



MINUTES

**Barth Syndrome Foundation, Inc.
Board of Directors Meeting
February 9, 2013**

Members in Attendance:

Stephen B. McCurdy	Chairman
Lindsay Groff, Executive Director	Board Member, <i>ex-officio</i>
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/cardioliipin (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* shRNATet-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,



Susan A. McCormack
Secretary