



**Barth Syndrome Foundation, Inc.**  
**Board of Directors Meeting**  
**April 29, 2012**

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**Members in Attendance:**

Stephen B. McCurdy	Chairman
Lindsay Groff, Executive Director	Board Member, <i>ex-officio</i>
David Axelrod, MD	Board Member
Randy Buddemeyer	Treasurer, Board Member
Michaela Damin	Board Member
Stephen Kugelmann	Board Member
Susan A. McCormack	Board Member
Katherine R. McCurdy	Board Member
Susan Osnos	Board Member
Marcus E. Sernel	Corporate Secretary, Board Member
John Wilkins	Board Member
Susan V. Wilkins	Board Member

**Additional Invitees**

Valerie (Shelley) Bowen, Director, Family Services & Awareness  
Lynda Sedefian, Executive Assistant  
Matthew J. Toth, PhD, BSF Science Director  
Ellen Bruno, BSF Accountant/Bookkeeper  
Diane Gibson, Gray, Gray & Gray, LLP

Diane Gibson of Gray, Gray & Gray was an invited guest who joined the meeting via teleconference to disclose BSF's 2011 Audited Financial Statements and Form 990.

Ellen Bruno was also invited to join the meeting to provide an overview of the 2011 audited financial statements.

***Our Mission - Saving lives through education, advances in treatment, and finding a cure for Barth syndrome.***

**Agenda Items:**

1. Ratification of Board Minutes
2. 2011 Audit Report and Form 990
3. 2011 Year-End Financial Review & IRS Filings
4. March Year-to-Date Financial Results
5. (Re)Election of Board Members
6. Other Business
7. Staff Evaluation & Compensation

The meeting was called to order by the Chairman on Sunday, April 29, 2012 at 3:00 PM EDT.

**1. Ratification of Minutes**

The Board approved the February 4, 2012 and February 25, 2012 Board minutes, as amended on this date.  
The Board approved the April 18, 2012 Board minutes, as submitted on this date.

**2. 2011 Audit Report and Form 990**

Diane Gibson, Gray, Gray & Gray, has delivered a clean audit of BSF's 2011 financial statements. Diane reviewed all of the financial statements and the contents of the 2011 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 2011 Audited Financial Statements and 990, as submitted by Gray, Gray & Gray, Certified Public Accountants, LLC.

The Barth Syndrome Foundation will renew its registrations with all fourteen (14) states where BSF solicits funds concurrently with the filing of its 2011 Auditor's Report and IRS Form 990.

**3. 2011 Year-End Financial Review**

Diane Gibson provided an overview of the 2011 audited financial statements, which reflected the following:

**Final Statement of Revenue and Expenditures All Funds – (01/01/2011 - 12/31/2011)**

Total Revenues of \$715,418; including unrestricted donations of \$626,686.

Total Expenses of \$752,666; for Net Assets of \$1,895,211.

Total Current Assets	\$ 1,994,513
Total Current Liabilities	\$ 99,302
<b>Total Fund Balance</b>	<b>\$ 1,895,211</b>

**4. March Year-to-Date Financial Results**

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 \$46,521; including unrestricted donations of \$43,802.

Total Expenses of \$473,120; for a Net Excess of Expenses over Revenue of \$426,599.

Total Current Assets	\$ 1,806,524
Total Current Liabilities	\$ 358,739
<b>Total Fund Balance</b>	<b>\$ 1,447,785</b>

**5. (Re)Election of Board Members**

The Board of Directors thanked Stephen Kugelmann, Susan Osnos, and Marc Sernel 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 Stephen Kugelmann as a member of the Board of Directors for an additional 3-year term. Said term will run thru April 2015.

**VOTED:** That the Board of Directors re-elect Susan Osnos as a member of the Board of Directors for an additional 3-year term. Said term will run thru April 2015.

**VOTED:** That the Board of Directors re-elect Marc Sernel as a member of the Board of Directors for an additional 3-year term. Said term will run thru April 2015.

*Note: Each board member mentioned above was not present during the discussion of this issue and also abstained from voting on the re-election of their seat to the Board.*

**6. Other Business**

**Board Nominating and Development Committee Report**

Suze Osnos reported that the committee has discussed creating a new position as Vice Chairman of the Board of Directors. Said term will run annually. Following a discussion, and upon **MOTION** duly made and **Seconded**, it was:

**VOTED:** To establish a new position as Vice Chairman of the Board of Directors, as described above.

**VOTED:** To elect Marcus Sernel to serve as the Vice Chairman of the Board of Directors. Said term will run on an annual basis.

Suze Osnos and Steve McCurdy will make the appropriate announcements of this new position to our community.

A discussion then ensued regarding Board succession planning, term limits, and filling key board roles as needed.

### **2012 Conference Planning**

Lindsay Groff reported that the 2012 conference planning is well underway. Matt Toth reported that the presenters of the Scientific/Medical Session are secured. Shelley Bowen reported that the Family Session is in the process of being finalized. Lindsay also reported on total sponsorships for said conference.

### **Barth Syndrome Registry & Repository (BRR) – Update**

Lindsay Groff provided an update on the BRR regarding the transition of bringing the Registry in-house, with a staff member serving as PI and using an independent IRB, per the Board's vote on April 18, 2012.

### **Family Services – Update**

Shelley Bowen provided an overview of the number of affected families involved with BSF. She reported that nearly 50% of the living boys are currently enrolled in the BRR.

### **Clinical Grants System**

Matt Toth proposed that we alter the budget process of the BSF Research Grant Program to place clinical projects on a more level playing field with the other applications submitted in a single grant cycle. Matt explained that clinical projects, by their nature, tend to incur more expenses because of the need for patient coordination and involvement (e.g. transportation of the individuals to the proposed testing/evaluation site(s)). Matt Toth will seek the advice and approval of the Scientific & Medical Advisory Board and report back to the Board with a specific recommendation.

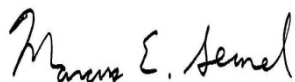
## **7. Staff Evaluation & Compensation**

At this time Matt Toth, Shelley Bowen, and Lynda Sedefian were dismissed from the meeting. A discussion ensued regarding the performance of and compensation for each of these employees.

## **ADJOURNMENT**

The meeting was adjourned at 5:00 PM EDT. The next Board meeting is scheduled for Sunday, June 24, 2012.

Respectfully submitted,



Marcus E. Sernel  
Corporate Secretary

**2012 Meeting Dates:**

**Board of Directors**

Tuesday, January 24, 2012	Teleconference @ 8:00 PM EST
Saturday, February 4, 2012	Teleconference @ 12:00 PM EST
Sunday, April 29, 2012	Teleconference @ 3:00 PM EST
Sunday, June 24, 2012	Face-to-Face (Conference)
Tuesday, September 11, 2012	Teleconference @ 8:00 PM EST
Friday, Jan. 25-Sunday, Jan. 27, 2013	Face-to-Face ( <i>Location TBD</i> )

**Executive Committee**

Tuesday, May 15, 2012	Teleconference @ 8:30 PM EST
Tuesday, July 17, 2012	Teleconference @ 8:30 PM EST
Tuesday, October 16, 2012	Teleconference @ 8:30 PM EST