



# MINUTES

**Barth Syndrome Foundation, Inc.  
Board of Directors Meeting  
January 25, 2013**

**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	Secretary, Board Member
Katherine R. McCurdy	Board Member
Susan Osnos	Board Member
Marcus E. Sernel	Vice-Chairman
John Wilkins	Board Member
Susan V. Wilkins	Board Member

**Additional Invitees**

Lynda Sedefian, Executive Assistant

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

**Agenda Items:**

1. Ratification of Minutes
2. Update – 2012 Year-to-Date Financials
3. Update – Year-End Fundraising Results
4. Update – Barth Syndrome Registry & Repository Transition
5. Update – Board Development
6. Discussion – Staff Performance & Evaluation
7. Discussion – Executive Director Performance & Evaluation
8. Discussion – Other Business

The meeting was called to order by the Chairman on Saturday, January 25, 2013 at 8:20 AM ET.

**1. Ratification of Minutes**

The Board approved the October 16, 2012 executive committee minutes, as amended on this date.

The Board approved the December 6, 2012 board minutes, as amended on this date.

The Board approved the January 15, 2013 executive committee minutes, as amended on this date.

**2. Update – 2012 Year-to-Date Financials**

Steve McCurdy provided an over of the 2012 year-end financials.

**Final Statement of Revenue and Expenditures All Funds – (01/01/2012 – 12/31/2012)**

Total Revenues of \$878,237; including unrestricted donations of \$768,457.

Total Expenses of \$956,309; for a Year-to-Date Deficit of \$78,072.

Total Current Assets	\$ 1,909,785
Total Current Liabilities	\$ 113,474
<b>Total Fund Balance</b>	<b>\$ 1,796,311</b>

\*Items needing follow-up.

\*\*Items placed on the board's April 23, 2013 annual meeting.

The board was pleased to report that BSF performed much better than anticipated with increased revenue and decreased expenses in 2012. The Chairman thanked Lindsay for her achievement in guiding BSF to perform better than budgeted.

**3. Update – Year-End Fundraising Results**

Lindsay Groff provided a report on 2012 year-end fundraising results. Lindsay reported that the “Henry” Card Campaign was quite successful, with over \$6,500 in donations. More encouraging was the number of families who participated in this fundraising campaign. Lindsay also reported that Randy Buddemeyer’s Barth Syndrome/JDRF Golf Tournament netted nearly \$40,000 for BSF. Lindsay reported the McCurdy year-end appeal was very successful with over \$332,000 raised.

**4. Update – Barth Syndrome Registry & Repository (BRR)**

Lindsay Groff reported that a meeting was held with Drs. Barry Byrne, Carolyn Spencer, Matt Toth, and Lindsay via teleconference on January 24, 2013 to discuss outstanding issues with the BRR. In summary, both Barry and Carolyn continue to be committed to BSF and offered support in the transition.

**5. Update - Board Development**

Susan Osnos reported that the Organizational Development Committee has identified several candidates as potential new board members. It was proposed that the Organization Development Committee move forward and finalize these discussions and invite the potential candidates to serve on BSF’s Board of Directors commencing April 2013 for a three-year term.

Note: In April 2013, Steve McCurdy, Chairman, and Michaela Damin, Board Member & President, Barth Trust (UK & Europe) will step off the board per BSF’s by-laws.\*\*

**6. Staff Performance & Evaluation**

*\*At this time Lynda Sedefian left the meeting.*

**7. Executive Director Performance & Evaluation**

*\*At this time Lindsay Groff left the meeting.*

**8. Discussion – Other**

At this time, a strategic planning session was held with all participants to prioritize goals as we move forward.

**ADJOURNMENT**

The meeting was adjourned at 9:45 AM ET. The next Board meeting is scheduled for Saturday, February 9, 2013. The next Executive Committee Meeting is scheduled for Tuesday, March 19, 2013.

Respectfully submitted,



Susan A. McCormack  
Secretary

*\*Items needing follow-up.*

*\*\*Items placed on the board’s April 23, 2013 annual meeting.*