trust in the nonprofit community. The video will be released in the coming weeks.

**Adjournment**

The Board of Directors adjourned the meeting at 8:45 pm ET. The next Board meeting is scheduled for Tuesday, November 1, 2016 at 8:00 pm ET, via GoToMeeting.

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" being the most prominent part.

Susan A. McCormack  
Secretary