



# MINUTES

Barth Syndrome Foundation, Inc.  
Board of Directors Meeting  
December 16, 2014

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**Members in Attendance:**

|                                   |                                 |
|-----------------------------------|---------------------------------|
| Marcus E. Sernel                  | Chairman                        |
| David Axelrod, MD                 | Board Member                    |
| Randy Buddemeyer                  | Treasurer, Board Member         |
| Lindsay Groff, Executive Director | Board Member, <i>ex-officio</i> |
| Stephen Kugelmann                 | Board Member                    |
| Susan A. McCormack                | Secretary, Board Member         |
| Stephen B. McCurdy                | Chairman <i>Emeritus</i>        |
| Susan Osnos                       | Board Member                    |
| Catharine Lynne Ritter            | Board Member                    |
| John Wilkins                      | Board Member                    |
| Kevin Woodward                    | Board Member                    |

**Invited Guests:**

Shelley Bowen, Director, Family Services & Awareness  
Lynda Sedefian, Executive Assistant  
Sandra Stevens, Fundraising Project Manager  
Matthew J. Toth, PhD, BSF Science Director

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

**Agenda Items:**

1. Review – Minutes for Approval
2. Review – 2014 Year-to-Date Financials
3. Discussion – Fundraising
4. Review – 2015 Draft Budget
5. Update – Science & Medicine
6. Update – Family Services & Awareness

The meeting, held via GoToMeeting, was called to order by the Chairman on Tuesday, December 16, 2014 at 8:04pm ET.

**1. Review and acceptance of minutes**

The board approved the September 16, 2014 board minutes, as amended on this date.

The board approved the October 16, 2014 executive committee minutes, as submitted on this date.

**2. Review - 2014 Year-to-Date Financials**

Lindsay Groff, Executive Director provided an overview of the 2014 year-to-date budget comparison financial statements, which reflected the following:

**Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2014 – 11/30/2014**

Total Revenues of \$611,282; including unrestricted donations of \$570,833.

Total Expenses of \$1,137,647; and a Deficiency of Revenue over Expenditures of \$526,365.

|                           |                     |
|---------------------------|---------------------|
| Total Current Assets      | \$ 1,455,264        |
| Total Current Liabilities | \$ 158,742          |
| <b>Total Fund Balance</b> | <b>\$ 1,296,522</b> |

**3. Discussion - Fundraising**

Lindsay provided a review of 2014 fundraising activities, metrics, and the impact on revenue.

- There have been three direct mail appeals which included lapsed donors (March, October, December). Additional year-end appeals have been sent by the McCurdys, Wilkins, and several other family members within our community.
- We were contacted by American Express to submit a grant application for \$25,000 with a 48- hour turnaround. That application is complete, and we were just notified that we received a \$25,000 grant.
- By all measures, #GivingTuesday was a great success. This year, we set a one-day goal of \$10,000 and offered a match, dollar-for-dollar for that first \$10,000. We exceeded that goal with \$15,025 total received from 137 donors. Lindsay thanked those board members who matched these donations.
- Other fundraising efforts were included in the Executive Update report.

**4. Review – 2015 Draft Budget**

Lindsay provided an overview of the 2015 draft consolidated budget. This item has been placed on the agenda for the February 28-March 1, 2015 board meeting for further discussion/approval.\*

**5. Update – Science & Medicine**

*Research Grant Program*

Twenty one applications were received for the 2014 BSF Research Grant Program. There is one application for each of the two RFAs that we had previously advertised. (BSF-01, Depression in Barth Syndrome, and BSF-02, Impact of Testing Positive as a Barth Syndrome Mutation Carrier.) Quality of the 2014 applications is very high. The SMAB will meet via teleconference on January 28, 2015 to review all grant applications. Matt Toth will present the SMAB’s recommendations at the BSF Board of Directors meeting in February 2015 wherein the board will vote on the grant awards.\*

*Bezafibrate Initiative*

Research Service Agreements with Drs. Khuchua, Ren & Phoon continue. Intermediate reports from both groups show everything is on track, but it is very early to conclude anything. Efforts to coordinate with Colin Steward’s NHS grant to test bezafibrate with BTHS individuals are progressing slowly.

*Drug development for BSF*

As proposed in the September Executive Report, Matt continues to suggest that it may be a good idea to think about a separate “Drug Development” capacity for the BSF; to at least separate out those expenses that cannot be properly handled by the BSF Research Grant Program but that are vital to the goals of BSF. This item has been placed on the agenda for the February 28-March 1, 2015 board meeting for further discussion.\*

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\*Items placed on the February 28 – March 1, 2015 board meeting agenda

**6. Update – Family Services & Awareness**

*BRR*

Barth Syndrome Registry and Repository 2.0 has 44 registrants so far. Matt spoke to Dr. Barry Byrne about the status of the biological samples of the BRR, and Barry will have his staff make up an inventory of what is available so it can be advertised for researchers to easily use.

*Clinic at Kennedy Krieger Institute (KKI)*

Matt, Sandra, and Lindsay attended the November 4 clinic at KKI to meet with the families and clinicians. The 2015 dates are: March 3, June 2, September 1, and November 3.

*2015 Budget*

Shelley has requested line items for attending two scientific conferences in 2015 to promote awareness, two regional outreaches, a volunteer workshop, and assistance in archiving the listserv. This item has been placed on the agenda for the February 28 – March 1, 2015 board meeting for further discussion.\*

**Adjournment**

At 10:00pm ET all staff members left the meeting. The Board of Directors convened the meeting via teleconference to discuss board development. The next Board meeting is scheduled for February 28-March 1, 2015 in Wellesley, MA.

Respectfully submitted,



Susan A. McCormack  
Secretary