

**Minutes of the  
BARTH SYNDROME FOUNDATION  
BOARD OF DIRECTORS  
July 11, 2009**

The Board of Directors of The Barth Syndrome Foundation, Inc. (BSF) met on Saturday, July 11, 2009, via teleconference.

Members in Attendance

Stephen B. McCurdy (Steve)	Chairman of the Board
Randy Buddemeyer	Board Member, Treasurer
Michaela Damin	Board Member
Stephen Kugelmann	Board Member
Katherine R. McCurdy (Kate)	Board Member
Marcus E. Sernel	Board Member, Corporate Secretary
Susan V. Wilkins (Sue)	Board Member
Linda Stundis, Executive Director	Board Member, <i>ex-officio</i>

Members Not in Attendance

Valerie Bowen (Shelley)	President, Board Member
Susan S. Osnos (Suze)	Board Member

Also in Attendance

Lynda Sedefian, Executive Assistant

Invited Attendees:

Matthew J. Toth, PhD, Science Director

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

**Agenda Items**

1. Welcome
2. Approval of Minutes
3. LPL Non-Corporate Resolution
4. Financial Report – Approval of 2009 Budget
5. Life is Good Discussion
6. Fundraising
7. Physician/Lab Awareness
8. Southeast Family Outreach Update
9. BSF of CA Update (Licensing)
10. BRR Update
11. NIH/R13 Update
12. NIH Committee Report
13. Testifying before Congress
14. Research Grant Request
15. SMAB+ Meeting Update
16. Science Research Update
17. Other Issues
18. Adjournment

## Minutes

The Board has approved the January, February and April 2009 Board minutes, as well as the June 2009 Executive Committee minutes, as submitted.

## LPL Non-Corporate Resolution

Following up on the Board's April 2009 meeting vote authorizing LPL to take direction from Stephen McCurdy, Chairman, Linda Stundis, Executive Director, and Randy Buddemeyer, Treasurer to buy, sell, assign and endorse for transfer, certificates representing stocks, bonds or other securities now registered or hereafter registered in the name of the Barth Syndrome Foundation, a discussion ensued regarding authorization limits. Following this discussion, it was agreed that Linda will contact Pinnacle Bank and LPL to discuss this matter.

## Financials

Linda, together with Ellen Bruno, BSF's bookkeeper who joined this portion of the meeting via teleconference, provided an overview of BSF's preliminary 2<sup>nd</sup> Q financial statements, which reflect the following:

Total Current Assets	\$ 2,126,708
Total Current Liabilities	\$ 175,746
Total Fund Balance	\$ 1,950,962
<b>Total Liabilities &amp; Fund Balance</b>	<b>\$ 2,126,708</b>

## 2009 Operational Budget

Following a lengthy discussion regarding the current economic environment, fund raising and program plans affecting BSF's 2009 budget, and upon Motion duly made and Seconded, it was

**VOTED:** To approve a 2009 operating budget of \$600,000.

## Life is Good Logo

Marc led a discussion regarding BSF's concerns as it relates to the apparent similarity between Life is Good's spiral-heart logo and BSF's trademarked logo (Ser. No. 78-204,806, Filed January 17, 2003). It was agreed that Linda, Steve M. and Marc would prepare a letter to Life is Good to address the issue.

## Fundraising

Linda reported that given the current state of the economy, we need to focus on existing donors, identify/re-engage lapsed donors, and leverage connections to identify/cultivate prospective new donors (individuals, foundations, corporate, and pharmaceutical companies with Foundation mission alignment or BSF connection).

Linda also reported that she has held a number of fundraisers, re-engaged several Boston based foundations, and identified prospective individuals with whom she has indirect connections. Board members then reported on their fundraising commitments and activities.

A discussion then ensued regarding potential funding relationships with pharmaceutical companies. It was agreed that Linda will develop a proposed set of policies to govern relationships with pharmaceutical companies.\*

### **Physician/Lab Awareness**

Linda reported, on behalf of Shelley, that Shelley met with Dr. Yuxin Fan, Laboratory Director, John Welsh Cardiovascular Diagnostic Laboratory in June 2009. It was noted that this is a major accomplishment resulting in a willingness of all CLIA-approved labs that screen for TAZ gene mutations to collaborate, and a new avenue to deliver BTHS educational material in a much more effective way.

### **Southeast Family Outreach Update**

Linda reported on the success of the recent Southeast Family outreach weekend. She highlighted that the presentations given by Dr. Paul Fernhoff, Clinical Geneticist, Emory University, Department of Human Genetics and Karlene Coleman, RN, MN, CGC, Emory University School of Medicine were well received by the families. Linda also reported that an informal meeting was held to discuss planning for the 2010 Conference.

### **BSF of CA Update (Licensing)**

Linda reported that all members of BSF of CA Board have received the revised draft Licensing Agreement. BSF of CA Board will address this at their upcoming meeting scheduled for July 15, 2009.

Following a brief discussion, it was agreed that a deadline of September 30, 2009 would be put into place for a final resolution. Linda will notify BSF of CA Board members of this deadline.

### **Barth Syndrome Medical Database & BioRepository Update (BRR)**

Linda reported that a meeting will be held in late September 2009 to review the data collected at the 2010 Conference, and to chart a course for scientific brainstorming and possible future research. Participants are expected to include Carolyn Spencer, Richard Kelley, Todd Cade, Matt, Kate, and herself.

### **NIH/R13 Update**

Matt reported that in order to receive an NIH R13 grant a letter from the appropriate NIH Institute/Center staff (National Heart, Lung and Blood Institute (NHLBI)) documenting advance permission to submit an R13 application must be completed. Said letter was sent to NHLBI on June 30, 2009. A response is expected by July 14<sup>th</sup>. Deadline for final submittal of the R13 application is August 12, 2009.

## **NIH Committee Report**

Kate reported that she, Matt, and Linda attended meetings at NHLBI and ORDR last month. As a result of these meetings, Kate reported that she has been invited to sit on the ORDR Rare Disease Patient Registry Workshop Planning Committee. Following up on suggestions made to her at these meetings, Kate requested that the Board consider the possibility of pursuing an opportunity to testify before Congress and how that could positively impact our relationship with NIH in supporting their research into rare diseases. Following a brief discussion, it was agreed that Linda will research the lobbying regulations for nonprofits.\*

## **Research Grant Request**

Matt reported that, due to a series of events in Dr. Genevieve Sparagna's laboratory, she has submitted a revised budget reallocating funds given for her 2008 grant. After discussion, and upon Motion duly made and Seconded, it was

**VOTED:** To make an exception to the existing application and approve the revised budget as submitted by Genevieve Sparagna, PhD.

## **SMAB+ Meeting Update**

Matt reported that the SMAB+ meeting is scheduled for December 10, 2009 in New York City. The focus of this meeting is "Links between pathophysiology and clinical manifestations of BTHS."

## **Science Research Update**

### BTHS Mouse

Matt reported that TAZ knock-down mice have been delivered to 3 laboratories. After further breeding of the mice, experimentation will determine if the mice provide a good experimental system for Barth Syndrome research as hoped.\*

### 2010 Conference

Matt reported that he has budgeted for 10 stipends at \$800/stipend for posters at the 2010 Conference. Linda asked Matt to draft an announcement for the 2010 Poster Session to be placed on BSF's website.

### 2009 Grant Process

The Board recommended to Matt that he be more pro-active regarding the grant program and questioned whether we are at the point of targeting research. In this regard, it was agreed that Matt will define five potential areas of inquiry/deliverables to be disseminated among SMAB members prior to the 2009 grant process, and define areas to be discussed at each SMAB meeting for the grant process in subsequent years.

### Antibodies

Matt reported that the first screen with the monoclonal antibodies that are being produced by the NIH did not show results superior to what we currently have.\*

## **Other Issues**

### 2008 Annual Report

Linda reported that she and Lynda are in the final stages of designing the 2008 Annual Report.

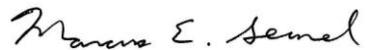
### Personnel Policies

It was agreed that Linda will develop an employee compensation policy as well as a written statement of personnel policies.\*

## **Adjournment**

The meeting was adjourned at 12:45 PM EST.

Respectfully submitted,



Marcus E. Sernel  
Corporate Secretary