



**2009 AUDIT REPORT**

Diane Gibson, Gray, Gray & Gray, has delivered a clean audit of BSF’s 2009 financial statements. Diane reviewed all of the financial statements and the contents of the 2009 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 2009 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 2009 Auditor’s Report and IRS Form 990.

*Per a Board consensus, the Audited Financial Statement/990 included a disclosure note regarding the impact of the biennial conference.*

**FINANCIAL STATEMENTS**

**Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2010 – 04/31/2010**

Total Revenues of \$125,959; including unrestricted donations of \$80,449.  
Total Expenses of \$514,561; for a Net Deficiency of Revenue over Expenses of \$388,602.

Total Current Assets	\$ 2,040,484
Total Current Liabilities	\$ 248,789
Total Fund Balance	\$ 1,791,695
<b>Total Liabilities &amp; Fund Balance</b>	<b>\$ 2,040,484</b>

**2010 BUDGET**

The Board approved the 2010 operating budget as presented, in lieu of it being a conference year.

**LOCKBOX SERVICE**

The Board agreed that using a lockbox service is a prudent measure to better insure safe handling of finances for the organization.

**VOTED:** That BSF move forward with the purchase of a lockbox at Pinnacle Bank, a service designed to accelerate the collection and deposit of check payments, sent with accompanying remittance document(s), through the mail.

Ellen will design the remittance envelope, likely to include the following categories: General Fund; Varner Restricted Fund; Science/Medicine Restricted Fund; Honorarium/Memorial; Other.

**RATIFICATION OF MINUTES**

The Board approved the February 20-21, 2010 Board minutes, as amended on this date.  
The Board approved the March 25, 2010 Executive Committee minutes, as submitted.

**FUNDRAISING UPDATE**

Linda Stundis reported that she is awaiting a final decision from a major funder in the greater Boston area in support of the BRR.

*\*Items placed on Board’s July 26, 2010 meeting agenda.*

Linda distributed a list of prospective foundations/organizations who share common interests with BSF's mission. The board was asked to review this list and respond to Linda within the next two weeks to assist in the identification of prospective funding sources.

### **DIVERSITY POLICY**

The Board approved the Diversity Policy, as submitted.

### **NATIONAL HEALTH COUNCIL UPDATE**

Linda Stundis reported that she has received informal notification from NHC that BSF is in compliance with NHC's standards regarding the re-election of voting BSF board members in the roles of Chairman and President.

### **BOARD & ORGANIZATIONAL DEVELOPMENT UPDATE\***

The Board & Organizational Development Committee was created with the responsibility for (1) defining Board roles, needs, and objectives; (2) developing a process for identifying, vetting, and recommending the recruitment of prospective board members to the BSF Board; (3) and developing a Board succession plan. Steve Kugelmann reported that the committee is in the process of creating a charter and developing policies and procedures. This item was placed on the agenda for the Board's July 26, 2010 meeting for further discussion.

### **BOARD SELF ASSESSMENT\***

Steve Kugelmann reported that the board assessment surveys have been completed and the results are currently being compiled. This item was placed on the agenda for the Board's July 26, 2010 meeting for further discussion.

### **RE-ELECTION OF BOARD MEMBERS**

The Board of Directors thanked Stephen McCurdy and Michaela Damin 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 McCurdy as Chairman of the Board of Directors for an additional 3-year term. Said term will run thru April 2013.

**VOTED:** That the Board of Directors re-elect Michaela Damin as a member of the Board of Directors for an additional 3-year term. Said term will run thru April 2013.

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

### **EXECUTIVE SESSION**

An executive session has been scheduled for Saturday, May 22, 2010 from 9:00-11:30 AM EST to discuss employee performance evaluations.

### **2010 CONFERENCE UPDATE**

Linda Stundis reported that she has received formal notification from the NIH that BSF has been awarded \$25,000 in support of BSF's 2010 Conference. She also reported that she continues to work on increasing sponsorship in support of BSF's 2010 Conference, and to date we have received a number of donations in support of the Conference.

Shelley Bowen reported that she, Jan Kugelmann and Lynda Sedefian conducted a site visit at the Renaissance to finalize details. Shelley also reported that she is currently working on obtaining financial assistance (travel and/or hotel accommodations) for those families who are in need of financial support.

To stimulate additional research in modifying gene factors of Barth syndrome, Shelley recommended that BSF invite Dr. Karen Orstavik, Consultant in Clinical Genetics, University of Oslo, Norway, to attend and participate in BSF's 2010 Conference. Dr. Orstavik has been very interested in the X chromosome inactivation pattern in Barth syndrome. After a thorough discussion, the Board agreed that there is great benefit to having Dr. Orstavik attend the 2010 Conference. The Board also agreed that BSF would fund Dr. Orstavik's travel/hotel accommodations if said invitation is accepted.

Shelley also reported on the planning of BTHS clinics that will be held at the 2010 Conference.

Matt Toth reported on the planning of the Scientific/Medical Session and Poster Session of the 2010 Conference.

Kate McCurdy reported that, in an effort to engage new advisors in the field of Neurology, that BSF extend an invitation to a prospective neurologist to attend the 2010 Conference. The Board agreed that this was an important step forward and agreed to fund travel and hotel accommodations of said candidate.

### **RESEARCH GRANT PROGRAM**

#### **Grant Extension Request**

Matt Toth reported that he has received a proposal from Todd Cade, PhD, a 2010 grant recipient, to increase the amount of time allotted for the grant awarded for the 2009 grant cycle, and thus increase the amount of the total grant awarded.

**VOTED:** That the Board of Directors accept Todd Cade's proposal to increase the amount of time allotted for the completion of the 2009 grant from one year to two years, with an increase in the total grant awarded from \$29,304 to \$39,600.

#### **Grant Program – Proposed Revisions**

Matt Toth submitted proposed revisions to BSF's Grant Application Guidelines and Requirements. The proposed revisions were accepted, subject to Marc Sernel's review and suggestions.

### **STRATEGIC PLANNING MEETING**

A four-day strategic planning meeting has been scheduled for November 2010, to discuss strategic planning and prioritization of programs. Steve will notify Randy Buddemeyer. Matt Toth has also been invited to attend.

### **OTHER**

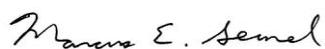
#### **Barth Syndrome Medical Database & Biorepository (BRR)**

Linda Stundis reported that, as a priority of BSF to get as much data entered into the database prior to the 2010 Conference, additional data entry persons have been brought on to populate this data. Linda reported that the complete relocation of the BRR is scheduled to take place in June 2010.

### **ADJOURNMENT**

The meeting was adjourned at 1:30 PM EST.

Respectfully submitted,



Marcus E. Sernel  
Corporate Secretary