

**Minutes of the  
BARTH SYNDROME FOUNDATION  
BOARD OF DIRECTORS**  
February 7, 2009

The Board of Directors of The Barth Syndrome Foundation, Inc. (BSF) met on Saturday, February 7, 2009, via teleconference.

Members in Attendance

Stephen B. McCurdy (Steve)	Board Member, Chairman
Valerie Bowen (Shelley)	Board Member, President
Randy Buddemeyer	Board Member, Treasurer
Michaela Damin	Board Member
Stephen Kugelmann	Board Member
Katherine R. McCurdy (Kate)	Board Member
Susan V. Wilkins (Sue)	Board Member
Linda Stundis, Executive Director	<i>ex officio</i>
Lynda Sedefian, Secretary to the Board	<i>ex officio</i>

Members Not in Attendance

Susan S. Osnos (Suze)	Board Member
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Invited Attendees:

Matthew J. Toth, PhD	Science Director
Lynn Elwood	President, BSF of Canada
Jeannette Thorpe	Chair, Barth Trust of South Africa

Additional participants:	Cathy Ritter and Chris Hope BSF CA board members
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The meeting was called to order by the Chairman at 9:00 AM EST.

<u>Agenda Items</u>
Summary of 2008 Grant Proposals
BSF Board 2008 Grant Funding Discussion
Other Issues

The Chairman, Steve McCurdy, reported that Susan Osnos was unable to attend the meeting but had expressed her support in advance to fund those grants that the SMAB recommended, and that she had sent in a proxy vote for the board recruitment agenda item.

Steve then welcomed Dr. Matthew Toth, BSF Science Director. Matt presented an overview of the grant applications submitted for BSF's 2008 Research Grant Program, and informed the Board of the Scientific and Medical Advisory Board's 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 (the qualifications of the investigator(s) to carry out the proposed work); (c) expertise, experience, and commitment; (d) availability of all the elements required for the project (such as technology, reagents, and human subjects); and (e) prospect of long-term funding (the likelihood of subsequent NIH or other major funding for any potential follow-on work (if appropriate)).

### **Research Grant Program - 2008 Grant Cycle**

Matt Toth reported that a total of nine grants were submitted, reflecting a wide range of research topics, and that BSF is now leveraging its exposure within the scientific and medical community via the SMAB's external grant review process.

After the presentation by Matt, and careful review and discussion of each proposal by the members of the Board, it was

**VOTED:** That the Barth Syndrome Foundation will fund the following four highly qualified grant applications totaling approximately US \$140,000 from the 2008 Research Grant Program submissions, The Board of BSF Canada indicated that they intend to help support one of these grants by partially funding it. They will meet soon to decide which grant they will partially fund and in what amount, and they have agreed to let the BSF Board and Dr. Toth know of their decision before February 20, 2009 when it is expected that the final grant award letters will be sent to the recipients.

#### **Miriam Greenberg, PhD**

Professor and Associate Dean

Wayne State University

Detroit, MI

***“The role of tafazzin in mitochondrial protein import—implications for Barth syndrome”***

Award: US \$40,000 for 1 year (this figure could be reduced if it is found that there is any overlap between this grant and the R21 award Dr. Greenberg recently received from the NIH; she is being asked to submit clarification regarding this subject)

#### **W. Todd Cade, PT, PhD**

Assistant Professor

Washington University School of Medicine

St. Louis, MO

***“Characterization of nutrient metabolism in Barth syndrome”***

Award: US \$39,996 for 1 year (after resubmission of a revised protocol more specifically tailored to BTHS individuals and approval of such by Dr. Richard Kelley)

**Genevieve Sparagna, PhD**

Faculty Research Associate  
University of Colorado at Boulder  
Boulder, CO

*“Fatty acid combinational therapy for Barth syndrome investigated using a rat model of heart failure”*

Award: US \$40,000 for 2 years

**Ashim Malhotra, PhD**

Postdoctoral Fellow, New York University School of Medicine  
New York, NY

*“The role of cardiolipin and phosphatidylethanolamine in the maintenance of mitochondrial membrane architecture”*

Award: Funding for 1 year “Aim 3 supercomplex assembly” (requires a resubmission and a reformulated budget which should be less than the originally submitted \$40,000 over 1 year; also required will be a statement from NYU that Dr. Malhotra will be employed there for the duration of the grant period).

The BSF Board of Directors expressed their appreciation to Dr. Richard Kelley, Chairman of the BSF Scientific and Medical Advisory Board (SMAB), and to all the members of the SMAB who served as grant reviewers, as well as the 19 additional experts who served as outside reviewers. Additionally, the Board expressed its appreciation to Matt Toth for his coordination of this 2008 grant process on behalf of BSF.

**OTHER ISSUES**

**Board of Directors Recruitment**

Following discussions among the Board during the January board meeting and individual meetings between Marc Sernel and four BSF Board members, Steve McCurdy formally nominated Marc Sernel as a BSF Board member.

Following a thorough discussion, and upon Motion duly made and Seconded, it was:

**VOTED: Unanimously** that the Board of Directors elect Marcus Sernel to serve as a BSF Board member for a term of three years, commencing immediately and ending at BSF's annual meeting in 2012.

Board members expressed their appreciation for Marc's willingness to devote his time and resources to BSF and look forward to welcoming him to the Board in person.

**Barth Syndrome Medical Database & BioRepository Update**

Linda Stundis reported that she had visited the University of Florida on January 26, 2009 to meet with Melissa Maisenbacher, Barry Byrne, MD, PhD (Co-Principal Investigator), and Matt Fletcher (Information Technology professional), to survey the facilities and view the newly designed web-based platform and redundant storage systems.

Linda also met with Dan Estrada (Contract Administrator) and successfully negotiated a settlement for Year 3 (\$48,450), as well as discussed expected budgets, objectives and deliverables for Year 4.

Linda also reported that during the month of February there would be a conference call with Carolyn Spencer, MD, Barry Byrne, MD, PhD, Melissa Maisenbacher, Dan Estrada, and herself to discuss Year 4 program budget and objectives.

Finally, Linda reported that the newly developed web-base platform of the database appears to be a securely authenticated, user-friendly platform for both data input and extraction.

### **National Exposure**

Steve McCurdy reported that the PARADE magazine article focusing on BSF and the McCurdy Family would appear in the on-line version of PARADE on Saturday, February 14, 2009, and that Kate and Steve McCurdy would be featured on NBC TV's TODAY show on Monday, February 16, 2009.

### **Adjournment**

The meeting was adjourned at 12:30 PM EST.

Respectfully submitted,



Lynda M. Sedefian  
Secretary to the Board