MINUTES

Barth Syndrome Foundation, Inc. Board of Directors Meeting February 19, 2011

The Board of Directors of the Barth Syndrome Foundation, Inc. (BSF) met on February 19, 2011, via teleconference.

Board Members in Attendance

Stephen B. McCurdy Valerie "Shelley" Bowen Randy Buddemeyer Stephen Kugelmann Susan A. McCormack Katherine R. McCurdy Susan S. Osnos Marcus E. Sernel John Wilkins Susan V. Wilkins

Chairman President, Board Member Treasurer, Board Member Board Member Board Member Board Member Corporate Secretary, Board Member Board Member Board Member Board Member

Board Members Not in Attendance

Michaela Damin

Additional Invitees

Matthew J. Toth, PhD, BSF Science Director Lynda Sedefian, Executive Assistant Lynn Elwood Chris Hope Susan Hone

President, BSF of Canada (BSFCa) Treasurer, BSFCa Board Member Secretary, BSFCa Board Member

The meeting was called to order by the Chairman at 9:00 AM EST.

Dr. Matthew Toth, BSF Science Director presented an overview of the 15 grant applications submitted for BSF's 2010 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).

Board Member

Research Grant Program - 2010 Grant Cycle

Matt Toth reported that a total of 15 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 as well as encouraging new young investigators.

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 seven highly qualified grant applications totaling US \$273,770 from the 2010 grant application submissions. The Board of BSF of Canada indicated that they intend to fund one of these grants.

Barry J. Byrne, MD, PhD, Associate Chair Pediatrics, Director Powell Gene Therapy Center, Professor of Cardiology, University of Florida, Gainesville, FL *"Gene therapy in mouse model of Barth syndrome"* Award—US \$39,820 over 1-year period

Colin K. Phoon, MPhil, MD, Associate Professor, New York University School of Medicine, New York, NY

"Cardiomyopathy in a mouse model of Barth syndrome" Award—US \$35,600 over 2-year period

Adam J. Chicco, PhD, Assistant Professor, Colorado State University, Overt Collins, CO *"Targeting cardiolipin deficiency in the taz shRNA mouse model of Barth syndrome"* Award—US \$40,000 over 2-year period

Anton I. De Kroon, PhD, Docent (Associate Professor), Utrecht University, Utrecht, The Netherlands "The preferred acyl chain donor of Taz1p in the acylation of monolysocardiolipin" Award—US \$40,000 over 2-year period

Bram Van Raam, PhD, Postdoctoral Associate, Sanoverd-Burnham Medical Research Institute La Jolla, CA

"Caspase-8 in control of mitochondrial metabolism" Award—US \$40,000 over 2-year period

Miriam Greenberg, PhD, Professor and Associate Dean, Wayne State University, Detroit, MI *"Loss of cardiolipin leads to defective mitochondrial iron/sulfur biosynthesis and iron homeostasis"* Award—US \$40,000 over 1-year period

Christopher McMaster, PhD, Professor, Dalhousie University, Halifax, Nova Scotia, Canada *"A screen over drug leads over the treatment of Barth syndrome"* Award—US \$38,350 over 1-year period *Funding for this award will be provided by the Barth Syndrome Foundation of Canada

The Board of Directors expressed their appreciation to Dr. Richard Kelley 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 2010 grant process on behalf of BSF.

ADJOURNMENT

The meeting was adjourned at 1:00 PM EST. The next Board meeting is scheduled for April 8-10, 2011.

Respectfully submitted,

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Marcus E. Sernel Corporate Secretary