

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
 January 27, 2011

The Board of Directors of the Barth Syndrome Foundation, Inc. (BSF) met on January 27, 2011, via teleconference.

Board Members in Attendance

Stephen B. McCurdy	Chairman
Valerie “Shelley” Bowen	President, Board Member
Randy Buddemeyer	Treasurer, Board Member
Michaela Damin	Board Member
Stephen Kugelmann	Board Member
Susan A. McCormack	Board Member
Katherine R. McCurdy	Board Member
Susan S. Osnos	Board Member
Marcus E. Sernel	Corporate Secretary, Board Member
John Wilkins	Board Member
Susan V. Wilkins	Board Member

Additional Invitees

Matthew J. Toth, PhD, Science Director
 Lynda Sedefian, Executive Assistant

The meeting was called to order by the Chairman at 3:00 PM EST.

Steve McCurdy welcomed John Wilkins and Susan McCormack as the newest members to the Board of Directors. Being affected by Barth syndrome gives John a unique insight into the issues facing the Barth Syndrome Foundation. John recently earned an A.S. in Computer Information Technology from Southeast Community College and works part time as a computer consultant. John has grown up along with BSF, and in recent years has played an especially useful role in organizing conversations among older Barth boys/men both virtually and at the last conference. Our second new member is Susan McCormack, whose younger daughter is a carrier of Barth syndrome. Susan is a portfolio manager with a prominent firm in Boston. She graduated from Dartmouth College in 1986 with a degree in mathematics and received her MBA from Stanford Graduate School of Business in 1990. She is a CFA charterholder. Susan attended the 2010 Conference, and has become an active voice on BSF’s listserv.

The Board extended its appreciation to John and Susan for their willingness to devote their time and resources to BSF and looks forward to welcoming them in person at the April 2011 annual meeting. John and Susan were elected to the Board of Directors effective January 1, 2011 and will serve a three-year term, ending April 2014.

ITEMS OF DISCUSSION

1. Ratification of Minutes
2. Board Development
3. 2010 Financial Review
4. 2011 Budget Review & Approval
5. 2011 Family Services Update & Awareness Events
6. Scientific & Medical Advisory Board (SMAB) & Scientific Initiatives
7. 2010 Research Grant Program
8. Barth Registry and BioRepository (BRR) Update
9. Executive Director Search
10. New Licensed International Affiliate

**Items placed on agenda for Board’s annual meeting (April 8-10, 2011)*

***Items placed on agenda for next Executive Committee Meeting (March 15, 2011)*

1. **Ratification of Minutes**

The Board approved the November 12-14, 2010 Board minutes, as amended on this date.
The Board accepted the December 15, 2010 Executive Committee minutes, as submitted on this date.

2. **Board Development Update**

Susan Osnos reported that the BSF Board of Directors will continue to add new members in a thoughtful and strategic way to meet our needs in the future for expertise, leadership and fund-raising. After a decade in operation, several of our original board members will begin to step down over the next few years as their terms expire under the provisions of our by-laws, which also require that at least half of the board be comprised of family members. The Board is interested in potential new members with specialized scientific or medical knowledge of Barth syndrome; fund-raising experience; BTHS sibling; experience with navigating National Institutes of Health; and connections to/knowledge of pharmaceutical industry.

3. **2010 Financial Review**

Randy Buddemeyer provided an overview of the pre-audited 2010 year-end financial statements, which reflected the following:

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2010 – 12/31/2010

Total Revenues of \$778,272; including unrestricted donations of \$382,653.
Total Expenses of \$1,069,481; for a Net Deficiency of Revenue over Expenses of \$291,210.

Total Current Assets	\$ 2,033,511
Total Current Liabilities	\$ 140,971
Total Fund Balance	\$ 1,892,540
Total Liabilities & Fund Balance	\$ 2,033,511

4. **2011 Budget Review**

Randy also presented a comparison review of the 2011 preliminary consolidated budget vs. 2010 budget. The Board engaged in a conversation regarding (1) maximum deficit allowable as well as expense reduction targets; (2) research grant budget; (3) additional expense approval; and (4) board fund-raising targets. Following this discussion it was recommended that BSF's operational programs and priorities be re-evaluated at the annual meeting scheduled for April 2011.*

5. **Family Services Update & Awareness Events**

Shelley Bowen reported that she is in the process of evaluating stakeholder participation within our community of families (i.e., financial giving; volunteer; time/advice; list serve participation; BRR participation; fund-raising; etc.). Shelley also reported that there are two family outreaches planned for 2011. These outreaches offer families the opportunity to form/strengthen bonds with other families in their region and learn about on-going initiatives of the organization.

Shelley also reported that the 2010 Conference DVDs have been edited and sent to the duplication center for reproduction. Shelley will notify the families/physicians when ready for delivery.

Shelley also reported that the 2012 Conference hotel registration process has been set up by The Don Cesar. This information will be posted to BSF's website shortly.

*Items placed on agenda for Board's annual meeting (April 8-10, 2011)
**Items placed on agenda for next Executive Committee Meeting (March 15, 2011)

6. **Scientific & Medical Advisory Board (SMAB) & Scientific Initiatives**

Kate McCurdy reported that we have received a letter of resignation from Richard I. Kelley, MD, PhD, in the role of Chairman of the SMAB in order to allow him more time to concentrate on his work to better understand the biochemical underpinnings of Barth syndrome and develop nutritional treatments for the disorder. Dr. Kelley will continue to serve as a member of the SMAB and is completely devoted to our cause and to our organization. Please join us in thanking Dr. Kelley for his extremely generous and thoughtful ten years of service as SMAB Chairman. We truly appreciate his dedication and contributions.

The Board asked Kate to notify the SMAB of Dr. Kelley's resignation and request that they move forward and elect a chairman from amongst the ranks of the SMAB member slate to serve out Dr. Kelley's current term. This election then needs to be ratified by the BSF Board in order to become official.

Fellowship Program

Kate McCurdy reported that she has had several conversations regarding succession planning for key people in Barth syndrome research and BSF's desire to fund a Barth-specific fellowship program. The board authorized Kate and Matt Toth to continue these conversations and report back to the Board with recommendations and details of funding said fellowship program for Board ratification.

ICD-10 Code

Kate also reported that Barth syndrome will have an ICD-10 code ("International Classification of Disease" code or diagnosis code) which will be effective October 1, 2013. This has been a very long-term effort and a huge accomplishment on the part of Shelley Bowen, Kate McCurdy, Matt Toth, and Michaela Damin. BSF will educate our community of this important news at the appropriate time.

7. **2010 Research Grant Program**

Matt Toth reported that the SMAB met on January 26, 2011 to review 15 grant applications received for the 2010 grant cycle. The BSF Board of Directors would like to express our sincere appreciation to Dr. Richard Kelley, SMAB Chairman, and to all members of the SMAB who served as grant reviewers, as well as to the additional experts who served as outside reviewers.

The Board of Directors will meet on February 19, 2011, and Matt will present a summary of the grants received and the SMAB's recommendations. BSF affiliate board members will be invited to participate in this meeting. The BSF Board will then vote on grant funding for the 2010 research grant cycle.

8. **Barth Registry and BioRepository (BRR) Update**

Matt Toth reported that on December 13, 2010 a meeting was held to discuss BRR priorities going forward. In attendance were Dr. Amy Roberts, Judith Geva, both of Children's Hospital Boston. Dr. Carolyn Spencer and Kate McCurdy joined the meeting via telephone. Matt reported that progress is being made with regard to defining specific goals, objectives and deliverables for 2011. Matt also reported that updates have been made to the BRR website and that these changes have been reflected on BSF's website. This item has been placed on the agenda for the Board's annual meeting for a more in-depth follow-up discussion.*

9. **Executive Director Search**

Steve McCurdy reported that no action has been taken to date. Following a discussion, the Board agreed to move forward with the search for an Executive Director and authorized the Board and Organizational Development Committee to contact the search firm to begin this process.

**Items placed on agenda for Board's annual meeting (April 8-10, 2011)*

***Items placed on agenda for next Executive Committee Meeting (March 15, 2011)*

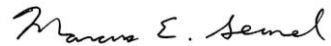
10. **New Licensed International Affiliate**

Steve McCurdy reported that the Association Barth France has signed the Trademark License Agreement, effective January 1, 2011. BSF plans to file for trademark rights for BSF's logo in Europe and the UK.

ADJOURNMENT

The meeting was adjourned at 6:00 PM EST. The next Board meeting is scheduled for Saturday, February 19, 2011.

Respectfully submitted,



Marcus E. Sernel
Corporate Secretary

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