

**Minutes of the
BARTH SYNDROME FOUNDATION
BOARD OF DIRECTORS**
January 21, 2010

The Board of Directors of The Barth Syndrome Foundation, Inc. (BSF) met on January 21, 2010, via teleconference.

Members in Attendance

Stephen B. McCurdy	Board Member, Chairman
Valerie Bowen (Shelley)	Board Member, President
Randy Buddemeyer	Board Member, Treasurer
Michaela Damin	Board Member
Stephen Kugelmann	Board Member
Katherine R. McCurdy (Kate)	Board Member
Susan S. Osnos	Board Member
Marcus E. Sernel	Board Member, Corporate Secretary
Susan V. Wilkins	Board Member
Linda Stundis, Executive Director	Board Member, <i>ex-officio</i>

Additional Attendee

Lynda Sedefian, Executive Assistant

Agenda Items:

1. 12-Month Financial Report
2. 2009 Audit Update
3. National Health Council
4. Nominating and Board Development Committee
5. Fundraising Report
6. BRR
7. NIH ORDR
8. SMAB Meeting

The meeting was called to order by the Chairman at 8:30 PM EST.

1. 12-Month Financial Report

Ellen Bruno, BSF bookkeeper (who joined this portion of the meeting via teleconference), provided an overview of the 12-month preliminary financial statements, which reflected the following:

Total Current Assets	\$ 2,298,113
Total Current Liabilities	\$ 111,744
Total Fund Balance	\$ 2,186,369
Total Liabilities & Fund Balance	\$ 2,298,113

Statement of Revenue and Expenditures All Funds – Year-End 12/31/2009

Total Revenues of \$732,825; including unrestricted donations of \$332,857.

Total Expenses of \$753,085; for a net Deficit of \$20,260.

2. **2009 Audit Update**

Linda reported that BSF's 2009 audit is underway. Linda and Ellen have been working with Gray, Gray & Gray, LLP and have provided all requested documentation.

3. **National Health Council**

Linda reported that BSF's three-year membership is up for renewal, and as a requirement BSF is required to adopt the policies listed below.

Corporate Relations Policy/Guidelines

Linda distributed a revised Corporate Relations Policy for Board approval.

Following a discussion, and upon Motion duly made and Seconded, it was

VOTED: The Corporate Relations Guidelines were approved, as amended on January 21, 2010.

BSF-NHC Animal Research Policy

Linda distributed a proposed Animal Research Policy for Board approval. After a discussion, the Board agreed that the content of this policy be taken from the wording that currently exists in BSF's Research Grant Guidelines.

Following a discussion, it was agreed that Linda will rewrite this policy to incorporate the wording that currently exists in BSF's Research Grant Guidelines and will distribute to the Board for approval via e-mail.

Employment Policies

Linda distributed proposed Employment Policies to the Board for approval.

Following a discussion, and upon Motion duly made and Seconded, it was

VOTED: The Employment Policies were approved, as submitted on January 21, 2010.

Linda will contact NHC for their approval of the above-mentioned policies.

4. **Nominating and Board Development Committee**

Steve M. reported that this committee has not met since the last Board meeting. He has committed to having this committee meet prior to the Board's next meeting.

5. **Fundraising Report**

A successful end-of-year fundraising push resulted in BSF exceeding its fundraising goal for 2009, raising over \$700,000 in a difficult economic year. The Board expressed appreciation to all who engaged in fundraising efforts over the past year, but agreed that these efforts will need to be increased in the coming years to meet our budgetary needs for the worthy projects BSF would like to fund.

Linda reported that she is working with a Boston-based foundation which has shown an interest in funding a portion of the BRR. She anticipates cultivating another larger foundation for additional funding of the BRR.

6. **Barth Syndrome Medical Database & BioRepository (BRR) Update**

Linda reported that the BRR contract has been signed.

7. **NIH Office of Rare Diseases Research (ORDR)**

Kate reported that she attended the Uniting Rare Disease Research: The Intersection of Patient Registries, Biospecimen Repositories, and Clinical Data Workshop held by the NIH ORDR on January 11-12, 2010. The workshop objective was to discuss the development of an infrastructure for an internet-based platform with common data elements utilizing a federated rare disease registry able to incorporate existing rare disease registries; patient organizations with no registry looking to establish one; and patients with no affiliation with a support group looking to belong to a registry.

8. **SMAB+ Meeting Update**

Linda reported that the SMAB meeting was held on December 10, 2009. Agenda items included presentations of the 2008 clinical data as well as information gained from the Clinical Data Meeting that was held in September 2009 in Boston, MA. These meetings have stimulated very positive results which will have a positive impact on BSF's 2010 Conference.

10. **Other**

Strategic Planning Meeting

Steve M. proposed that a face-to-face Board meeting be scheduled for February 20-21, 2010 to discuss strategic planning and prioritization of programs. After a discussion, it was agreed that the Board will meet on these dates at a location to be determined.

Barth Syndrome Trusts Receives NHS Funding

The Board would like to join in celebration with Michaela and the Barth Syndrome Trust who has received NHS funding in support of the Bristol Clinic. This funding will provide long term sustainability and growth of the clinic.


Confirmed Meetings

<u>Board of Directors</u>	<u>Executive Committee</u>
January 21, 2010	March 25, 2010
February 20-21, 2010 (Face-to-Face)	June 17, 2010
?April/May - TBD	September 30, 2010
July 25, 2010	
November 18, 2010	

Adjournment

The meeting was adjourned at 11:15 PM EST.

Respectfully submitted,



Marcus E. Sernel
Corporate Secretary