MINUTES

Barth Syndrome Foundation, Inc. Board of Directors Annual Meeting July 25, 2010

The Board of Directors of the Barth Syndrome Foundation, Inc. (BSF) held a face-to-face meeting on Sunday, July 25, 2010 in Orlando, Florida.

Chairman of the Board

President, Board Member

Members in Attendance Stephen B. McCurdy Valerie "Shelley" Bowen Randy Buddemeyer Stephen Kugelmann Katherine R. McCurdy Susan S. Osnos Marcus E. Sernel Susan V. Wilkins

<u>Additional Invitees</u> Lynda Sedefian, Executive Assistant

<u>Members Not in Attendance</u> Michaela Damin Treasurer, Board Member Board Member Board Member *(joined via teleconference)* Board Member Corporate Secretary, Board Member Board Member

Board Member

The meeting was called to order by the Chairman at 7:30 PM EST.

ITEMS OF DISCUSSION

- 1. 2010 Financials
- 2. Open Access for Selected Articles
- 3. 2010 Conference Review
- 4. Strategic Planning Session
- 5. Other

FINANCIAL STATEMENTS

Preliminary Statement of Revenue and Expenditures All Funds - 01/01/2010 - 06/31/2010

Total Revenues of \$220,801; including unrestricted donations of \$87,200. Total Expenses of \$650,139; for a Net Deficiency of Revenue over Expenses of \$429,338.

Total Current Assets	\$ 1,979,321
Total Current Liabilities	\$ 224,207
Total Fund Balance	\$ 1,755,113
Total Liabilities & Fund Balance	\$ 1,979,321

OPEN ACCESS PUBLISHING

Kate McCurdy recommended that, in an effort to increase accessibility of a scientific paper that is being written by Dr. Colin Steward advancing the knowledge of prenatal diagnosis of Barth syndrome, BSF and BSTrust agree to fund the cost of publishing said article as open-access literature. The Board agreed that this was an important step forward in describing significant male fetal loss in Barth syndrome, and agreed to fund the publication of said article as open-access.

LINDA STUNDIS TRANSITION

Marc Sernel and Steve McCurdy reported on the negotiation and finalization of Executive Director Linda Stundis' resignation agreement and announcement. The BSF Board is thankful to Linda for her contributions over the past two years and looks forward to building on Linda's contributions in the future.

2010 CONFERENCE REVIEW

Shelley Bowen gave a brief update on the agenda for the 2010 Conference. Discussion ensued regarding various aspects of the conference the coming week.

SMAB Meeting

The Scientific and Medical Advisory Board (SMAB) will meet on Saturday, July 31, 2010 to discuss insights gained from the 2010 Conference and strategies for future advances. Kate McCurdy recommended that there be a presence of BSF Board members at this meeting to participate in this discussion. Steve McCurdy, Steve Kugelmann, Shelley Bowen, Marc Sernel, and Sue Wilkins have agreed to join the SMAB meeting.

STRATEGIC PLANNING MEETING

A four-day strategic planning meeting has been scheduled for November 2010 to discuss strategic priorities and planning. Steve McCurdy reviewed the key question analysis that was drafted as a result of the Board's February 2010 meeting. Steve, Randy, Marc, and Kate will outline the priorities for the November 2010 strategic planning meeting.

ADJOURNMENT

The meeting was adjourned at 9:00 PM EST.

Respectfully submitted,

Marine E. Semel

Marcus E. Sernel Corporate Secretary