

**Minutes of the  
BARTH SYNDROME FOUNDATION  
BOARD OF DIRECTORS**  
November 14, 2009

The Board of Directors of The Barth Syndrome Foundation, Inc. (BSF) met on November 14, 2009, via WebEx/Teleconference.

Members in Attendance

Stephen B. McCurdy	Board Member, Chairman
Valerie Bowen (Shelley)	Board Member, President
Randy Buddemeyer	Board Member, Treasurer
Michaela Damin	Board Member
Stephen Kugelmann	Board Member
Katherine R. McCurdy (Kate)	Board Member
Susan S. Osnos	Board Member
Marcus E. Sernel	Board Member, Corporate Secretary
Susan V. Wilkins	Board Member
Linda Stundis, Executive Director	Board Member, <i>ex-officio</i>

Additional Attendees

Lynda Sedefian, Executive Assistant  
Matthew J. Toth, PhD, Science Director

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Agenda Items:

1. Approval of Minutes
2. Financial Report
3. 2009 Auditor
4. Fundraising/Development Update
5. Family Services
6. 2010 Conference Update
7. BRR Update
8. BSF / BSFCa Licensing Agreement Update
9. Board Recruitment Process
10. BSF Policies & By-Laws
11. Clinical Data & Genetic Lab Meetings
12. 2009 Research Grant Cycle
13. 2010 Conference Sci/Med Sessions
14. SMAB+ Meeting Update
15. Science Research Update
16. Other Issues

The meeting was called to order by the Executive Director at 8:30 PM EST.

**1. Approval of Minutes**

The Board approved the July 11, 2009 and October 22, 2009 Board minutes, as well as the September 14, 2009 Executive Committee minutes, as submitted.

The Board approved the October 28, 2009 Board minutes, as amended on November 14, 2009.

2. **Financial Report**

Linda and Ellen Bruno, BSF bookkeeper (who joined this portion of the meeting via teleconference) provided an overview of the 3<sup>rd</sup> Q financial statements, which reflected the following:

Total Current Assets	\$ 1,974,570
Total Current Liabilities	\$ 133,564
Total Fund Balance	\$ 1,841,006
<b>Total Liabilities &amp; Fund Balance</b>	<b>\$ 1,974,570</b>

**Statement of Revenue and Expenditures All Funds (Period: 01/01/2009 to 10/31/2009)**

Total Revenues of \$266,176; including unrestricted donations of \$133,345.  
Total Expenses of \$631,798; for a net Deficit of \$365,622.

3. **2009 Auditor**

Linda reported that she has completed the evaluation process for a certified public accountant to conduct the 2009 audit, and following a teleconference meeting with Steve M., Randy, and Ellen, is recommending Gray, Gray & Gray, LLP, Certified Public Accountants, Westwood, MA. After discussion, and upon Motion duly made and Seconded, it was:

**VOTED:** To hire Gray, Gray & Gray, LLP, Certified Public Accountants for the 2009 audit, and to attempt to negotiate a three-year, no cost increase contract with option to terminate.

4. **Fundraising/Development Update**

Steve M. reported that he sent out a personal annual appeal, and reported that five members of “*Team Will*” will be participating in the Tempe Ironman on November 22, 2009. Randy reported that he will send a year-end personal appeal to his family, friends, neighbors, and clients, as will Marc. Susan reported that she will also send a personal appeal mailing.

Linda reported that she continues to nurture relationships with foundations in the Greater Boston area for future funding. A discussion then ensued regarding lapsed donors, and it was agreed that a year-end appeal will be sent by the staff to lapsed donors unless Board members requested that the appeal not be sent to donors they had solicited.

5. **Family Services**

Shelley reported that there has been a female patient from Australia who has been genetically diagnosed with Barth syndrome. Given this fact, Shelley recommended that BSF be sensitive to the language used in BSF’s communications (‘primarily affecting boys’). Shelley also reported that she is awaiting final approval on the cardiomyopathy and neutropenia documents she has written. Once finalized, these documents will be posted to BSF’s website as a point of reference.

6. **2010 Conference Update**

Linda reported that the contract with Bay Point Marriott, Panama City has been terminated, and the penalty has been paid. She reported that negotiations with Renaissance at SeaWorld, Orlando, FL have been completed and the contract has been signed.

The Board discussed whether it was financially worthwhile to use WebEx at the 2010 Conference to broadcast the sessions over the internet for those who unable to attend the Conference. Following a discussion, Steve M. authorized Shelley to poll families to discern the number of families who would prefer to join the Conference via WebEx versus attending in person, so a WebEx cost per person could be determined.

**7. Barth Syndrome Medical Database & BioRepository (BRR) Update**

Linda reported that in October 2009 the Scientific Review Board approved the BRR project. The project has now been entered into the IRB-approval phase and all documentation has been submitted. Linda also reported that she is in discussion with the Contract Office.

Shelley, who is UFL IRB-approved to enter data, reported that she has begun entering back data. A discussion ensued regarding the need to establish criteria for the type of data being entered and the methodology for how that data will be interpreted.

**8. BSF / BSFCa Licensing Agreement Update**

Linda reported that BSFCa has signed the BSF-BSFCa License Agreement, and will begin discussions with Michaela Damin, Chair, Barth Syndrome Trust (BST), to amend BSF-BST's License Agreement so that the License Agreement is consistent across affiliates. Linda will then initiate discussions with Jeannette Thorpe, Barth Trust South Africa.

**9. Board Recruitment Process**

Steve M. recommended that a Board Nominating and Development Committee be created with responsibility for defining Board roles, needs, and objectives; developing a process for identifying, vetting, and recommending the recruitment of prospective board members to the BSF Board; and developing a Board succession plan.

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

**VOTED:** To establish a Board Nominating and Development Committee charged with a) defining Board roles, needs, and objectives; b) developing a process to identify prospective candidates, vet nominations, and recommend prospective candidates to the BSF Board; and c) developing a Board succession plan.

Following an additional brief discussion, and upon Motion duly made and Seconded, it was

**VOTED:** To elect Steve McCurdy, Susan Osnos, Sue Wilkins, and Steve Kugelmann to serve on the Board Nominating and Development Committee.

**10. BSF Policies & By-Laws**

Corporate Policy

Linda distributed a draft Corporate Policy required by the National Health Council. Following a brief discussion, this item was tabled until the January 2010 meeting.\*

Nondiscrimination Policy

The Nondiscrimination Policy was approved, as amended on November 14, 2009.

Diversity Policy

The Diversity Policy was approved, as amended on November 14, 2009.

### Lobbying Guidelines

Linda prepared and reviewed Lobbying Guidelines (not requiring Board approval) for future reference.

### BSF By-Laws

The By-Laws were approved, as amended on November 14, 2009.

#### **11. Clinical Data & Genetic Lab Meetings**

Linda reported that on September 29, 2009, Carolyn Spencer, MD, hosted a meeting to review the clinical data collected at the 2008 Conference. Meeting participants were: Richard Kelley, MD, PhD; Todd Cade, PT, PhD; Amy Roberts, MD; Renee Margossian, MD; Paul Benni, PhD; Gerard Berry, MD; William Pu, MD; Matt, Kate, and Linda.

Linda also reported that on October 13, 2009, Carolyn Spencer, MD, following up on the work of Shelley, hosted a meeting to encourage collaboration among US diagnostic laboratories. Participants included Yuxin Fan, MD, PhD, FACMG (Baylor College of Medicine – John Welsh Cardiovascular Diagnostic Laboratory); Iris Gonzalez, PhD (A.I. duPont Hospital for Children – Molecular Diagnostic Laboratory); Birgit Funke, PhD, FACMB (Harvard Medical School - Laboratory for Molecular Medicine); Richard Kelley, MD, PhD; Amy Roberts, MD; Matt, and Linda. To continue this collaboration, a meeting of international genetic laboratory representatives will be scheduled during the 2010 Conference.

#### **12. 2009 Research Grant Cycle**

Matt reported that he has received 14 grant applications for the 2009 research Grant Cycle. A discussion ensued regarding ways to increase awareness and grow the grant program. The Board asked Matt to begin developing a plan to reach a greater number and wider spectrum of researchers whose work could be relevant to any aspect of BTHS.

#### **13. 2010 Conference Sci/Med Sessions**

Matt reported that the Chairs for the Scientific and Medical session will be Dr. Richard Kelley, Dr. Barry Byrne, Dr. Miriam Greenberg, and Dr. Michael Schlame, and that twenty seven speakers have accepted invitations to present the results of their recent research.

Matt also reported that Dr. Douglas Wallace has agreed to be the keynote speaker for the Sci/Med portion of the Conference. Dr. Wallace is Donald Bren Professor of Molecular Medicine and Director of the Center for Molecular and Mitochondrial Medicine & Genetics at the University of California at Irvine, and one of the earliest pioneers in defining the importance of the mitochondria in human disease.

Finally, Matt reported that the NIH R13 grant application is scheduled for review on November 19-20, 2009.

#### **14. SMAB+ Meeting Update**

Matt reported that all SMAB members (except Drs. Barth and Steward), along with Drs. Spencer, Cade and Ren, and Linda are scheduled to attend the meeting on December 10, 2009. The agenda items will include presentations of the 2008 clinical data. It was recommended that the agenda address the intersection of clinical data and science in anticipation of the 2010 Conference.

#### **15. Science Research Update**

Matt reported that there are currently four laboratories studying the tafazzin knockdown mice.

**Adjournment**

The meeting was adjourned at 4:00 PM EST.

Respectfully submitted,

*Marcus E. Sernel*

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Corporate Secretary