

**Barth Syndrome Foundation, Inc.**  
**Board of Directors Meeting**  
April 9-10, 2011

The Board of Directors of the Barth Syndrome Foundation, Inc. (BSF) held its annual meeting on April 9-10, 2011, in Larchmont, New York.

**Board Members in Attendance**

Stephen B. McCurdy	Chairman
Valerie “Shelley” Bowen	President, Board Member
Michaela Damin	Board Member
Stephen Kugelmann	Board Member
Susan A. McCormack	Board Member
Katherine R. McCurdy	Board Member
Susan S. Osnos	Board Member
Marcus E. Sernel (April 9 only)	Corporate Secretary, Board Member
John Wilkins	Board Member
Susan V. Wilkins	Board Member

**Board Members Not in Attendance**

Randy Buddemeyer	Treasurer, Board Member
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**Additional Invitees**

Matthew J. Toth, PhD, BSF Science Director  
Lynda Sedefian, Executive Assistant  
Ellen Bruno, Bookkeeper  
Diane Gibson (Gray, Gray & Gray, LLP)  
Joseph McCormack, McCormack & Associates  
Caroline McCormack, McCormack & Associates

Diane Gibson of Gray, Gray & Gray was also an invited guest who joined the meeting via teleconference on Saturday morning, April 9<sup>th</sup>, to disclose BSF’s 2010 Audited Financial Statements and Form 990.

Joe McCormack and Caroline McCormack of McCormack & Associates were invited guests who joined the meeting on Saturday afternoon, April 9<sup>th</sup>, to discuss the process for the search for a new Executive Director.

**Agenda Items:**

1. Welcome Susan McCormack and John Wilkins
2. Motion to Accept 2010 Audit Report and Form 990
3. Review of Financial Statements
4. Ratification of Minutes
5. NHC – Standard on Diversity of Funding Sources Compliance
6. Status of BBB Filing
7. Election of Board Members
8. Staff Evaluation and Compensation Plans
9. Executive Director Search
10. Science and Medicine Discussion and Brainstorming
11. BRR Update
12. Trademark Registration – Update
13. Family Services – Update
14. Website and Internet Platform Plans
15. International Update – BST and BSF

*\*Items tabled.*

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

**1. Welcome**

Steve McCurdy welcomed BSF's two newest board members, John Wilkins and Susan McCormack, to their first first-to-face board meeting and thanked them for their willingness to devote their time and resources to BSF.

**2. 2010 Audit Report and Form 990**

Diane Gibson, Gray, Gray & Gray, has delivered a clean audit of BSF's 2010 financial statements. Diane reviewed all of the financial statements and the contents of the 2010 audit in detail with the members of the Board, who were satisfied with the financial statements and pleased with the findings of BSF's auditor. Following a discussion and upon Motion duly made and Seconded, it was:

**VOTED:** That the Board of Directors accept the 2010 Audited Financial Statements and 990, as submitted by Gray, Gray & Gray, Certified Public Accountants, LLC.

The Barth Syndrome Foundation will re-register its By-Laws with all thirteen (13) states where BSF solicits funds concurrently with the filing of its 2010 Auditor's Report and IRS Form 990.

**3. Financial Statements**

Ellen Bruno, BSF bookkeeper (who joined this portion of the meeting via teleconference), provided an overview of the 2010 audited financial statements, which reflected the following:

**Preliminary Statement of Revenue and Expenditures All Funds – Year-End 12/31/2010**

Total Revenues of \$795,131; including unrestricted donations of \$394,881.  
Total Expenses of \$1,066,992; for a Net Asset of \$1,932,459.

Total Current Assets	\$ 2,032,501
Total Current Liabilities	\$ 100,042
<b>Total Fund Balance</b>	<b>\$ 1,932,459</b>

Ellen also provided an overview of the March year-to-date 2011 budget comparison preliminary financial statements, which reflected the following:

**Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2011 – 03/31/2011**

Total Revenues of \$32,511; including unrestricted donations of \$26,087.  
Total Expenses of \$397,629; for a Net Excess of Revenue over Expenses of \$365,118.

Total Current Assets	\$ 1,895,455
Total Current Liabilities	\$ 349,490
<b>Total Fund Balance</b>	<b>\$ 1,545,965</b>

**4. Ratification of Minutes**

The Board approved the January 27, 2011 and February 19, 2011 Board minutes, as submitted on this date. The Board accepted the March 24, 2011 Executive Committee minutes, as amended on this date.

\*Items tabled.

**5. NHC – Standard on Diversity of Funding Sources Compliance**

Ellen Bruno reported that in 2010, NHC approved a revision of the standard on diversity of revenue sources. The intent of the revised standard is to demonstrate that voluntary health agencies get their funding from a broad base of sources to ensure public accountability, promote financial stability, and avoid undue influence from any one contributor. The standard requires VHAs to maintain compliance with IRS regulations governing 501(c)(3) public charities, which require them to demonstrate a broad base of public support. It also requires VHAs to establish certain annual benchmarks related to funding sources and to measure performance against them.

**6. Status of BBB Filing**

Steve McCurdy reported that he is in the process of submitting all required documentation for the renewal of BBB's seal program.

**7. Election of Board Members**

The Board of Directors thanked Katherine McCurdy, Susan Wilkins, and Randy Buddemeyer for their dedicated services on the Board. Following a discussion, and upon Motion duly made and Seconded, it was:

**VOTED:** That the Board of Directors re-elect Katherine McCurdy as a member of the Board of Directors for an additional 3-year term. Said term will run thru April 2014.

**VOTED:** That the Board of Directors re-elect Susan Wilkins as a member of the Board of Directors for an additional 3-year term. Said term will run thru April 2014.

**VOTED:** That the Board of Directors re-elect Randy Buddemeyer as a member (and Treasurer) of the Board of Directors for an additional 3-year term. Said term will run thru April 2014.

*Note: Each board member mentioned above abstained from voting on the re-election of their seat to the Board.*

**8. Staff Evaluation and Compensation Plans**

Steve McCurdy tabled this item. An executive session will be scheduled to discuss employee performance evaluations.\*

**9. Executive Director Search**

Joseph McCormack and Caroline McCormack joined the meeting to discuss the search process for a new Executive Director. An open discussion ensued outlining the Executive Director's responsibilities and the resources and skills required to meet the growth and operational challenges that BSF expects to face over the next 5-10 years. The Search Committee (Susan Osnos [Chairman], Randy Buddemeyer, Stephen Kugelmann, Stephen McCurdy, Sue Wilkins) will lead the effort initially, but the Board will meet any final candidates and make any hiring decisions on behalf of BSF.

An announcement will be made on BSF's listserv and website informing our community of the new search for an Executive Director.

**10. Science and Medicine Discussion and Brainstorming**

Kate McCurdy reported on a meeting held on May 21<sup>st</sup> with Drs. Richard Kelley and Gary Goldstein to discuss ways in which to broaden the scope of the metabolic scientific thinking of Barth syndrome and continue discussion of a possible fellowship program.

\*Items tabled.

Current needs discussed include:

- Need to create a natural history study of Barth syndrome;
- Need global view of disease (not just cardiology);
- Need to design a program to incentivize publication of analyzed clinical data;
- Need to hire a Nurse Practitioner who would eventually become our clinical “first line of defense” by taking calls from families and physicians, triaging them and deciding on a course of action -- taking the problem to BHHS experts, learning from the expert responses, and then getting back to the family member if that’s the appropriate response in the specific situation;
- Need for BRR Tissue Bank Advisory Committee to be more proactive;

#### **11. BRR Update**

Matt Toth reviewed the quarterly report received from Drs. Carolyn Spencer and Amy Roberts pertaining to the BRR. Highlights of the report include:

- The Barth Registry has been moved from the University of Florida (UF) to Children’s Hospital Boston (CHB) under the guidance of Amy Roberts, MD with Judith Geva as the coordinator. The majority of DNA is currently in Dr. Robert’s lab, and her lab extracted all of the DNA from new subjects at the 2010 Barth Conference. Carolyn Spencer, MD remains a Co-PI for the Registry.
- Dr. Spencer has also assumed some of the previous role of Melissa Maisenbacher, who is no longer employed by the Registry. New enrollees are now signing CHB Registry consent, and we have had new subjects registered this year from CHB.
- Freezerworks™, a specimen tracking software program, has been purchased jointly by the Registry and Dr. Roberts’ lab and is being used to catalog the samples. Lymphoblast lines remain at Johns Hopkins Cell Center.
- Data continues to be entered primarily by Connie Nixon, RN. She enters the data remotely from UF and has entered a tremendous amount of data. She is now entering past medical records on subjects. Matt Fletcher at UF continues to maintain the database and run queries and has been extremely responsive.

Michaela Damin proposed, and the Board strongly agreed, that Dr. Beverly Tsai-Goodman be considered a candidate to serve on the BRR Tissue Bank Advisory Committee. This addition to the advisory board would help to increase the interaction with Bristol Royal Hospital and the BRR.

#### **12. Trademark Registration – Update**

Marc Sernel reviewed the cost of registering BSF’s logo (Pantone 285) and our international logo (international flags) with the entire European Union. After a discussion, the Board encouraged Marc to move forward with registering BSF’s logos with the entire European Union.

#### **13. Family Services – Update**

Shelley Bowen reported that the 2010 Conference presentations are now available on-line via YouTube and have received numerous views. A discussion ensued on how to better educate the families while making clear that BSF does not endorse any drugs, tests, or treatments that BSF’s website may report.

#### **14. Website and Internet Platform Plans**

Shelley Bowen reported that she and Lynda Sedefian have been researching different internet platforms to provide the needs of our community. A discussion ensued regarding BSF’s website and how to make it more interactive (*i.e.*, streaming videos). It was suggested that Shelley, Matt Toth, and Lynda work on the content to be included in a short presentation video and the audience to which the message is targeted. Michaela Damin noted that she is currently working on a short presentation/educational message video for BSTrust’s website.

\*Items tabled.

**15. International Update – BST and BSF**

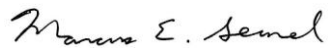
Michaela Damin reported that there were 12 families in attendance at the NHS Barth Syndrome Clinic held in March 2011, and that the clinic continues its ongoing success offering expert advice to families.

Steve McCurdy reported that Florence Mannes (Chair, Barth France) has begun translating information from BSF's website into French to populate [Barth France's website](#).

**ADJOURNMENT**

The meeting was adjourned on Sunday, April 10, 2011 at 1:00 PM EST. The next Board meeting is scheduled for September 16-18, 2011.

Respectfully submitted,



Marcus E. Sernel  
Corporate Secretary