



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

Members in Attendance:

Stephen B. McCurdy	Chairman
Lindsay Groff, Executive Director	Board Member, <i>ex-officio</i>
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
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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 Sandler, 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 Research University, Cleveland, OH
“Causative and correlative role of cardiolipin on integrated mitochondrial function in Barth syndrome”
Award—US \$40,000 over 1-year period

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, FRCPC, 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,



Marcus E. Sernel
Corporate Secretary

*Action item

2012 Meeting Dates:

Board of Directors

Tuesday, January 24, 2012

Teleconference @ 8:00 PM EST

Saturday, February 4, 2012

Teleconference @ 12:00 PM EST

Sunday, April 29, 2012

Teleconference @ 3:00 PM EST

Sunday, June 24, 2012

Face-to-Face (Conference)

September, 2012

Teleconference (TBD)

November, 2012

Face-to-Face (TBD)

Executive Committee

Tuesday, March 13, 2012

Teleconference @ 8:30 PM EST

Tuesday, May 15, 2012

Teleconference @ 8:30 PM EST

Tuesday, July 17, 2012

Teleconference @ 8:30 PM EST

Tuesday, October 16, 2012

Teleconference @ 8:30 PM EST