

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

January 24, 2009

The Board of Directors of The Barth Syndrome Foundation, Inc. (BSF) met on Saturday, January 24, 2009, via teleconference.

Members in Attendance

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

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

Agenda Items:

1. Approval of November 2008 minutes
2. 2009 Board Meeting Dates – Confirmed
3. Preliminary 2008 Full Year Financial Results
4. Better Business Bureau Update
5. BSF of Canada Update (website; licensing agreement)
6. BRR Update
7. Finance & Audit Committee Vote
8. Financial/Administration Transition Update
9. 2009 Budget
10. Board Recruitment Update
11. National Exposure / Communication Plan
12. Other issues

1. Approval of Minutes

The minutes of November 14, 2008 were approved, as submitted.

2. 2009 Calendar for BSF Board Meetings

Proposed dates for the 2009 calendar of meetings was distributed and confirmed.

Saturday, January 24, 2009

Saturday, February 7, 2009

Saturday, April 4 – Sunday, April 5, 2009

Saturday, July 11, 2009

Saturday, November 14 – Sunday, November 15, 2009

3. Review of 2008 Financial Results Year-to-Date

Preliminary 2008 Year-End Total Fund Balance = \$2,213,404. Preliminary Statement of Revenues and Expenditures indicates a net deficiency of \$168,880 through December 31, 2008. These figures are expected to change slightly as we make final year end entries.

Note: Schall & Ashenfarb are in the process of completing BSF's 2008 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 2008 Audited Financial Report and IRS Form 990 will be sent to BSF's major donors for their information. These documents will also be posted to BSF's website for open access.

4. Better Business Bureau Wise Giving Alliance Update

Linda Stundis reported that after working with BBB since November 2008, BSF has now met all twenty charity accountability standards, is accredited by the BBB, and has received the BBB seal of endorsement. Linda has been working with Lynda Sedefian to reorganize BSF's website (www.barthsyndrome.org) to meet the standards of BBB, as well as make it more user friendly. Throughout the year there will be additional areas in which we are required to make changes to conform to BBB standards. The Board would like to acknowledge and thank Linda for her exceptional work in accomplishing this goal.

5. BSF of Canada Update*

Linda Stundis reported that she has had ongoing conversations with Lynn Elwood, President, BSF of CA regarding issues that were discussed at BSF's previous Board meeting. As a result of these conversations, BSF of CA's website is now under construction to ensure that all information is up-to-date. Linda reported that she will be joining BSF of CA's Board meeting on Wednesday, January 28, 2009, to further discuss the issues surrounding the licensing agreement.

6. Barth Syndrome Medical Database & Biorepository Update*

Linda Stundis reported that on January 26, 2009, she will visit the BRR to meet with Melissa Maisenbacher and Barry Byrne, MD, PhD, survey the facilities, and view the newly designed web-based platform (access and security) and redundant storage systems. Linda will also be meeting with the Contract Administrator to negotiate a settlement for Year 3, as well as expected budgets, objectives and deliverables for Year 4.

**Issues placed on agenda for future Board meeting.*

Michaela Damin, Chair, Barth Syndrome Trust, reported that all UK samples have been submitted to the medical database. From a Dutch point of view, Michaela has had contact with Dr. Poll-The, who is doing the final medical checks for the Dutch families. Once completed the Dutch patients' medical background information will be submitted to the medical database.

7. Finance & Audit Committee

Steve McCurdy proposed that BSF establish a formal Finance & Audit Committee in accordance with BBB's Standards of Excellence. Said governance committee is responsible for overseeing investments and assets, audits, and risk management. In accordance with BBB standards, it was proposed that the Committee be comprised of the following officers: **Chairman; Treasurer; Executive Director, *ex officio*; and Secretary to the Board.**

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 establish a formal Finance & Audit Committee, as described above.

8. Financial/Administration Transition Update

Linda Stundis reported that after conducting a search into fundraising and financial management solutions, and following lengthy discussions amongst the Board, it was recommended that we continue to work with FundEZ, given the economic climate. The Board was in agreement. Linda reported that if we find that FundEZ has not been fully utilized thus far, in six months to one year we may want to look at a third-party hosting solution to gain multiple-user access. Steve McCurdy also mentioned that there is a remote possibility that BSF could establish our own server and gain appropriately restricted and password protected access to a server for multiple users. Linda also reported that Ellen Bruno, new bookkeeper, has begun training of FundEZ.

9. 2009 Operational Budget

After a lengthy discussion regarding the current economic environment, fund raising and program plans affecting BSF's 2009 budget, it was proposed, given the state of the economy, that we commit to a targeted revenue of \$600,000.00, and that BSF adjust its plans to ensure a deficit of no more than \$300,000 for 2009.

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 commit to a targeted revenue of \$600,000.00, and that BSF set its plans to ensure a deficit of no more than \$300,000 for 2009.

In addition, the Board endorsed proposals that maximum budgets be set for Research Grants and for year 4 of the BRR, and for staff compensation for 2009.

The Chairman requested that each Board member inform Linda of their level of commitment in terms of fundraising so that she can develop a fundraising plan with a goal of reaching \$600,000 in 2009.

10. Board Recruitment

The Board further discussed the ongoing need to recruit new board members. Steve McCurdy reported that he has had conversations with a potential candidate who has indicated an interest in serving on BSF's Board of Directors. Said candidate is a patent lawyer, have experience in the pharmaceuticals & biotechnology areas, and has a son with Barth Syndrome. There was unanimous agreement that said candidate definitely has the qualifications that the Board is in search of, and it was agreed that BSF further pursue said candidate as a Board member.

It was recommended that Linda Stundis, Randy Buddemeyer, Michaela Damin and Steve Kugelmann contact said candidate to introduce themselves and familiarize themselves with the qualifications that said candidate would bring to the Board.

As appropriate, this candidate will be considered for a Board seat at the next meeting of the Board

11. National Exposure / Communication Plan

Steve and Kate McCurdy reported that the Barth Syndrome Foundation (through one Barth family -- Steve, Kate and Will McCurdy) will be featured on the Today Show on Monday, February 16, 2009, and profiled in Parade Magazine (on-line version) shortly following the Sunday, February 15, 2009 issue. These are the largest NBC TV Morning Show and Sunday newspaper magazine insert in the US, respectively, so this will give our cause huge exposure. Susan Osnos, Nick Bogert and Christine Elliot – all with expertise in Media and public relations have agreed to advise and prepare the McCurdy's.

Other Issues

Ex Officio Board Members

After a discussion describing the role of an *ex officio* member of the Board, it was agreed that an *ex officio* officer is a non-voting Board Member. It was proposed that the role of **Executive Director** (Linda Stundis) and **Secretary to the Board** (Lynda Sedefian) be designated *ex officio* members of BSF's Board of Directors.

Policies and Procedures

As required by BSF policy annually, Lynda Sedefian will distribute for the following documents for signature to all Board members, employees, and program leads:

- Confidentiality Acknowledgement
- Conflict of Interest

ICD Code 11

Michaela Damir reported that she has contacted Orphanet to determine their status in establishing an ICD code for Barth syndrome. The Orphanet team is preparing the first draft of proposals which are going to be sent to the experts, and then posted on the WHO website for public discussion later in 2009. Michaela reported that following review and acceptance by WHO, Barth syndrome could be listed in the next edition of the International Classification of Diseases (ICD) in 2012.

Since this is going up for public comment at year end, it was recommended that Michaela Damir and Shelley Bowen, along with Kate McCurdy and Linda Stundis review benchmarking other organizations have done to ensure the successful acceptance of a Barth syndrome ICD code. Michaela, Shelley, Kate and Linda will report back to the Board at its July meeting.*

Because obtaining an ICD code for Barth syndrome has been a long-time goal of BSF, the Board would like to thank Michaela for her work on this to date.

Adjournment

The meeting was adjourned on Saturday, January 24, 2009 at 12:45 PM EST.

Respectfully submitted,



Lynda M. Sedefian
Secretary to the Board

*Issues placed on agenda for future Board meeting.