

**Minutes of the
BARTH SYNDROME FOUNDATION
BOARD OF DIRECTORS
November 15-16, 2008**

The Board of Directors of The Barth Syndrome Foundation, Inc. (BSF) met on Saturday and Sunday, November 15-16, 2008 in Greenwich, CT.

Members in Attendance

Stephen B. McCurdy (Steve)	Chairman of the Board
Valerie Bowen (Shelley)	Board Member, President of BSF
Randy Buddemeyer	Board Member
Michaela Damin	Board Member
Stephen Kugelmann	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>

Invited Attendees

Matthew J. Toth, PhD, BSF Science Director joined this meeting on Sunday, November 16, 2008.

The meeting was called to order by the Chairman at 9:00 AM EST on Saturday, November 15, 2008.

Approval of Minutes

The minutes of September 27, 2008 were approved as amended.

Review of BSF Financial Results Year-to-Date

Year-to-Date (as of October, 2008) Total fund balance = \$2,105,801.84. Preliminary Statement of Revenues and Expenditures indicates a net deficiency of \$276, 483.17 through October. If contributions come in as planned, BSF is within reach of another year with a zero deficit. However, Steve McCurdy raised concern about the impact of the recession on fund raising late in the year and the possibility of a modest deficit by year end.

Ratification of President's Job Description

Following a brief discussion, the Board of Directors endorsed the job description created for the role of BSF President, Shelley Bowen, which provides a summary of duties and responsibilities focused on Family Services and Physician Awareness.

Ratification of Mission Statement

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

VOTED: That the Board of Directors accept and ratify the mission statement to read as follows: "Today, BTHS is a rarely understood, frequently fatal, genetic disorder primarily affecting males. The Barth Syndrome Foundation is an engaged, global community whose mission is...*"Saving lives through education, advances in treatment, and finding a cure for Barth syndrome."*

2010 Long-Range Conference Planning

NIH Grant Consideration

Following a discussion focusing on the need to seek funding to support BSF's scientific and medical conferences/meetings (biennial conferences, SMAB meetings, etc.), it was suggested that Linda Stundis develop new contacts within the NIH (NHLBI, NINDS, ORD, etc.) to research potential funding sources.

CME Credit Consideration

Following a discussion focusing on BSF's desire to support physician learning to benefit the quality of care in BTHS patients, Shelley Bowen will investigate the possibility of offering CME credits for practicing physicians and other healthcare professionals (doctors, nurses, physical/occupational therapists) who attend BSF's 2010 International Conference. It was agreed that Shelley will contact the University of Florida to determine BSF's eligibility and to determine whether or not providing CME credits would change the content or community of BSF's Conference.

IRB-Approved Clinic Consideration

Following a discussion focusing on BSF's desire to offer IRB-approved BTHS clinics at its 2010 International Conference, it was suggested that Linda Stundis, together with the BRR Advisory Board, revise clinical protocols for obtaining IRB-approved data to maintain reliability and validity of the Barth Syndrome Medical Database. Linda agreed to work together with Carolyn and the BRR Advisory Board to clarify and extend the following: (1) What data do we want to collect? (2) What is the aim of BTHS clinics? and (3) What do we expect the outcome of the clinics to be?

A discussion then ensued regarding the urgent need for treatment protocols. It was decided that Kate McCurdy would follow up with Drs. Tyler Reimschisel and Ariel Sherbany on the protocol for neurology and that the protocols previously done would be revisited (anesthesia, cardiomyopathy, hematology). Once Kate has contacted Drs. Reimschisel and Sherbany, Kate, Linda, and Shelley will review the old documents and meet to determine next steps.

Subsidized Travel for Families to attend the BS International Conference

Following a discussion regarding BSF's desire to have as many families attend its 2010 Conference, it was agreed that Randy Buddemeyer would begin the process of designing a sponsorship program which would allow BSF and/or third parties to subsidize families (affected child and one parent) in need of financial assistance, in an equitable, nondiscriminatory fashion.

Suggested Registration Donation (Physician/Scientist Family Members)

Following a discussion regarding the cost of BSF's 2008 Conference, it was decided that all attendees must register prior to the conference, including extended family members and family members of the scientific/medical community, and a suggested registration donation will be requested. It was also decided that BSF would pay for half the cost of meals for non-participating family members of the scientific/medical community.

Barth Syndrome Medical Database & Biorepository 2008 Update

Linda Stundis reported on an issue that was raised at the Board's September meeting regarding a subject in the database/registry who had been clinically but not genetically diagnosed with BTHS. That subject has now been genetically tested and is enrolled with all appropriate samples and documents.

Linda Stundis reported that the development of a web-based medical data extraction platform is underway and is scheduled to be completed by the end of November 2008. Following a discussion, the Board agreed that Stephen McCurdy and Linda Stundis will determine next steps. It was also agreed that Linda Stundis will visit BRR and meet with Melissa Maisenbacher and Barry Byrne, MD, PhD and view the web-based platform. Following the visit of BRR, a BRR advisory board meeting will be scheduled.

2008 Barth Syndrome International (BSI) Update

Linda Stundis presented a planning outline regarding the philosophy and guidelines of the BSI, as well as the organizational relationships between the Barth Syndrome Foundation, Barth Syndrome Trust (UK & Europe), Barth Syndrome Foundation of Canada, and the Barth Trust of South Africa. However, the first step will be to engage BSF of Canada's board regarding the unsigned licensing agreement.

The Board recommended that Linda Stundis speak with Lynn Elwood regarding the BSF of Ca website, which contains significant amounts of out-of-date information.

Accounting/Fundraising System

Linda Stundis conducted a search focusing on integrated fundraising and financial management solutions that would meet the needs of BSF. The presentation and discussion focused upon Blackbaud's Comprehensive Fundraising and Financial Management Solutions.

After a lengthy discussion including accessibility, overall cost, and comprehensive fundraising and financial management solutions, the Board asked Linda to extend the search comparing Blackbaud vs. Sage for both hosted and non-hosted solutions.

Board Recruitment

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

VOTED: To elect Randy Buddemeyer as BSF Treasurer.

The Board further discussed the ongoing need to recruit new board members, particularly legal counsel, those with fundraising expertise and contacts, and those with non-profit board experience.

2008 Grant Process Update

Matt Toth reported that the deadline for BSF's 2008 grant cycle was October 31, 2008. Ten applications were received. A teleconference has been scheduled for 12:00 PM EST on Wednesday, January 28, 2009 for the Grant Committee members to review the applications.

2008 Mouse Research Update

Matt Toth reported that in 2008 USD \$82,750 was committed to TaconicArtemis to produce a tafazzin knockdown mouse line. The funds for this knockdown mouse line were provided by BSF's Paula & Woody Varner Fund. Expenditures in 2008 to date are USD \$41,375 + an extra \$2,500 to grow ES cells. The remaining commitment to the TaconicArtemis contract is \$41,375 with regard to the tafazzin knockdown mouse line.

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

VOTED: That the Board of Directors accept and ratify the decision to notify TaconicArtemis to move forward with the creation of a tafazzin knockdown mouse line and provide the remaining funds needed to complete this research project.

2008 Antibodies Research Update

Matt Toth reported that on October 31, 2008 the NIH requested suggestions for protein targets to make monoclonal antibodies under the sponsorship of the Office of Rare Diseases and the NINDS. Currently there are no documented antibodies available that recognize human tafazzin, a fact that likely contributes to the absence of a mouse model of Barth syndrome. Three scientists involved with BSF submitted 'tafazzin' as a good target candidate and this request appeared to be quickly accepted. There is no cost for this to BSF. Matt Toth will keep the Board informed of the progress of this research project.

Other Research

Matt Toth reported that over the last three months he has been trying to obtain the antitermination compound from PTC therapeutics, PTC-124. The BSF has been added to a list of potential collaborators with PTC. There is no cost for this at this time. Matt Toth will keep the Board informed of the progress of this research.

2009 Programs, Goals & Budgets

Family Services

Shelley Bowen reported on her strategies on improving timely diagnosis and treatment of BTHS, including global harmonization of care, patient centered care and improved disease classification. In summary, the goal is to ensure that the work that BSF continues to serve our mission and remains relevant and valuable to our members and constituents.

Physician Awareness

Shelley Bowen reported on her strategies to enhance awareness of BTHS by expanding on how information is disseminated amongst physicians. The presentation focused on ways to leverage collaboration with professional organizations, government agencies and peer charities with like-minded interests. Several creative ideas were discussed (website vignettes from various subspecialties involved in the care of a BTHS patient; CME audio cassettes; educational materials created for each subspecialty; promoting speakers at large conferences; grand rounds; etc.).

SMAB Conference – July 2009

Matt Toth reported on the planning process to host BSF's 2009 Scientific and Medical Meeting in Amsterdam, The Netherlands. The intent of this meeting is to leverage collaboration internationally focusing on the pathophysiology of BTHS. The goal of this meeting is to gain specific guidance on where BSF should be advancing research.

Matt anticipates inviting eight US members of BSF's SMAB along with four European members, and submitted an estimated budget of \$27,600 (which may decrease depending on airfare). The Board suggested that Matt contact Dr. Ronald Wanders (Genetic Metabolic Diseases, AMC, Amsterdam, The Netherlands) to confirm the date, location, and logistics management of this meeting.

The Board has asked Michaela Damin to investigate possible UK funding to help offset expenses for the SMAB meeting and In addition, the Board asked Matt Toth to speak with Dr. Wanders about continental European funding to help offset conference expenses, and they asked Michaela Damin to investigate possible UK funding.

2009 Research Grant Process

Matt Toth reported that the deadline for BSF's 2009 grant cycle is October 31, 2009. Grants will be awarded early March 2010. After a brief discussion, the Board asked Matt Toth to provide quarterly reports on how the grants that have been awarded to date are advancing the knowledge of BTHS and what research opportunities are on our radar screen.

2009 Budget

After a lengthy discussion of BSF's 2009 operational programs, it was recommended, given the state of the economy, that Linda Stundis develop a 2009 budget with targeted revenue of \$900,000.00. The budget will be reviewed by the board for approval.

Ratification to Scientific and Medical Advisory Board Operating Guidelines

Revised Scientific and Medical Advisory Board Operating Guidelines were approved as amended.

2009 Calendar for BSF Board Meetings

Proposed dates for the 2009 calendar of meetings was distributed. The Board was asked to review their calendars and reply to Lynda Sedefian with available dates.

Adjournment

The meeting was adjourned on Sunday, November 16, 2008 at 3:00 PM EST.

Respectfully submitted,



Lynda M. Sedefian
Secretary to the Board