

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

January 24, 2008

The Board of Directors' of The Barth Syndrome Foundation, Inc. (BSF) met on Thursday, January 24, 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

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

The Board expressed its appreciation for Randy Buddemeyer's 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.

The Board acknowledged the adoption of the Whistleblower Policy and Documents Retention Policy, effective December 31, 2007.

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

DEVELOPMENT

Financials

Steve McCurdy submitted the Preliminary December 2007 Balance Sheet and Statement of Revenue and Expenditures All Funds, along with the 2007 Year-End Statement of Revenue and Expenditure All Funds for review.

Preliminary BSF Balance Sheet – All Funds – as of December 31, 2007

Total Liabilities and Fund Balance	\$2,609,309
Total Fund Balance	\$2,432,947

Preliminary Statement of Revenue and Expenditures All Funds -- (Time Period 12/01/07 – 12/31/07)

Total Revenues of \$269,927; including unrestricted donations of \$257,244
Total Expenses of \$29,164; for a net Surplus of \$238,488

Preliminary Statement of Revenue and Expenditures All Funds -- 2007 Year End

Total Revenues of \$790,912; including unrestricted donations of \$519,599
Total Expenses of \$687,119; for a net Surplus of \$103,792

Note: Schall & Ashenfarb are in the process of completing BSF's 2007 Audit and Form 990 to be filed with the IRS. Once filed, registration for all appropriate states where BSF is registered, including Delaware, will be completed as well. As is custom, BSF's 2007 Audited Financial Report and IRS Form 990 will be sent to BSF's major donors for their review. These documents will also be posted to BSF's website for open access.

ADMINISTRATION

2008 Meeting Calendar

The Board approved the 2008 meeting calendar for the Board of Directors (and Executive Committee), as follows:

Board of Directors

Thursday, January 24, 2008 @ 8:30 PM EST (Teleconference)
Saturday, February 16, 2008 @ 9:00 AM EST (Teleconference/2007 grant cycle)
Friday, March 28 - Monday, March 31, 2008 (Face-to-Face)
Tuesday, July 8, 2008 @ 8:30 PM EST (Teleconference)
Friday, November 14 – Monday, November 17, 2008 (Face-to-Face)

Executive Committee

Tuesday, February 12, 2008 @ 8:30 PM EST (Teleconference)
Tuesday, May 20, 2008 @ 8:30 PM EST (Teleconference)
Tuesday, September 16, 2008 @ 8:30 PM EST (Teleconference)

New York State Disability/Unemployment Insurance

BSF was unaware, at the time that Lynda Sedefian was hired as a full-time employee, that the State of New York requires an employer to purchase New York State Disability Insurance and Unemployment Insurance for New York State employees. It was brought to BSF's attention by the State of New York Insurance Fund that BSF was not in compliance with this requirement. Steve McCurdy has since followed up on this issue and has applied for and purchased Disability Insurance and Unemployment Insurance from the New York State Insurance Fund. The State of New York has waived all penalties for this oversight on BSF's behalf.

Update on Executive Director Search

Susan Osnos gave a summary of where BSF is in the search process for a new Executive Director. Steve McCurdy, Shelley Bowen and Susan Osnos (the Search Committee) have had

many conversations on how best to proceed with this search process in a timely and efficient way. It is BSF's desire to introduce this new addition to the Barth community at our July 2008 Conference.

Considering the timeframe given to complete this process, Susan, Steve and Shelley strongly believe that we should consider finding a search firm to assist us in this process. The Board has also asked of its members to seriously consider their own networks and to bring to the Board names of possible candidates or leads to possible candidates, for discussion.

Susan, Steve and Shelley have spoken to contacts at a few larger search firms to get an idea of the cost range for this type of search and to see whether there are other options that we might be able to pursue. As a result of these conversations, we now have leads on 4-5 qualified search firms and are determining the best firm to assist us in this search.

Based on information obtained from conversations that Susan, Steve and Shelley have had with contacts in the search field, the cost for this type of search varies considerably depending on the depth of the search and involvement of the search firm.

The Board has asked its Members to identify any qualified executive search firm with which any Member has experience and to provide a reference to the Search Committee. The Board has also asked its Members to take it upon themselves to circulate the job description where appropriate, once complete. The Search Committee will begin to define a job description for this position for the Board's review.

All were in agreement with the Search Committee's recommendation to move forward with the hiring of a search firm to help in this process. Randy Buddemeyer shared with the Board his past experience with search firms and, considering the timeframe allowed for this process, he recommended going with a firm where the fee is tied to the performance as opposed to an hourly fee. At this time, permission was requested of the Board of Directors to allow a budget of up to \$30,000 to move forward with the hiring of a search firm.

It was **PROPOSED** and **SECONDED** that the Board of Directors accept the recommendation to allow a budget of up to \$30,000 to hire a search firm to conduct the search for an Executive Director.

RESOLVED, that the Board of Directors accept the recommendation to allow a budget of up to \$30,000 to hire a search firm to conduct the search for an Executive Director.

OVERVIEW OF OPERATIONAL PROGRAMS

Science/Medicine:

2008 International Scientific, Medical and Family Conference (July 21-26, 2008)

Matt Toth, PhD, BSF Science Director gave an overview on the progress of coordinating the Scientific and Medical Sessions. Currently twenty-four scientists/physicians have been formally invited of which 20 have accepted this invitation. Matt anticipates having approximately 24 speakers (4 sessions / 6 speakers per session – 2 sessions per day). Matt will also be coordinating with Jan Kugelmann to work through the details of those speakers who will be presenting during both the Scientific and Medical Sessions and Family Sessions.

As is custom, BSF has agreed to incur the cost of coach travel and hotel accommodations for all SMAB members to attend this Conference.

Steve McCurdy has asked Dr. Matt Toth to distribute to the Board of Directors and BSF's Affiliate Leads a list of those scientists/physicians who have accepted the invitation to give a presentation on BTHS at BSF's 2008 Conference for the purpose of dividing funding costs on a regional basis.

Shelley Bowen is coordinating audio/visual arrangements. Jan Kugelmann is coordinating child care arrangements. Leslie Buddemeyer is coordinating ground transport arrangements. Shelley Bowen and Dr. Carolyn Spencer are coordinating the cardiac clinic. Eileen Juico is coordinating the Youth Sessions.

Barth Registry at the University of Florida (BRR)

Dr. Matt Toth reported on several changes to the leadership of the BRR with which the Board concurred. Dr. Carolyn Spencer, the BRR's Principal Investigator at the University of Florida has recently accepted a position at Boston Children's Hospital and relocated to Boston, but wishes to remain as a co-PI on the BRR. Dr. Barry Byrne has agreed to become a Co-Principal Investigator of the BRR with Dr. Carolyn Spencer. Dr. Byrne has agreed to serve without compensation. The University of Florida has agreed to make its own arrangements with Boston Children's Hospital to transfer Dr. Spencer's allotted compensation as co-PI of the BRR.

Dr. Matt Toth advised the Board of Directors of the upcoming BRR Advisory Board meeting scheduled for Thursday, February 28, 2008. The Board of Directors has asked that Matt approach the subject of the need to define a clearer set of long term and annual objectives, as well as measures of progress and success toward a specific vision with the desire to grow this medical database and Biobank into a more clearly successful resource.

Research Grant Program - 2007 Grant Cycle

Dr. Matt Toth presented an overview of BSF's SMAB meeting which was recently held to discuss the advisory board's recommendations for funding BSF's 2007 grant cycle. In attendance were Drs. Richard Kelley, Barry Byrne, Gerry Cox, Iris Gonzalez, Grant Hatch, Michael Schlame, Colin Steward, Ronald Wanders, and Matt Toth and Kate McCurdy, both *ex officio*.

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 wonderful. 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 able to compare multiple projects that have been submitted in some areas of research. We are also leveraging exposure amongst the scientific and medical community via the SMAB's external grant review process.

BSF's Board of Directors has invited Dr. Matt Toth and our Affiliate Leads to meet on Saturday, February 16, 2008 to participate in an in-depth conversation regarding the awarding of grants for our 2007 grant cycle.

Family Services

Census of individuals known by BSF to be affected by Barth syndrome

	<u>Diagnosed</u>	<u>Deceased</u>	<u>Confirmation Pending</u>
Asia	4	1	0
Canada	8	8	1
Europe	15	28	2
Mexico	0	0	1
Oceania	8	8	0
South Africa	2	1	0
United Kingdom	16	7	0
United States	61	39	3
TOTAL	114	92	7

Physician Awareness

BSF is registered to exhibit at the following professional scientific and medical conferences in 2008:

11th Annual Update on Pediatric Cardiovascular Disease
New and Evolving Practices
February 6-10, 2008 (Scottsdale, AZ)

American College of Medical Genetics
15th Annual Clinical Genetics Meeting
March 12-16, 2008 (Phoenix, Arizona)

Listed below are scientific/medical meetings that Steve Kugelmann feels would be beneficial to attend to promote physician awareness of Barth syndrome.

Society for Inherited Metabolic Disorders 2008 Annual Meeting
March 2-5, 2008 (Pacific Grove, California)

Pediatric Academic Societies & Asian Society for Pediatric Research Joint Meeting
May 2-6, 2008 (Honolulu, Hawaii)

American Society of Pediatric Hematology/Oncology 21st Annual Meeting
Duke Energy Center & Hyatt Regency
May 14-17, 2008 (Cincinnati, OH)

American Society of Human Genetics
November 11-15, 2008 (Philadelphia, PA)

Pediatric Cardiac Intensive Care Society / Annual Symposium 2008
Dec. 2-7, 2008 (Miami Beach)

Steve Kugelmann is in the process of creating a new design for BSF's tabletop/banner display and will submit an estimate along with graphics to the Board for review within a few weeks.

Steve McCurdy has asked Steve Kugelmann to submit a detailed program budget for 2008 to the Board for review.

Publications

Volume 7, Issue 2 was distributed late December 2007 to approximately 1,700 constituents within the United States.

Acknowledgements

1. The Board of Directors would like to acknowledge and express gratitude to Seth Barad for guidance on how best to approach the search for an Executive Director.
2. The Board of Directors would like to acknowledge and express gratitude to Richard Kearns for guidance on how best to approach the search for an Executive Director.
3. The Board would like to acknowledge and express gratitude to Sue Wilkins and her Family for their continuous efforts in raising funds via the Paula and Woody Varner Fund to help support BSF's mission.
4. The Board of Directors extends its sincere condolences to the Reece Family for the untimely loss of their son, Michael, who passed on January 11, 2008.

The meeting was adjourned at 11:30 PM EST. The next scheduled Board meeting will be held via teleconference on Saturday, February 16, 2008 @ 9:00 AM EST.

Respectfully submitted,

Lynda M. Sedefian

Lynda Sedefian
Secretary to the Board