

**Minutes of the
BARTH SYNDROME FOUNDATION
BOARD OF DIRECTORS**
February 20-21, 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
Randy Buddemeyer	Board Member, Treasurer
Michaela Damin	Board Member
Stephen Kugelmann	Board Member
Katherine R. McCurdy	Board Member
Marcus E. Sernel	Board Member, Corporate Secretary

Members Not in Attendance

Valerie Bowen	Board Member, President
Susan S. Osnos	Board Member

Attendees via Teleconference

Linda Stundis, Executive Director	Board Member, <i>ex-officio</i>
Susan V. Wilkins	Board Member
Lynda Sedefian, Executive Assistant	

Agenda Items:

1. Ratification of Minutes
2. Board Policies – NHC Update
3. 2009 Preliminary Financial Statement
4. 2010 Budget
5. Science Update
6. BRR Update
7. Barth Syndrome Trust Clinic Update
8. 2010 Conference Update
9. 2010 Fundraising
10. 2009 Grant Cycle

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

1. Ratification of Minutes

The Board approved the November 14, 2009 and January 21, 2010 Board minutes, as submitted.

2. BSF Policies - National Health Council Update

Linda Stundis reported that NHC has accepted the following required policies and guidelines:

- Corporate Relations Guidelines
- BSF-NHC Animal Research Policy
- Employment Policies

3. Financial Update

*Steve asked Ellen to produce the following reports: 1) ALL 2009 donors; 2) total donations by event; 3) total donations by solicitor.

Items placed on agenda for Board of Directors' May 15, 2010 meeting.

Ellen Bruno, BSF bookkeeper (who joined this portion of the meeting via teleconference), provided an overview of the 2009 year-end and January 2010 preliminary financial statements, which reflected the following:

Preliminary 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 \$20,259.

Total Current Assets	\$ 2,298,113
Total Current Liabilities	\$ 111,744
Total Fund Balance	\$ 2,188,369
Total Liabilities & Fund Balance	\$ 2,298,113

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

Total Revenues of \$52,878; including unrestricted donations of \$36,511.

Total Expenses of \$33,478; for a Net Excess of Revenue over Expenses of \$19,400.

Total Current Assets	\$ 2,279,533.95
Total Current Liabilities	\$ 79,837.29
Total Fund Balance	\$ 2,199,696.66
Total Liabilities & Fund Balance	\$ 2,279,533.95

4. Update on 2010 Conference Planning

Linda Stundis reported that the Conference Management Committee/Subcommittees have been meeting and invitations to the clinic providers/family track presenters are underway as well as sponsorship documents.

She also reported that the Management Committee had considered two options for the 10th anniversary T-shirt discussion: a photo mosaic and a statement of accomplishment design. It was the consensus of the Board that the statement of accomplishment design be used. She reported that the theme will be a New Year Eve/Decade Party for the Friday social event.

Sue Wilkins reported that the clinic subcommittee has begun meeting and has the basic framework of the clinic plan based upon what was successful in 2008 and the results of a recent survey. Kate reported that there is a lot of interest in quality of life data and suggested collecting such data during the conference.

Linda also reported that Amy Roberts will have a BRR booth at the clinic and she and Carolyn will be presenting during the Family Sessions.

Matt Toth presented a list of speakers who will present during the Science/Medicine Session, and noted that he has asked the invited speakers to extend invitations to their colleagues and other researchers who are involved in research related to BTHS. There was a consensus that BSF would be willing to cover costs for a couple of non-BSF researchers to attend the conference. He also reported that planning for the poster session was underway.

A discussion regarding a fundraising presentation during the conference then ensued, and there was a consensus to have a panel discussion at the conference relating to fundraising efforts.

Following a brief discuss of whether to support WebEx access for the upcoming conference, it was decided that Michaela Damin would seek input from the UK/European families and then a decision would be made.

5. **Science Update**

Matt reported that there are currently four laboratories studying the tafazzin knockdown mice, as well as interest from a researcher in Germany. He also reported that purified rabbit antibodies were being used to visualize the human tafazzin protein from BTHS lymphoblasts, representing a way to visualize the human protein directly in unmodified human cells.

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

Linda provided an update on the BRR, including the hiring of an additional data entry person (\$15,000) at no further expense to BSF, and the recruitment of multi-specialty physicians/researchers. She also noted that the BRR Advisory Board membership needs to be addressed, and a proposed Advisory Board will be submitted to the BSF Board. A discussion then ensued regarding the information families need to submit prior to or at the conference and the need for a substantive presentation on specific deliverables.

7. **Barth Syndrome Trust Clinic Update**

Michaela Damin reported that the UK Barth Clinic has received NHS funding for a Barth syndrome service to include such diverse input as social work, psychology, physio, OT, genetic counselling, CPR training, education, cardiology, hematology, neurology, metabolics, endocrinology, nutrition, gastroenterology, cardioplipin testing, genetic testing, phlebotomy, play therapy and overnight accommodation for UK families. She also reported that an ICD-11 meeting had been held in Geneva and that final drafts are expected in 2014.

2010 Budget

Linda Stundis distributed a working draft 2010 budget for review. A discussion ensued regarding the level of deficit that could be budgeted as well as Board fundraising commitments as follows. Linda then reported that foundation funding and conference sponsorship had been budgeted at \$85,000 and that the R13 grant application was still pending.

8. **2009 Grant Cycle**

BSF international affiliate board members were invited to participate in this portion of the call. Matt Toth presented an overview of the fourteen grant applications submitted for BSF's 2009 Research Grant Program as well as the Scientific and Medical Advisory Board's recommendations for funding.

Following the presentation, and upon careful review of each proposal, the BSF Board of Directors, upon Motion duly made and Seconded,

VOTED: To fund the following seven grant applications totaling \$280,000:

Zaza Khuchua, PhD, Research Associate Professor, Children's Hospital Medical Center, Cincinnati, OH
"The shRNA-mediated tafazzin knockdown mouse model for Barth syndrome"
Award—US \$39,998 for 2 years

Michael A. Kiebish, PhD, Postdoctoral Research Associate, Washington University School of Medicine, St. Louis, MO
"Does cardioplipin synthase upregulation alleviate cardioplipin abnormalities and bioenergetic dysfunction in Barth syndrome?"
Award—US \$40,000 for 2 years

Miriam Greenberg, PhD, Professor and Associate Dean, Wayne State University, Detroit, MI
"Perturbation of the osmotic stress response in cardioplipin deficient mutants"
Award — US \$40,000 over 1-year period
*Funding for this award was provided by the Barth Syndrome Trust (UK & Europe)

Yang Xu, PhD, MD, Instructor, New York University School of Medicine, New York, NY
“Expression levels, localization, and function of tafazzin isoforms”
Award—US \$38,370 for 1 year

W. Todd Cade, PT, PhD, Assistant Professor, Washington University School of Medicine, St. Louis, MO
“Safety and efficacy of aerobic exercise training in Barth syndrome: a pilot study”
Award—US \$40,000 for 1 year (including 5-6 BTHS boys as opposed to 3 BTHS/3 controls)

Grant Hatch, PhD, Professor, University of Manitoba, Winnipeg, Manitoba, Canada
“Role of human monolysocardiolipin acyltransferase in Barth syndrome”
Award—US \$40,000 over 1-year period
*Funding for this award was provided by the Barth Syndrome Foundation of Canada

William Pu, MD, Associate Professor, Children’s Hospital of Boston, Boston, MA
“Analysis of metabolic abnormalities in TAZ-deficient cardiomyocytes”
Award—US \$40,000 for 1 year

The BSF Board expressed their appreciation to Dr. Richard Kelley, Chairman of the BSF Scientific and Medical Advisory Board (SMAB), the members of the SMAB who served as grant reviewers, the outside reviewers for their added expertise, and Matt for his coordination of the grant program.

Adjournment

This portion of the Board’s meeting was adjourned at 6:00 PM EST and scheduled to resume at 8:30 AM EST on Sunday, January 21, 2010.

Sunday, January 21, 2010

1. Deficit closing 2010 fundraising plan

A lengthy discussion was held focusing on an additional fundraising goal of \$200,000 to help address the budgeted deficit, and ways in which to attract additional funding for BSF programs (Family Services & Education, the Research Grant program, Physician Awareness, and the International Conference) by further delineating the goals and objectives, criteria, measures of success, and expected outcomes.

The discussion concluded with the need for the conference sponsorship documents, expanded program descriptions, a list of prospective foundations for Q4 2009, as well as an overall fundraising plan to address the short-term deficit and long-term objectives.

2. Board Nominating and Development Committee Report

Steve Kugelmann reported that the committee met on February 14, 2010. Following the presentation and discussion, and upon Motion duly made and Seconded, it was

VOTED: To change the name of the Board Development Committee to Organizational Development Committee and to expand the responsibilities to the following: (1) ensure the full introduction and orientation of new Board members; (2) lead the search as needed for open ED and President positions; and (3) oversee the annual evaluation and compensation process for the Executive Director and President.

A discussion then ensued regarding Board succession planning, term limits, and filling key board roles as needed. In this regard, current board assets and limitations were briefly discussed and the Committee was asked to develop a plan to address the following:

- Develop a description of the BSF community and Board cultures

- Establish goals to recruit board members totaling 15-16, including two external Board members in 2010-2011, three in 2013 and four in 2014
- Develop a plan for the recruitment and introduction of external members
- Develop a plan to identify and cultivate prospective family board members

Steve McCurdy then reported that Board members will be asked to complete a board self-assessment survey on Zoomerang. The results will be reported at the May board meeting.*

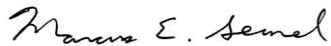
3. 2010-2013 Strategic Priorities & Planning

Steve McCurdy led a discussion of strategic priorities and planning in preparation for a meeting in October/November 2009. There was a brief discussion about reporting on the planning goals at the Conference in July. The discussion concluded with assignments for Board members and staff to develop brief reports for the May Board meeting. Steve, Randy, Marc, Kate, and Linda will then outline the priorities for the Fall meeting.

Adjournment

The meeting was adjourned at 4:00 PM EST.

Respectfully submitted,



Marcus E. Sernel
Corporate Secretary

*Items placed on agenda for Board of Directors' May 15, 2010 meeting.