



# MINUTES

Barth Syndrome Foundation, Inc.  
Board of Directors Meeting  
April 10, 2014

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**Members in Attendance:**

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

**Members Not in Attendance:**

|                                     |              |
|-------------------------------------|--------------|
| Catharine Lynne Ritter              | Board Member |
| Lynda Sedefian, Executive Assistant |              |

**Additional Invitees**

|  |                          |
|--|--------------------------|
| Shelley Bowen, Director, Family Services/Awareness |                          |
| Ellen Bruno, Simple Office Solutions               |                          |
| Diane Gibson, Gray, Gray & Gray, LLP               |                          |
| Stephen B. McCurdy                                 | Chairman <i>Emeritus</i> |
| 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. Board Terms & Elections
2. Review – 2013 Audited Financials
3. Review – 2014 Year-to-Date Financials
4. Review – Executive Summary
5. Update – BRR 2.0
6. Update – Science & Medicine
7. Other

The meeting, held via teleconference, was called to order by the Chairman on Thursday, April 10, 2014 at 8:00 pm ET. Marc officially welcomed Kevin Woodward who was elected to serve on BSF's Board of Directors commencing April 2014 for a three-year term. Said term will run through April 2017.

**1. Board Terms**

Marc reviewed the term limits of the current Board of Directors. Kate McCurdy and Sue Wilkins’s terms ended, as of April 2014, as members of the Board of Directors. Marc thanked Kate and Sue for their dedicated service to BSF.

Randy Buddemeyer, Susan McCormack and John Wilkins’s 3-year terms ended as of April 2014. The board voted unanimously to re-elect all three members for an additional 3-year term.

**VOTED:** That the Board of Directors re-elect Randy Buddemeyer to serve an additional 3-year term. Said term will run through April 2017.

**VOTED:** That the Board of Directors re-elect Susan McCormack to serve an additional 3-year term. Said term will run through April 2017.

**VOTED:** That the Board of Directors re-elect John Wilkins to serve an additional 3-year term. Said term will run through April 2017.

**2. Review – 2013 Audited Financials**

Diane Gibson of Gray, Gray & Gray, LLP was also an invited guest who joined the meeting via teleconference to disclose BSF’s 2013 Audited Financial Statements and Form 990. Diane delivered a clean audit of BSF’s 2013 financial statements. Diane reviewed the contents of the 2013 audit with the members of the Board who were satisfied with the financial statements and pleased with the findings of BSF’s auditor. Following a discussion, it was:

**VOTED:** That the Board of Directors accept the 2013 Audited Financial Statements and 990, as submitted by Gray, Gray & Gray, Certified Public Accountants, LLC.

At this time, Diane Gibson and Ellen Bruno left the meeting. The Barth Syndrome Foundation will register with all fifteen (15) states where BSF solicits funds concurrently with the filing of its 2013 Auditor’s Report and IRS Form 990.

**3. Review – 2014 Year-to-Date Financials**

Randy Buddemeyer, BSF Treasurer, provided an overview of the 2014 year-to-date budget comparison preliminary financial statements, which reflected the following:

**Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2014 – 03/31/2014**

Total Revenues of \$60,894; including unrestricted donations of \$57,759.

Total Expenses of \$492,983; and a Total Fund Balance of \$432,089.

|                           |                     |
|---------------------------|---------------------|
| Total Current Assets      | \$ 1,710,115        |
| Total Current Liabilities | \$ 318,884          |
| <b>Total Fund Balance</b> | <b>\$ 1,391,231</b> |

**4. Review – Executive Summary**

Lindsay introduced Sandra Stevens to the board. Lindsay then provided an executive summary which outlined recent activities among BSF’s programs, including: Awareness, Conference, Science & Medicine, Fundraising and Publications/Communications.

**Fundraising**

Lindsay reported that she and Sandra attended the Principles & Techniques of Fundraising Course at Indiana University on March 24-27, 2014. Both felt it was a very worthwhile training course.

Lindsay reported that the Spring appeal was mailed on April 10, 2014 and will be sent to approximately 700 donors. The theme of the appeal is the 2014 conference. Lindsay and Sandra are planning additional targeted appeals throughout 2014, using techniques learned at the IUPUI training course. They also plan to repeat the Giving Tuesday campaign in November. The Board discussed various issues regarding these fundraising appeals to ensure that are well-received by donors and potential donors.

Lindsay reviewed the overall 2014 priorities which include: drug development possibilities, research grant program, BRR 2.0, 2014 conference, website upkeep, ongoing publications, and enhanced fundraising.

Lindsay reported that conference planning is ongoing. Shelley Bowen has increased emphasis this year on carriers, young men transitioning to adulthood, transplanted individuals, and bereaved families.

**5. Update – BRR 2.0**

Shelley Bowen reported that the target date for launch is now early May. If there were no further delays the possibility of having a demo of BRR 2.0 at the conference was discussed. Shelley will keep the Board updated on further developments.

**6. Update – Science & Medicine**

Bezafibrate Initiative

Matt Toth reported on the status of the bezafibrate initiative. Two developments have resulted in a delay in seeking FDA approval of a clinical trial: (1) the FDA raised certain questions and concerns about the proposal that will need to be addressed, and (2) a recent paper was published that might raise questions about the expected efficacy of bezafibrate in treating Barth Syndrome. Matt reports that he and the SMAB still believe that bezafibrate holds great promise as a potential therapy for Barth Syndrome, but that further animal testing should be done to bolster the case for a clinical trial. As a result, Matt requested that the board fund a total of \$100,000 for two labs to perform pre-clinical bezafibrate studies with the knockdown mouse. It is hoped that with positive data from these studies the FDA will approve a clinical trial of bezafibrate.

**VOTED:** That the Board of Directors accept Matt's request to fund a total of \$100,000 for two labs to perform pre-clinical bezafibrate studies with the knockdown mouse.

**7. Other**

The next board meeting will be Monday, June 23, 2014 at 8:00 am ET at the Conference hotel. Board members will be expected to arrive at the conference hotel by Sunday evening.

Marc Sernel will be working with Susan Osnos to further develop a list of potential candidates for Board service.

**Adjournment**

The meeting was adjourned at 10:20 pm ET. The next Board meeting is scheduled for Monday, June 23, 2014 at 8:00 am ET at the conference location.

Respectfully submitted,



Susan A. McCormack  
Secretary