

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
November 13-14, 2010

The Board of Directors of the Barth Syndrome Foundation, Inc. (BSF) held a face-to-face meeting on November 13-14, 2010 in Larchmont, New York.

Board Members in Attendance

Stephen B. McCurdy	Chairman
Randy Buddemeyer	Treasurer, Board Member
Michaela Damin	Board Member
Stephen Kugelmann	Board Member
Katherine R. McCurdy	Board Member
Susan S. Osnos	Board Member
Marcus E. Sernel	Corporate Secretary, Board Member
Susan V. Wilkins	Board Member

Board Members Not in Attendance

Valerie “Shelley” Bowen	President, Board Member
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Additional Invitees

Matthew J. Toth, PhD, Science Director
Lynda Sedefian, Executive Assistant
Heller An Shapiro, Consultant, TransitionGuides

The meeting was called to order by the Chairman at 8:45 AM EST on Saturday, November 13, 2010.

Steve McCurdy welcomed Heller An Shapiro and thanked her for her willingness to participate in this meeting. Heller An was invited to attend the meeting as a consultant to advise particularly on strategic planning, succession planning, transition management, and organizational sustainability.

ITEMS OF DISCUSSION

1. Minutes
2. Financials
3. 2010 Auditor
4. 2012 Conference
5. Affiliates
6. NHS Barth Syndrome Service Clinic (BSTrust)
7. 2010 Research Grant Program
8. Barth Registry & BioRepository (BRR)
9. 2011 Preliminary Budget
10. Strategic Planning Discussion
11. Development/Fundraising
12. International Affiliate Strategy
13. Organization Success Planning, Staffing, Volunteers
14. Other

1. **Ratification of Minutes**

The Board approved the May 15, 2010 and July 26, 2010 Board minutes, as amended on this date.
The Board accepted the September 30, 2010 Executive Committee minutes, as amended on this date.

2. **Financial Statements**

Randy Buddemeyer provided an overview of the 2010 year-to-date financial statements, which reflected the following:

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2010 – 10/31/2010

Total Revenues of \$302,259; including unrestricted donations of \$163,177.

Total Expenses of \$946,784; for a Net Deficiency of Revenue over Expenses of \$644,525.

Total Current Assets	\$ 1,663,311
Total Current Liabilities	\$ 124,085
Total Fund Balance	\$ 1,539,226
Total Liabilities & Fund Balance	\$ 1,663,311

3. **2010 Auditor**

Steve McCurdy reviewed Gray, Gray & Gray’s proposal to conduct BSF’s 2010 audit. Following a discussion and upon Motion duly made and Seconded, it was:

VOTED: To hire Gray, Gray & Gray, LLP, Certified Public Accountants to conduct BSF’s 2010 audit.

4. **2012 Conference**

Shelley Bowen completed a venue comparison for BSF’s 2012 conference. The Board reviewed the venue comparison and after a thorough discussion, the Board authorized Marc Sernel to work with Shelley to continue the negotiating process with a venue located in central Florida. Marc will report back to the board regarding these negotiations, with the hope that a venue decision and contract could be finalized by year end.

5. **Barth France**

Steve McCurdy reported on the start-up of an Association, called “Barth France,” dedicated to creating an opportunity for increasing awareness of Barth syndrome; creating the ability to provide more direct “family support” to those families located in France; and raising funds within said location. Michaela Damin reported that she has been in close contact with this association, and that BStrust is willing to assist said association in order to accomplish these goals.

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

VOTED: The Barth Syndrome Foundation, together with Barth Syndrome Trust (UK & Europe), will provide “Barth France” with a founding \$2,000 donation to assist with the financial fees in obtaining official non-profit status.

6. **NHS Barth Syndrome Service Clinic Update**

Michaela Damin reported on the success of the first-ever NHS-funded Barth Syndrome Service Clinic in Bristol, England, held on September 24, 2010. Families had the opportunity to hear educational presentations and were offered clinical evaluations and time to consult with many of the physicians involved in the clinic team (cardiology, CPR training, psychology, physio, OT, genetic counselling, education, haematology, neurology, metabolics, endocrinology, nutrition, gastroenterology, phlebotomy).

The Board commended Michaela on the success in receiving NHS funding for said clinic and agreed that the structure of this clinic is a role model for future BTHS clinics in the US.

7. **2010 Research Program Update**

Matt Toth reported that he has received 15 grant applications for BSF's 2010 research grant cycle and provided a brief overview of the applications. A discussion ensued regarding ways to increase awareness and grow the grant program.

It was noted that there is a Board meeting tentatively scheduled for February 19, 2011 to review all grant applications and the SMAB's recommendations, and to vote on those grants that will be awarded for the 2010 grant cycle.

8. **Barth Registry and BioRepository (BRR) Update**

The Board discussed ongoing issues of concern with regard to the BRR. The Board of Directors appointed Matt Toth as primary contact between Dr. Amy Roberts, Co-Principal Investigator (Children's Hospital Boston) and BSF. The Board asked Matt to lead discussions with Amy to arrange for a meeting in the near future to discuss these issues.

9. **2011 Preliminary Budget**

Steve McCurdy distributed a 2011 preliminary budget for review. A discussion ensued regarding the level of deficit that could be budgeted as well as Board fundraising commitments.

10. **Strategic Planning Discussion**

Leveraging other Institutions/Setting Priorities

The Board discussed ways in which to actively invest in our relationship with various professional organizations, government agencies and peer charities with like-minded interests. It was noted that BSF has done some of this successfully in the past, but needed to step up its efforts, as augmenting support is a very effective way of increasing support and awareness of BTHS research.

Science/Medicine Strategic Planning

Matt Toth presented an overview of a meeting held on November 11, 2010 to discuss scientific/medical priorities and focused on developing a framework to accelerate BTHS treatments and research. In attendance were Dr. Richard Kelley, Chairman, BSF Scientific and Medical Advisory Board; Matt Toth, BSF Science Director; Kate McCurdy, Sue Wilkins, and Michaela Damin, BSF Board members.

The Board would like to express our sincere appreciation to Dr. Kelley and Matt, whose input was invaluable in assisting in the development of BSF's scientific/medical strategic plan.

Fellowship Program

The Board engaged in a conversation regarding the desire to create a fellowship program to expand the metabolic scientific thinking by pushing thought processes beyond their normal limits.

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

VOTED: The Barth Syndrome Foundation will fund a fellowship program of up to \$60,000 for a one-year period to expand the metabolic scientific thinking of BTHS.

SMAB+ Meeting

Steve McCurdy encouraged Matt to develop a plan for the 2011 SMAB+ meeting, including a financial budget, to propose to the Board of Directors for consideration.

Physician Awareness

Kate McCurdy proposed that we consider resumption of BSF attendance at smaller scientific/medical conferences with particular relevance to BTHS (and those where BTHS is being presented on). Steve McCurdy asked Steve Kugelmann to put together a plan, along with a budget, for Board consideration.

11. **Development/Fundraising**

Steve McCurdy reported that two members of *Team Will* participated in the Ironman Florida on November 6, 2010. Steve also reported that Gary Rodbell and members of *Team Will* participated in the Jarden Westchester Triathlon on September 26, 2010.

Randy Buddemeyer reported that the 5th Annual JDRF & Barth Syndrome Golf Tournament was held on October 18, 2010, and was once again very successful in raising funds and awareness.

Steve noted that he will once again be sending a year-end personal appeal to his family, friends, neighbors, and clients. A discussion then ensued regarding the 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).

12. **International Affiliate Update**

Steve McCurdy reported that BSF's amended Trademark License Agreement has been signed by the Barth Syndrome Trust (UK & Europe).

Steve noted that he will contact Jeannette Thorpe, Chair, Barth Trust of South Africa, to finalize the Trademark License Agreement with this affiliate.

13. **Organization Success Planning, Staffing, Volunteers**

Susan Osnos, Chair, Board and Organizational Development Committee, presented an overview summarizing the following:

- recommendations around succession planning for Board consideration
- organizational development
- staff structure

Board Expansion

The Board currently has nine members, and according to term limits, two will step down in 2013, three more in 2014, and four in 2015. In order to maintain the Board, the Board and Organizational Development Committee identified four potential candidates. A thorough discussion ensued regarding said potential candidates. The Board of Directors authorized the Board and Organizational Development Committee to proceed with the interview process and select a slate of candidates for Board consideration.

The Board of Directors agreed that two to three (maximum of three) new board members would be brought on in April 2011 to serve a three-year term.

Organizational Development

A discussion then ensued regarding Board succession planning, term limits, and filling key board roles as needed. In this regard, current board assets and limitations were discussed. The Committee has developed a plan to address the following: (1) Develop a description of the BSF community and Board cultures; (2) Establish goals to recruit board members totaling 15-16, including two external Board members in 2010-2011, three in 2013 and four in 2014; (3) Develop a plan for the recruitment and introduction of external members; and (4) Develop a plan to identify and cultivate prospective family board members.

Staff Structure

There was a collective realization that we will need to augment our leadership resources and skills if we are to successfully address the growth and challenges we expect in the future. A thorough discussion ensued regarding what kind of structure might make the best sense for BSF going forward.

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

VOTED: The Barth Syndrome Foundation will begin the search for a new Executive Director who will report directly to the Board; and that a search committee consisting of at least Steve McCurdy, Susan Osnos, and Randy Buddemeyer would lead the search and report back to the Board on their progress and the candidate slate periodically, and that the Board would make the final selection after interviewing all final candidates.

The Committee also suggested the development of non-Board committees to encourage involvement of BSF family members.


14. Other

Kate McCurdy reported that Will McCurdy is scheduled to make a presentation on Barth syndrome to the 2nd year genetic counseling graduate students of the Sarah Lawrence College, one of the largest in the United States.

ADJOURNMENT

The meeting was adjourned at 6:00 PM EST on Sunday, November 14, 2010.

Respectfully submitted,



Marcus E. Sernel
Corporate Secretary