

Barth Syndrome Foundation, Inc. Board of Directors Meeting January 24, 2012

MINUTES

Members in Attendance:

Stephen B. McCurdy Lindsay Groff, Executive Director David Axelrod, MD Stephen Kugelmann Susan A. McCormack Katherine R. McCurdy Susan Osnos Marcus E. Sernel John Wilkins Susan V. Wilkins

Board Members Not in Attendance

Randy Buddemeyer Michaela Damin

Additional Invitees

Ellen Bruno, BSF Accountant Lynda Sedefian, Executive Assistant Matthew J. Toth, PhD, BSF Science Director Shelly Bowen, Director of Family Services & Awareness

Chairman Board Member, *ex-officio* Board Member Board Member Board Member

Board Member Board Member Corporate Secretary, Board Member Board Member Board Member

Treasurer, Board Member Board Member

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

Agenda Items

- 1. Decision Vote to Accept Minutes
- 2. Discussion Financial & Audit Update
- 3. Decision Revised 2012 Budget
- 4. Discussion 2012 Staff Goals
- 5. Discussion 2012 Conference Update
- 6. Discussion BRR Update
- 7. Other Items (April board mtg.)

The meeting was called to order by the Chairman on Tuesday, January 24, 2012 at 8:00 PM EST.

1. <u>Ratification of Minutes</u>

The Board approved the November 15, 2011 Board minutes, as amended on this date.

2. Financial & Audit Update

Ellen Bruno provided an overview of the 2011 year-end preliminary pre-audit financial statements, which reflected the following:

*Items placed on the next scheduled Board meeting. **Task items

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2011 – 12/31/2011

Total Revenues of \$762,726; including unrestricted donations of \$497,628. Total Expenses of \$814,019; for a Deficiency of Revenue over Expenditures of \$51,293.

Total Current Assets	\$ 1,980,469
Total Current Liabilities	\$ 120,679
Total Liabilities & Fund Balance	\$ 1,980,469

Ellen reported that the 2011 audit is well underway and that she has been working with Gray, Gray & Gray, LLP to provide all requested documentation. Steve McCurdy reported that the auditor will join the Board of Directors' April 29, 2012 meeting to present an overview of the 2011 Audited Financial Statements and Form 990.

3. 2012 Budget

Lindsay Groff and Ellen Bruno presented a review of the proposed 2012 consolidated budget. The Board engaged in a conversation regarding maximum deficit allowable.

After discussion, and upon Motion duly made and Seconded, it was:

VOTED: To accept the proposed 2012 consolidated budget which will reflect an increase of approximately \$50,000 in target donations over 2011 donations.

4. Staff Goals

Lindsay reviewed the 2012 staff goals with the Board members. At this time, Shelley Bowen joined the call to review her goals with the Board. A discussion ensued regarding top priorities for all staff members in 2012. Recommended changes from this discussion will be incorporated into the staff goals and re-distributed to the Board.

5. <u>2012 Conference Update</u>

Lindsay provided a detailed update on the 2012 Conference, and reported that the Steering Committee and Sub-Committees are well underway with the planning. Lindsay reported that registration is now open. Lindsay encouraged all Board members and members of the Conference Steering Committee and Sub-Committees to distribute the Sponsorship Prospectus far and wide.

Lindsay also reported that BSF has received discounted flights with Continental/United and is working on receiving similar discounts with other airlines. This information will be placed on the website.

John Wilkins and Sue Wilkins reported that they have a meeting scheduled next week to discuss the Varner Award for Pioneers in Science & Medicine. They will update the Board at its next meeting.*

6. Barth Registry & Repository (BRR) Update

Kate McCurdy, Matt Toth and Shelley Bowen provided an overview of the status of the BRR. After the discussion, it was proposed that the sub-committee will meet via teleconference within the next few days to discuss these issues.** This item has been placed on the next scheduled Board meeting for discussion.*

7. Other Items

The board decided to change the April 2012 face-to-face board meeting to a teleconference meeting which will be held on Sunday, April 29, 2012 @ 3:00 PM EST. Lynda Sedefian will work with Steve and Lindsay in scheduling the September (teleconference) and November 2012 (face-to-face) board meetings.**

Lindsay reported that she has been invited to attend BSFCa's Annual Meeting scheduled for April 21, 2012. The Board agreed that Lindsay should attend this meeting in support of our international affiliate. In an effort to share expenses, BSF will pay for her flight and BSFCa will pay for accommodations.

ADJOURNMENT

The meeting was adjourned at 10:00 PM EST. The next Board meeting is scheduled for Saturday, February 4, 2012 @ 12:00 PM EST via teleconference.

Respectfully submitted,

Manun E. Semel

Marcus E. Sernel Corporate Secretary

2012 Meeting Dates:

Board of Directors

Tuesday, January 24, 2012 Saturday, February 4, 2012 Sunday, April 29, 2012 Sunday, June 24, 2012 September, 2012 November, 2012

Executive Committee Tuesday, March 13, 2012

Tuesday, March 13, 2012 Tuesday, May 15, 2012 Tuesday, July 17, 2012 Tuesday, October 16, 2012 Teleconference @ 8:00 PM EST Teleconference @ 12:00 PM EST Teleconference @ 3:00 PM EST Face-to-Face (Conference) **Teleconference (TBD) Face-to-Face (TBD)**

Teleconference @ 8:30 PM EST Teleconference @ 8:30 PM EST Teleconference @ 8:30 PM EST Teleconference @ 8:30 PM EST