

Barth Syndrome Foundation, Inc. Board of Directors Meeting December 6, 2012

MINUTES

Members in Attendance:

Stephen B. McCurdy Lindsay Groff, Executive Director David Axelrod, MD Michaela Damin Stephen Kugelmann Susan Osnos Marcus E. Sernel John Wilkins Susan V. Wilkins

Members not in Attendance

Randy Buddemeyer Susan A. McCormack Katherine R. McCurdy

Additional Invitees

Matthew J. Toth, PhD, Science Director

Chairman Board Member, ex-officio Board Member **Board Member Board Member Board Member** Corporate Secretary, Board Member Board Member **Board Member**

Treasurer, Board Member **Board Member Board Member**

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

Agenda Items:

- 1. Ratification of Minutes
- 2. Decision Board Development
- 3. Update October Year-to-Date Financials
- 4. Update Year-end Forecast & Fundraising Initiatives
- 5. Update 2014 Site Selection
- 6. Strategic Planning Discussion
- 7. Update 2012 Grant Cycle
- 8. Discussion Other

The meeting was called to order by the Chairman on Thursday, December 6, 2012 at 8:00 PM EDT.

1. Ratification of Minutes

The Board approved the September 11, 2012 board minutes, as amended on this date.

2. Board Development

Susan Osnos reported that the Organizational Development Committee nominates Susan McCormack for the position of Secretary. Marc Sernel offered to continue to review the minutes.

VOTED: To grant elect Susan McCormack to the position of Secretary.

3. Financial Update

Stephen McCurdy provided an overview of the October year-to-date financial statements, which reflected the following:

Final Statement of Revenue and Expenditures All Funds – (01/01/2012 – 10/31/2012)

Total Revenues of \$300,421; including unrestricted donations of \$231,915. Total Expenses of \$858,872; for a Year-to-Date Deficit of \$558,451.

Total Current Assets	\$ 1,437,569
Total Current Liabilities	\$ 121,637
Total Fund Balance	\$ 1,315,932

4. Update – Year-end Forecast & Fundraising Initiatives

Stephen McCurdy and Lindsay Groff provided a report on the year-end financial forecast and fundraising initiatives. Lindsay reported that the Fundraising & Development Committee was established with John Wilkins and Stephen McCurdy as co-chairs. Additional members include: Leslie Buddemeyer, Ashley Cade, and Kevin Woodward. Lindsay reported that the committee's first task has been the "Henry" card campaign which has increased participation in fundraising by the families. In addition, BSF has been approved as a member charity by Community Health Charities of New York as a new source of potential donations.

5. <u>Update – Site Selection</u>

Lindsay Groff provided an update for the selection of the 2014 conference site. Lindsay is finalizing all of the open bids and will provide a summary along with a final recommendation to the Board via email. The Board will have 48 hours to review and evaluate the recommendation from the Site Selection Committee. If discussion is needed, an ad hoc Board meeting will be called before year-end.

6. <u>Strategic Planning</u>

Lindsay Groff and Marc Sernel provided an update on what to expect at the strategic planning meeting scheduled for January 2013.

7. Discussion – 2012 Grant Cycle

Mathew Toth provided an update on the grant applications received to date.

8. Discussion – Other

VOTED: \$500 for the National Health Council Policy & Development Fund in addition to paying the 2013 dues.

A discussion regarding potential new affiliates ensued. It was recommended that a small sub-committee be formed on the process of becoming an affiliate. Members include: Michaela Damin, Stephen McCurdy, Marc Sernel, John Wilkins and Sue Wilkins.

ADJOURNMENT

The meeting was adjourned at 10:10 PM ET. The next Board meeting is scheduled for January 25-27, 2013 in Greenwich, CT. The next Executive Committee Meeting is scheduled for January 15, 2013.

Respectfully submitted,

Manuna E. Semel

Marcus E. Sernel Corporate Secretary