



**Barth Syndrome Foundation, Inc.
Board of Directors Meeting
September 11, 2012**

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 |
| 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 |

Members not in Attendance

| | |
|--------------------|--------------|
| Susan A. McCormack | Board Member |
|--------------------|--------------|

Additional Invitees

Lynda Sedefian, Executive Assistant
Matthew J. Toth, PhD, Science Director

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

Agenda Items:

1. Ratification of Minutes
2. Update – Board Development
3. Update – August Year-to-Date Financials
4. Update – Year-end Forecast & Fundraising Initiatives
5. Update – Post-Conference Report & Site Selection
6. Strategic Planning Discussion
7. Update – Barth Registry & Repository
8. Discussion – SMAB Membership
9. Discussion – BTHS Clinical Trials

The meeting was called to order by the Chairman on Tuesday, September 11, 2012 at 8:00 PM EDT.

1. Ratification of Minutes

The Board approved the June 24, 2012 and April 29, 2012 board minutes, as amended on this date.
The Board approved the May 21, 2012 and July 17, 2012 Executive Committee minutes, amended on this date.

2. Board Development

Susan Osnos reported that the Organizational Development Committee is in the process of identifying and naming potential new board members. It was recommended that the Organizational Development Committee identify and name the proposed candidates and inform the board of the committee's recommended suggestions prior to the January 2013 meeting.*

*Items needing follow-up action.

**Items placed on the next Board meeting agenda scheduled for January 25-27, 2013.

3. **Financial Update**

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

Final Statement of Revenue and Expenditures All Funds – (01/01/2012 – 08/31/2012)

Total Revenues of \$224,163; including unrestricted donations of \$159,028.

Total Expenses of \$800,698; for a Year-to-Date Deficit of \$576,535.

| | |
|---------------------------|---------------------|
| Total Current Assets | \$ 1,551,431 |
| Total Current Liabilities | \$ 253,583 |
| Total Fund Balance | \$ 1,297,849 |

4. **Update – Year-end Forecast & Fundraising Initiatives**

Lindsay Groff provided a report on year-end forecast and fundraising initiatives. A discussion then ensued regarding board year-end fundraising activities. It was proposed that a Fundraising & Development Committee be established and led by a board member. It was agreed that the committee will be co-chaired by Steve McCurdy and John Wilkins including additional members Lindsay Groff, international affiliate representatives, and a key volunteer(s).*

Lindsay reported that BSF's 2011 Annual Report is complete and will be distributed within the next two weeks. It was suggested that this report be used by the board as a tool for year-end fundraising.

Lindsay reported that she has created a written donor acknowledgement protocol for streamlining the process and procedure for acknowledging donors.

Lindsay reported that the next issue of the Barth Syndrome Journal will be published in the fall of 2012. Discussions have already begun regarding the table of content/authors.

Fundraising will also be a part of the discussion at the board's January 2013 board/strategic planning meeting.**

5. **Update – Post-Conference Report & Site Selection**

Lindsay Groff provided an overview of the post-conference variance report (2012 compared to budget and 2010). The post-conference surveys showed high ratings overall. Lindsay reviewed the 2012 post-conference financial report which revealed a significant savings in cost. The board thanked Lindsay for making this conference a success.

Lindsay proposed that a Site Selection Committee be established to begin the task of searching for the 2014 conference site.* Lindsay will present the committee's site/venue recommendations to the board prior to the January 2013 meeting.**

Lindsay reported that the 2012 Scientific & Medical Sessions are now available on BSF's website.

6. **Strategic Update**

Lindsay Groff provided a report on year-end priorities with reference to the Barth Registry & Repository (BRR), the Barth Syndrome Clinic at Kennedy Krieger Institute (KKI), year-end fundraising initiatives, BSF publications/communications, and the strategic planning meeting scheduled for January 2013.

*Items needing follow-up action.

**Items placed on the next Board meeting agenda scheduled for January 25-27, 2013.

Lindsay reported that Heller An Shapiro has agreed to facilitate the January 2013 strategic planning meeting under Lindsay's direction and guidance. The meeting will be chaired by Marc Sernel. Lindsay reported that the Task Force is in the process of finalizing the surveys which will be sent to all of BSF's constituents (*i.e.*, affected individuals, family members, volunteers, physicians/scientists).

Lindsay reported that she attended the first-ever Barth syndrome interdisciplinary clinic at KKI on September 4, 2012, where she had the opportunity of meeting the families in attendance. Lindsay was also able to shadow the physicians involved in the clinic (Drs. Richard Kelley, Hilary Vernon (Metabolism), Rebecca McClellan (Genetic Counseling), Dr. Reid Thompson (Cardiology), Dr. Cliff Takemoto (Hematology), Brittany DeCroes (Physical Therapy), and Jackie Krick and Patricia Miller (Nutrition). Lindsay noted that the clinic was considered a success.

Lindsay also reported that the second Clinic at KKI will be held on December 4, 2012. BSF will hold a staff meeting in Baltimore, MD and will attend the social activities.

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

Matt Toth provided a detailed update on progress being made with the transition from BRR 1.0 to BRR 2.0. Several phone meetings have been held with various parties (PateintCrossroads, ORDR, GRDR, WIRB, and Drs. Byrne, Spencer and Roberts). Matt reported that he will be transferring oversight from the existing IRBs at Boston Children's Hospital and the University of Florida to WIRB. Matt will be appointed as the Principal Investigator.

A discussion then ensued regarding ongoing issues and proposed solutions. After discussion by the board, it was:

VOTED: To allow a budget of up to \$15,000 for transitional fees involved with moving the data and biological samples from BRR 1.0 to 2.0.

The board thanked Matt, Lindsay, Shelley and Kate for their time and efforts throughout the BRR transitional process.

8. Discussion – Scientific & Medical Advisory (SMAB) Membership

Kate McCurdy reported on the term limits of the SMAB membership. Three SMAB members' terms will expire in the fall of 2012. A discussion ensued regarding the slate of potential new candidates to invite to serve on the SMAB. After discussion by the board, it was:

VOTED: To grant Kate McCurdy permission to move forward and invite the agreed upon candidates to serve on BSF's SMAB for a four-year term. Kate will also speak with Drs. Kelley and Gonzalez regarding their terms. It was also agreed that Marc Sernel will speak with Dr. Byrne.

9. Discussion – BTHS Clinical Trials

A discussion ensued regarding BSF and its potential role with respect to future clinical trials/studies. After discussion by the board, it was recommended that a more thorough plan be created with the appropriate consideration of potential legal issues.*

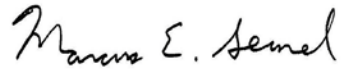
*Items needing follow-up action.

**Items placed on the next Board meeting agenda scheduled for January 25-27, 2013.

ADJOURNMENT

The meeting was adjourned at 10:50 PM EDT. The next Board call is scheduled for December 6, 2012, and the next in-person Board meeting is scheduled for January 25-27, 2013 in Greenwich, CT. The next Executive Committee Meeting is scheduled for Tuesday, October 16, 2012.

Respectfully submitted,

A handwritten signature in black ink that reads "Marcus E. Sernel". The signature is written in a cursive style with a large initial 'M'.

Marcus E. Sernel
Corporate Secretary

**Items needing follow-up action.*

***Items placed on the next Board meeting agenda scheduled for January 25-27, 2013.*