



Barth Syndrome Foundation, Inc.  
Board of Directors Meeting  
November 1, 2016

**Members in Attendance:**

Marcus E. Sernel	Chairman
David Axelrod, MD	Board Member
Matthew Blumenthal	Board Member
Randy Buddemeyer	Treasurer, Board Member
Nicole Derusha-Mackey	Board Member
Bruce J. Develle	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

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

**Agenda Items:**

1. Ratification of Minutes
2. Update – Financials
3. Update – Fundraising
4. Update – Science & Medicine

The meeting, held via GoToMeeting, was called to order by the Chairman on Tuesday, November 1, 2016 at 8:00 pm ET. Marc welcomed BJ Develle and Nicole Derusha-Mackey who were elected to serve on BSF's Board of Directors commencing November 1, 2016 for a three-year term.

**1. Ratification of Minutes**

The Board approved the July 20, 2016 Board minutes, as amended on this date.  
The Board approved the September 27, 2016 Board minutes, as amended on this date.

**2. Update – Financials**

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

**Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2016 – 09/30/2016**

Total Revenues of \$504,244, including unrestricted donations of \$404,328; the balance of \$99,916 is temporarily restricted (Science/Medicine, Varner, and Will McCurdy Funds).

Total Expenses of \$1,044,500; and a Deficiency of Revenue over Expenditures of \$540,255.

Total Current Assets	\$3,440,230
Total Current Liabilities	\$ 330,465
<b>Total Fund Balance</b>	<b>\$3,109,765</b>

**3. Update – Fundraising**

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

Lindsay provided an overview of the October 24th event in Boston which provided an opportunity to thank major donors in this region, leverage existing donors to find new donors, and increase awareness. Dr. Doug Melton and Dr. Bill Pu were 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. Fundraising activities will occur during the night, including inviting major donors to the owner’s box.

Three direct mail appeals will be sent in the fall/winter, including e-appeals. Many family members have also committed to sending a year-end appeal.

An appeal will be sent in support of #GivingTuesday on November 29, 2016.

**4. Update – Science & Medicine**

Marc Sernel provided an update on science and medicine initiatives, as follows:

Research Grant Program

The deadline for the 2016 cycle was October 31, 2016. Interest has been steady and 14 applications have been received.

United Mitochondrial Disease Foundation Conference

As noted at the last board meeting, the United Mitochondrial Disease Foundation (UMDF) has devoted an afternoon session of the UMDF 2017 Annual Meeting to Barth syndrome (BTHS). The 2017 UMDF Meeting will be held June 28 to July 1, 2017 at the Hilton in Alexandria, VA. This will 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 and has invited BSF SMAB members Dr. William Pu and Dr. Hilary Vernon to speak.

**VOTED:** To allow a budget of up to \$7,000 to support the UMDF Meeting.

Barth Registry & Repository2.0

Stealth BioTherapeutics requested and has received a download of data from the BRR2.0 database to facilitate the clinical trial that is planned for BTHS with their compound Elamipretide.

Meetings

Lindsay reported that Matt attended the Healthcare Executive Roundtable: "How Does Patient Engagement Drive Healthcare Value", which was held in Manhattan on October 13, 2016, and sponsored by the Center for Healthcare Innovation.

Matt also attended the inaugural meeting for Chief Medical/Scientific Officers and Research Directors of the National Health Council held in Baltimore on October 27-28, 2016.

**Adjournment**

The Board of Directors adjourned the meeting at 9:20 pm ET.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Susan A. McCormack". The signature is written in a cursive style with a large, stylized initial "S".

Susan A. McCormack  
Secretary