

**Minutes of the
BARTH SYNDROME FOUNDATION
BOARD OF DIRECTORS
September 27, 2008**

The Board of Directors of The Barth Syndrome Foundation, Inc. (BSF) met on Saturday, September 27, 2008 at 9:00 AM EST via teleconference.

Members in Attendance

Stephen B. McCurdy (Steve)	Chairman of the Board
Valerie “Shelley” Bowen	Board Member, President of BSF
Randy Buddemeyer	Board Member
Katherine R. McCurdy (Kate)	Board Member
Susan S. Osnos (Suze)	Board Member
Susan V. Wilkins (Sue)	Board Member
Linda Stundis, Executive Director,	Board Member <i>ex-officio</i>
Lynda Sedefian, Secretary to the Board	<i>ex-officio</i>

Members Absent:

Michaela Damin	Board Member
Stephen Kugelmann	Board Member

Invited Attendees

Matthew J. Toth, PhD, BSF Science Director and Lynn Elwood, President, BSF of Canada joined this meeting to discuss the dates and venue of the 2010 Barth Syndrome International Scientific, Medical & Family Conference.

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

APPROVAL OF MINUTES

Following a brief discussion, it was suggested that the minutes be amended to delete personal information. The minutes will be re-submitted to the Board for e-mail approval.

Goal: To stimulate the development of successful treatments for Barth syndrome, a multi-system disorder, and enable their delivery.

2010 Barth Syndrome International Scientific, Medical & Family Conference

Shelley Bowen conducted a search for a venue location for the 2010 BSF International Conference. The search consisted of contacting sites across Florida. Shelley opened her presentation by reminding the members that they had previously voted to hold the 2010 Conference in Orlando, Florida, but as a result of feedback from the families, Shelley sought a new venue.

The presentation and discussion focused upon the Bay Point Marriott Resort & Spa. Panama City Beach, FL.

After a lengthy discussion including consideration of conference space, overall cost, recreational options, cost and accessibility for families, etc., there was a unanimous consensus that BSF's 2010 Conference will be held at the Marriott Bay Point Resort & Spa, Panama City Beach, FL on **Monday, July 26, 2010 thru Saturday, July 31, 2010**. (<http://www.marriottbaypoint.com>)

Upon Motion duly made and Seconded, it was:

VOTED: That the Board of Directors accept and ratify the Executive Committee's recommendation to ask Shelley Bowen and Linda Stundis to negotiate a final contract with the Marriott Bay Point Resort & Spa, Panama City Beach, FL.

The Board further decided that Linda Stundis, Shelley Bowen and Susan Osnos will oversee the communication plan which will be distributed to the families announcing the date and venue location, and that Linda Stundis, Kate McCurdy, and Matt Toth will prepare the message that will be distributed to the scientific and medical community.

Steve McCurdy then asked Randy Buddemeyer to take the lead in finding outside funding for those families who need financial assistance to be able to attend the Conference.

Shelley Bowen agreed to contact the local hospitals in the area of Panama City Beach, FL to inform them of this meeting and to familiarize them with Barth syndrome prior to this meeting taking place.

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

BARTH SYNDROME MEDICAL DATABASE AND BIOREPOSITORY

Shelley Bowen reported that there are questions regarding the inclusion of medical data/biological samples in the Barth Syndrome Medical Database and Biorepository based upon a clinical diagnosis alone or a clinical diagnosis combined with genetic testing results.

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

VOTED: That the Board of Directors accept and ratify the Executive Committee's recommendation to adopt a policy wherein, in order to assure a complete BRR database, BSF would be willing to provide funding for genetic testing for families who have submitted medical data/biological samples to the Barth Syndrome Medical Database and Biorepository as of September 27, 2008, but have not yet received a confirmed genetic diagnosis of Barth syndrome.

Linda Stundis agreed to speak with Dr. Carolyn Spencer, Co-Principal Investigator of the Barth Syndrome Medical Database and Biorepository regarding this proposal. Linda will report back to the Board at the November 2008 meeting.

Goal: *To build and sustain a broad base of committed contributors who will provide the funds we need to achieve our vision.*

MEMORIAL POLICY

At the request of several Barth families, the Board discussed the creation of a policy to provide an appropriate recognition/memorial for the family of any Barth syndrome child who passes away. Upon Motion duly made and Seconded, it was:

VOTED: To provide an appropriate recognition/memorial for the family of any Barth syndrome child who passes away, and that the BSF President and Executive Director may use their discretion in determining appropriate memorials.

RECOGNITION OF MEMORIAL/THANKSGIVING DONATIONS

At the request of Barth families, the Board discussed the appropriate recognition of Memorial/Thanksgiving donations made to BSF. Upon Motion duly made and Seconded, it was:

VOTED: That such donations would be accorded their own place in the Power of Kindness section of the semi-annual Barth Syndrome Journal.

ADJOURNMENT

The meeting was adjourned at 11:30 AM EST.

The next scheduled Board of Directors meeting will be held at an off-site location on Friday, November 14, 2008 thru Monday, November 17, 2008.

Respectfully submitted,



Lynda M. Sedefian
Secretary to the Board