MINUTES
Barth Syndrome Foundation, Inc.
Board of Directors Meeting
February 4, 2012

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

Board Members Not in Attendance
David Axelrod, MD             Board Member

Additional Invitees
Lynda Sedefian, Executive Assistant
Matthew J. Toth, PhD, BSF Science Director
Lynn Elwood, President, BSF of Canada
Chris Hope, Treasurer, BSF of Canada
Cathy Ritter, Vice President, BSF of Canada
Florence Mannes, Chair, Association Barth France

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

Agenda Items
1. 2011 Research Grant Cycle
2. Other

The meeting was called to order by the Chairman on Tuesday, February 4, 2012 at 12:00 PM EST.

1. 2011 Research Grant Cycle

Dr. Matthew Toth, BSF Science Director presented an overview of the 16 grant applications submitted for BSF's 2011 Research Grant Program, and 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).

*Action item
After Matt’s presentation, and careful review and discussion of each proposal by the members of the Board, it was:

**VOTED:** To fund the following nine highly qualified grant applications totaling US $341,002 from the 2011 grant application submissions. The Board of BSF of Canada indicated that they intend to fund one of these grants. Florence Mannes, Chair, Barth France also indicated that they intend to fund one of these grants.

**Steven M. Claypool, PhD,** Assistant Professor  
The Johns Hopkins University, Baltimore, MD  
“Characterizing endogenous mammalian TAZ1”  
Award—US $40,000 over 1-year period

**William T. Pu, MD,** Associate Professor  
Children’s Hospital of Boston, Boston, MA  
“Using pluripotent stem cells and modified RNAs to model and correct Barth syndrome”  
Award—US $40,000 over 1-year period

**Mindong Ren, PhD,** Assistant Professor  
New York University School of Medicine, New York, NY  
“Drug repositioning for Barth syndrome”  
Award—US $40,000 over 1-year period

**Miriam Greenberg, PhD,** Professor and Associate Dean  
Wayne State University, Detroit, MI  
“Cardiolipin deficiency leads to defects in the TCA cycle”  
Award—US $40,000 over 1-year period

**W. Todd Cade, PT, PhD,** Assistant Professor  
Washington University School of Medicine, St. Louis, MO  
“Effects of resistance training on cardiac, metabolic, and muscle function and quality of life in Barth syndrome”  
Award—US $39,937 over 1-year period

**Grant Hatch, PhD,** Professor  
University of Manitoba, Winnipeg, Manitoba, Canada  
“MLCL AT-1 elevates cardiolipin and mitochondrial function in cardiac myocytes of taz knockdown mice”  
Award—US $40,000 over 1-year period

**Yana Sandlers, PhD,** Assistant Director of Biochemical Genetics  
Kennedy Krieger Institute, Baltimore, MD  
“Characterization of biochemical abnormalities in Barth syndrome patients and mouse model of BTHS”  
Award—US $21,065 over 1-year period

**Ji Zhang, PhD,** Assistant Project Scientist  
University of California at San Diego, San Diego, CA  
“Functional characterization of a mitochondrial lipid phosphatase that involves cardiolipin biosynthesis”  
Award—US $40,000 over 2-year period

**Junhwan Kim, PhD,** Research Associate  
Case Western Reserve University, Cleveland, OH  
“Causative and correlative role of cardiolipin on integrated mitochondrial function in Barth syndrome”  
Award—US $40,000 over 1-year period

*Action item*
The Board of Directors expressed their 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. Additionally, the Board expressed its appreciation to Matt Toth for his coordination of the 2011 grant process on behalf of BSF.

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 2011 research grant program.

2. **Other Items**

   **2012 Consolidated Budget**
   The Board of Directors reviewed the preliminary 2012 consolidated budget. Following this discussion it was recommended that the budget be revised to reflect affiliate funding support toward the 2011 research grant cycle. It was agreed that once BSF receives confirmation from the affiliates of the grants they intend to fund the budget will be revised and sent to the BSF Board via e-mail for approval within the next two weeks.*

   **FundEZ**
   Lindsay reported that we have received a complimentary upgrade of FundEZ which includes new features enhancing donation/database tracking along with the ability to create and track acknowledgement letters within each donor’s file.

   **Varner Award for Pioneers in Science & Medicine**
   Sue and John Wilkins reported that, after consideration of several candidates, it was their recommendation that the 2012 Varner Award be awarded to Dr. Colin Steward, FRCP, FRCPCH, PhD, Consultant in Bone Marrow Transplantation, Royal Hospital for Children, Bristol, England, for his commitment and dedication to BSF and the Barth Syndrome Trust. After discussion by the Board, it was:

   **VOTED:** To award the 2012 Varner Award to Dr. Colin Steward.

   Sue Wilkins will notify Dr. Steward of this award prior to the Conference.

   **ADJOURNMENT**
   The meeting was adjourned at 3:20 PM EST. The next Board meeting is scheduled for Sunday, April 29, 2012 @ 3:00 PM EST via teleconference.

   Respectfully submitted,

   [Signature]

   Marcus E. Sernel
   Corporate Secretary

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*Action item*
### 2012 Meeting Dates:

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<th>Board of Directors</th>
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<tr>
<td>Tuesday, January 24, 2012</td>
<td>Teleconference @ 8:00 PM EST</td>
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<tr>
<td>Saturday, February 4, 2012</td>
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<tr>
<td>Sunday, April 29, 2012</td>
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<td>Face-to-Face (Conference)</td>
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<td>Tuesday, March 13, 2012</td>
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*Action item*