

**Minutes of the
BARTH SYNDROME FOUNDATION
BOARD OF DIRECTORS**

February 16, 2008

The Board of Directors of The Barth Syndrome Foundation, Inc. (BSF) met on Saturday, February 16, 2008, via teleconference. All members of the Board of Directors were present, as follows:

Members in Attendance

Stephen B. McCurdy (Steve)	Chairman of the Board, Chief Financial Officer
Valerie “Shelley” Bowen	Board Member, President of BSF
Michaela Damin	Board Member
Stephen Kugelmann (Steve)	Board Member, Vice President, Awareness
Katherine R. McCurdy (Kate)	Board Member, Vice President, Science and Medicine
Susan S. Osnos (Suze)	Board Member
Susan V. Wilkins (Sue)	Board Member
Randy Buddemeyer	Board Member

Chairman Steve McCurdy welcomed Dr. Matthew J. Toth, BSF Science Director to the meeting who presented an overview of the grant applications submitted for BSF’s 2007 Research Grant Program. Dr. Toth also informed the Board of Directors of the Scientific and Medical Advisory Board’s recommendations for funding based on 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), feasibility (the qualifications of the investigator(s) to carry out the proposed work, based on expertise, experience, commitment; as well as the availability of all the elements required for the project (such as technology, reagents, and human subjects), and 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 also invited Lynn Elwood, President, Barth Syndrome Foundation of Canada, and members of her board (Cathy Ritter, Chris Hope, and Karen Gordon) to join this meeting, as our affiliates (Barth Syndrome Trust, Barth Syndrome Foundation of Canada and Barth Trust of South Africa) do participate in BSF’s Research Grant Program by funding grant applications that arise from their region, when appropriate.

Lynda Sedefian attended the meeting in the role of Secretary to the Board of Directors.

The Board expressed its appreciation to Randy Buddemeyer for his willingness to devote his time and resources to BSF and looks forward to welcoming him to the Board in person. Randy was elected to the Board of Directors on December 31, 2007, and will serve a three-year term, ending April 2011.

Policies and Procedures

The Board acknowledged the adoption of two new policies, effective December 31, 2007:

- Whistleblower Policy
- Documents Retention Policy

Confidentiality Acknowledgement / Conflict of Interest

Steve McCurdy requested all Board Members review BSF's 2008 Confidentiality Acknowledgement and Conflict of Interest Policy, and forward a signed copy to Lynda Sedefian to keep on file.

Goal: *To encourage, guide and fund additional research to improve diagnosis and treatment and ultimately to develop a cure for Barth syndrome.*

Research Grant Program - 2007 Grant Cycle

In summary, a total of fourteen grants were submitted. Of the fourteen grants submitted, nine were submitted by researchers new to BSF's grant program, which is a very important milestone. It is clear from the number of grants submitted and the wide range of research topics that we have definitely made progress in that we are now in a position to compare project versus project in a similar area. We are also leveraging exposure amongst the scientific and medical community via the SMAB's external grant review process.

After presentation by Dr Toth, and careful review and discussion of each proposal by the members of the Board of Directors, it was **PROPOSED** and unanimously **SECONDED** that the Barth Syndrome Foundation will fund the following nine highly qualified grant applications from the 2007 Research Grant Program totaling US \$333,454.

Miriam Greenberg, PhD

Professor and Associate Dean
Wayne State University
Detroit, MI

Perturbation of the osmotic stress response in cardiolipin deficient mutants

Award — US \$40,000 over 1-year period

Carol P. Moreno-Quinn, MD, PhD

Assistant Professor
Medical College of Wisconsin
Milwaukee, WI

Creation of a rat model of Barth syndrome

Award — US \$40,000 over 1-year period

Quan He, PhD

Research Scientist
Henry Ford Hospital
Detroit, MI

Are reactive oxygen species involved in the development of dilated cardiomyopathy in Barth syndrome?

Award — US \$39,996 over 2-year period

David Dale, MD

Professor of Medicine
University of Washington
Seattle, WA

Neutropenia in Barth syndrome

Award — US \$40,000 over 1-year period

Taco Kuijpers, MD, PhD

Professor
University of Amsterdam
Amsterdam, The Netherlands

Neutropenia in Barth syndrome: new in vitro models to study BTHS neutrophils

Award — US \$40,000 over 1-year period

Richard Epand, PhD

Professor
McMaster University
Hamilton, ON, Canada

Consequences of the alteration of cardiolipin structure on the properties of the mitochondrial membranes

Award — US \$38,900 over 1-year period

Susan Kirwin

Senior Research Associate, Assistant Director
Nemours Children's Clinic
Alfred I. duPont Hospital for Children
Wilmington, DE

Barth syndrome testing: Are we missing some patients?

Award — US \$24,145 over 1-year period

Matthew R. G. Taylor, MD, PhD

Associate Professor and Director of Adult Clinical Genetics
University of Colorado at Denver and Health Sciences Center
Aurora, CO

Prevalence of Barth syndrome in adult cardiomyopathies

Award — US \$33,701 over 1-year period

Christopher R. McMaster, PhD

Professor
Dalhousie University
Halifax, Nova Scotia
Canada

Synthetic genetics towards understanding Barth syndrome cell biology

Award — US \$36,712 over 1-year period

The BSF Board of Directors would like to express our sincere 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 to several additional experts who served as outside reviewers. We could not complete this process without the recommendations of these individuals as to the scientific merit of the applications. Additionally, we would like to especially thank Matthew J. Toth, PhD, Science Director and *ex officio* member of BSF SMAB for his coordination of this 2007 grant process on behalf of BSF.

The meeting was adjourned at 11:30 AM EST. The next scheduled Board meeting will be held in Greenwich, CT on March 28-31, 2008.

Respectfully submitted,

A handwritten signature in black ink that reads "Lynda M. Sedefian". The signature is written in a cursive, flowing style.

Lynda Sedefian
Secretary to the Board