



**Barth Syndrome Foundation, Inc.
Board of Directors Meeting
June 24, 2012**

Members in Attendance:

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

Members not in Attendance

David Axelrod, MD	Board Member
Michaela Damin	Board Member
Susan Osnos	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 Board/Executive Committee Minutes
2. Review – Year-To-Date Financial Report
3. Update – Barth Registry & Repository (BRR)
4. Discussion - Strategic Planning Meeting
5. Discussion – 2012 Conference

The meeting was called to order by the Chairman on Sunday, June 24, 2012 at 7:30 PM EDT.

1. Ratification of Minutes

Discussion was had regarding the April 29, 2012 Board minutes, and May 21, 2012 Executive Committee minutes. Suggested changes were discussed and the minutes will be submitted for formal ratification at the next Board meeting.

2. May Year-To-Date Financial Results

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

Final Statement of Revenue and Expenditures All Funds – (01/01/2012 – 05/31/2012)

Total Revenues of \$94,201; including unrestricted donations of \$86,112.

Total Expenses of \$564,120; for a year-to date Net Deficit of \$469,919.

Total Current Assets	\$ 1,690,702
Total Current Liabilities	\$ 286,237
Total Fund Balance	\$ 1,404,465

3. Barth Syndrome Registry & Repository (BRR) – Update

Lindsay Groff provided an update on BSF's acceptance into the two-year pilot project entitled the Global Rare Disease Registry (GRDR), sponsored by the National Institutes of Health. BSF will host a *Go To Meeting* with families to familiarize them with this new registry platform. Vanessa Rangel Miller, VP Genetic Services, PatientCrossroads, will also be in attendance to introduce this platform to our families.

Lindsay also reported on her initial efforts to transition the currently-existing BRR information into the GRDR program, including efforts to transition from and wind down the relationships with the University of Florida and Boston Children's Hospital regarding the currently-existing BRR.

4. Discussion – Strategic Planning Meeting

Lindsay Groff reported that Heller An Shapiro has agreed to provide consultation in the strategic planning process including the meeting that is scheduled for January 25-27, 2013. Heller An will also attend the conference which will provide her an opportunity to meet all board members in attendance and also meet many of our families to learn their hopes for the future of BSF.

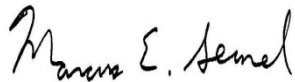
5. Discussion – 2012 Conference

A discussion ensued regarding the roles of the board members throughout the conference.

ADJOURNMENT

The meeting was adjourned due to local power failure! The next Board meeting is scheduled for Tuesday, September 11, 2012 @ 8:00 PM EST.

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