



**Barth Syndrome Foundation, Inc.  
Board of Directors Meeting  
February 11, 2014**

---

**Members in Attendance:**

Marcus E. Sernel	Chairman
Lindsay Groff, Executive Director	Board Member, <i>ex-officio</i>
David Axelrod, MD	Board Member
Randy Buddemeyer	Treasurer, Board Member
Stephen Kugelmann	Board Member
Susan A. McCormack	Secretary, Board Member
Katherine R. McCurdy	Board Member
Susan Osnos	Board Member
Catharine Lynne Ritter	Board Member
John Wilkins	Board Member
Susan V. Wilkins	Board Member

**Members Not in Attendance:**

**Additional Invitees**

Stephen B. McCurdy	Chairman <i>Emeritus</i>
Matthew J. Toth, PhD, BSF Science Director	
Shelley Bowen, Director, Family Services/Awareness	
Lynda Sedefian, Executive Assistant	
Lynn Elwood, President, BSF of Canada	
Chris Hope, Treasurer, BSF of Canada	

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

**Agenda Items:**

1. Executive Session – Staff evaluations and vote on compensation (BSF Board members only)
2. 2013 Research Grant Program
3. Other

**1. Executive Session**

The meeting, held via teleconference, was called to order by the Chairman on Tuesday, February 11, 2014 at 7:00 pm ET, at which time the BSF Board of Directors met to discuss staff evaluations and vote on compensation. At 7:15 pm ET, Marc welcomed BSF staff and BSF of Canada affiliate leads, Lynn Elwood and Chris Hope to the meeting.

**2. 2013 Research Grant Program**

Dr. Matthew Toth, BSF Science Director, presented an overview of the 19 grant applications submitted for BSF's 2013 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).

The Board of Directors expressed their appreciation to Matt Toth for his coordination of the 2013 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.

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:

**VOTED:** To fund the following seven highly qualified grant applications totaling US \$368,564 from the 2013 grant application submissions. Cathy Ritter, Vice-President, BSF of Canada, indicated that they intend to fund a portion of a grant.

**William T. Pu, MD**, Associate Professor  
Boston Children's Hospital, Boston, MA  
"Reactive oxygen species and mitochondrial dynamics in the pathogenesis of Barth syndrome"  
Award—US \$100,000 over 2-year period

**Douglas Strathdee, PhD**, Head of Transgenic Technology  
Beatson Institute for Cancer Research, Glasgow, Scotland  
"Characterization of a conditional knockout of *tafazzin* in the mouse"  
Award—US \$49,837 over 2-year period

**Grant Hatch, PhD**, Professor  
University of Manitoba, Winnipeg, Manitoba, Canada  
"*Tafazzin* knockdown alters hepatic lipid metabolism"  
Award—US \$49,995 over 1-year period  
*\*A portion of this grant will be funded by BSF of Canada*

(The following grants will be conditionally funded, provided the researchers agree to conditions imposed by the Board, as recommended by the Scientific & Medical Advisory Board.

**Miriam Greenberg, PhD**, Professor and Associate Dean  
Wayne State University, Detroit, MI  
"Identification of human cardiolipin phospholipases that are deleterious to *tafazzin*-deficient cells"  
Award—US \$50,000 over 1 or 2-year period

**Stacey Reynolds, PhD, OTR/L**, Associate Professor  
Virginia Commonwealth University, Richmond, VI  
"A systematic investigation into sensory and motor based feeding issues in boys with Barth syndrome"  
Award—US \$18,732 over 1-year period

**Michael T. Chin, MD, PhD**, Associate Professor  
University of Washington, Seattle, WA  
“*Tafazzin* enzyme replacement therapy in a mouse model of Barth syndrome”  
Award—US \$50,000 over 1 or 2-year period

**Nathan N. Alder, PhD**, Assistant Professor  
University of Connecticut, Storrs, CT  
“Investigation of cardiolipin-dependent respiratory complex activity and development of small molecule lipid analogs”  
Award—US \$50,000 over 1 or 2-year period

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 2013 Research Grant Program.

3. **Other**

Update – Open “Development Support” Position

Marc reported that Lindsay Groff has identified, and is close to proposing, a potential candidate to fill the open development support position. Lindsay has arranged meetings with the candidate who has met with several past and present members of the Board. Marc stated that, within the next few weeks, he would call a special Board meeting to discuss this further.

**Adjournment**

The meeting was adjourned at 10:40 pm ET. The next Board meeting is scheduled for Thursday, April 10, 2014 at 8:00 pm ET. The next Executive Committee meeting is scheduled for Tuesday, March 11, 2014 at 8:00 pm ET.

Respectfully submitted,



Susan A. McCormack  
Secretary