Members in Attendance:
Stephen B. McCurdy                               Chairman
Lindsay Groff, Executive Director                Board Member, ex-officio
David Axelrod, MD                               Board Member
Randy Buddemeyer                                 Treasurer, Board Member
Michaela Damin                                   Board Member
Stephen Kugelmann                                Board Member
Susan A. McCormack                               Secretary, Board Member
Katherine R. McCurdy                             Board Member
Susan Osnos                                      Board Member
Marcus E. Sernel                                 Vice-Chairman
John Wilkins                                     Board Member
Susan V. Wilkins                                 Board Member

Additional Invitees
Lynn Elwood, President, BSF of Canada
Susan Hone, Board Member, BSF of Canada
Chris Hope, Board Member, BSF of Canada
Florence Mannes, President, Association Barth France
Nigel Moore, Trustee, Barth Syndrome Trust (UK & Europe)
Lynda Sedefian, BSF Executive Assistant
Matthew J. Toth, PhD, BSF Science Director

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

Agenda Items:
1. 2012 Research Grant Program
2. 2013 Preliminary Consolidated Budget

The meeting was called to order by the Chairman on Saturday, February 9, 2013 at 12:00 PM ET.

1. 2012 Research Grant Program

Dr. Matthew Toth, BSF Science Director, presented an overview of the 17 grant applications submitted for BSF’s 2012 Research Grant Program. He informed the board of the Scientific and Medical Advisory Board’s (SMAB) recommendations for funding based upon: (a) importance and impact (the extent to which the research outlined could make a significant contribution to the understanding of Barth syndrome or the treatment of the disorder); (b) feasibility (qualifications of the investigator(s) to carry out the proposed work; expertise, experience, and commitment; availability of all the elements required for the project, such as technology, reagents, and human subjects); and (c) prospect of long-term funding (the likelihood of subsequent NIH or other major funding for any potential follow-on work, if appropriate).

After Matt’s presentation, with careful review and discussion of each proposal by the members of the BSF Board of Directors and other key stakeholders, it was:

*Items placed on next Board of Directors meeting*
VOTED: To fund the following eight highly qualified grant applications totaling US $354,250 from the 2012 grant application submissions. Michaela Damin, Chair, Barth Syndrome Trust (UK & Europe), indicated that they intend to fund one of these grants. Florence Mannes, Chair, Association Barth France, also indicated that they intend to fund one of these grants. Lynn Elwood, President, BSF of Canada, indicated that they intend to fund a portion of a grant.

**William T. Pu, MD, PhD**, Associate Professor  
Boston Children’s Hospital, Boston, MA  
“Maturation of Barth syndrome models for clinical translation”  
Award—US $40,000 for 1 year

**Colin Phoon, MD, MPhil**, Associate Professor  
New York University Medical Center, New York, NY  
“Role of mitochondria during myocardial morphogenesis in Barth syndrome”  
Award—US $40,000 for 1 year

**Yuguang (Roger) Shi, PhD**, Professor  
Pennsylvania State University School of Medicine, Hershey, PA  
“Regulation of cardiomyopathy by ALCAT1 in Barth syndrome”  
Award—US $40,000 for 1 year

**Adam Chicco, PhD**, Assistant Professor  
Colorado State University, Fort Collins, CO  
“Mechanisms of substrate-specific impairment of oxidative phosphorylation in taz-deficient cardiac mitochondria”  
Award—US $40,000 for 1 year

**Angela Corcelli, PhD**, Associate Professor  
University of Bari, Aldo Moro, Bari, Italy  
“Determination of the monolysocardiolipin/cardiolipin (MLCL/CL) ratio in intact nucleated cells: A new tool for the screening of Barth syndrome”  
Award—US $36,300 for 1 year

**Richard Epand, PhD**, Professor  
McMaster University, Hamilton, Ontario, Canada  
“Relationship between membrane physical properties and the action of tafazzin”  
Award—US $37,950 for 2 years

**Matthew P. Gillum, PhD**, Research Assistant Professor  
University of Iowa, Iowa City, IA  
“Implications of phosphatidylserine deficiency in skeletal muscle and heart of ROSA26-taz shRNA Tet-on mouse model of Barth syndrome”  
Award—US $40,000 for 1 year

**Robert Ryan, PhD**, Senior Scientist  
Children’s Hospital and Research Center at Oakland, Oakland, CA  
“Cardiolipin replacement therapy for Barth syndrome”  
Award—US $40,000 for 1 year

The Board also voted to conditionally fund the following grant to the extent preliminary data could be generated to show the feasibility of the proposed work, as judged by Matt Toth and two members of the SMAB chosen by Matt. Matt will follow up with Dr. Chin to assess and report back to the Board as appropriate.

**Michael T. Chin, MD, PhD**, Associate Professor  
University of Washington, Seattle, WA  
“Tafazzin enzyme replacement therapy for heart muscle in Barth syndrome”  
Award—US $40,000 over 1-year period

*Items placed on next Board of Directors meeting*
The Board of Directors expressed their appreciation to Matt Toth for his coordination of the 2012 grant process on behalf of BSF. Additionally, the Board expressed appreciation to Dr. Michael Schlame and to all the members of the SMAB who served as grant reviewers, as well as the additional experts who served as outside reviewers.

At this time Matt Toth and the affiliate leads left the meeting. The BSF Board of Directors thanked them for their involvement in and support of BSF’s 2012 Research Grant Program.

2. **2013 Preliminary Basic Operating Budget**

The Board of Directors reviewed the preliminary 2013 basic operating budget which was revised to reflect the approved expenses of the 2012 Research Grant Program. The budget shows a modest net surplus. It was agreed that this budget is subject to revisions based on further information from recent strategic planning.

**VOTED:** 2013 Budget was approved pending revision based on modifications resulting from new strategic plan.

**ADJOURNMENT**

The meeting was adjourned at 3:30 PM ET. The next Board meeting is scheduled for Tuesday, April 23, 2013. The next Executive Committee Meeting is scheduled for Tuesday, March 19, 2013.

Respectfully submitted,

[Signature]

Susan A. McCormack
Secretary

*Items placed on next Board of Directors meeting*