



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
September 16, 2014

Members in Attendance:

Marcus E. Sernel	Chairman
Lindsay Groff, Executive Director	Board Member, <i>ex-officio</i>
Stephen Kugelmann	Board Member
Susan A. McCormack	Secretary, Board Member
Susan Osnos	Board Member
John Wilkins	Board Member
Kevin Woodward	Board Member

Members Not In Attendance:

David Axelrod, MD	Board Member
Randy Buddemeyer	Treasurer, Board Member
Stephen B. McCurdy	Chairman <i>Emeritus</i>
Catharine Lynne Ritter	Board Member

Invited Guests:

Shelley Bowen, Director, Family Services & Awareness
Lynda Sedefian, Executive Assistant
Matthew J. Toth, PhD, BSF Science Director

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

Agenda Items:

1. Review – Minutes for Approval
2. Review – 2014 Year-to-Date Financials
3. Review – Executive Summary
4. Review – Conference Overview
5. Discussion – Fundraising
6. Update – Family Services & Awareness
7. Update – BRR 2.0
8. Update – Science & Medicine
9. Discussion – Board Development
10. Review – November Board Meeting
11. Discussion – Awareness Opportunity

The meeting, held via teleconference, was called to order by the Chairman on Tuesday, September 16, 2014 at 8:00 pm ET.

1. Review and acceptance of minutes

The board approved the March 11, 2014 executive committee minutes, as submitted on this date.

The board approved the June 23, 2014 board minutes, as submitted on this date.

2. Review - 2014 Year-to-Date Financials

Lindsay Groff, Executive Director provided an overview of the 2014 year-to-date budget comparison preliminary financial statements, which reflected the following:

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2014 – 05/31/2014

Total Revenues of \$316,731; including unrestricted donations of \$286,817.

Total Expenses of \$1,009,781; and a Deficiency of Revenue over Expenditures of \$693,050.

Total Current Assets	\$ 1,420,124
Total Current Liabilities	\$ 290,286
Total Fund Balance	\$ 1,129,838

3. Review - Executive Summary

Lindsay provided an executive summary which outlined recent activities among BSF’s programs, including: Awareness, Conference, Science & Medicine, Fundraising and Publications/Communications.

Affiliates

Lindsay reported that all three of our affiliates sponsored the 2014 Conference, making it a truly collaborative, international affair.

- South Africa
Our affiliate in South Africa has suspended operation and sent all remaining funds to BSF. Lynda has removed their information from the website and will exclude their information on materials moving forward.

Clinic at Kennedy Krieger Institute (KKI)

Lindsay reported that the next scheduled clinic date is November 4, 2014 and is completely full with 6 (possibly 7) patients. The 2015 dates are: March 3, June 2, September 1, and November 3. The June and September clinics were very successful as per Becky McClellan. Since starting in September 2012, the clinic has seen 23 different boys and young me with Barth syndrome.

Publications/Communications

Lindsay reported that the next issue of the Barth Syndrome Journal will be distributed early November.

4. Update - Conference Overview

2014 Conference

Lindsay reported that the 2014 International Scientific, Medical & Family Conference on Barth syndrome was a great success. Detailed reports provided by Shelley Bowen and Matt Toth revealed outstanding evaluations from the participants of both the Family sessions and the SciMed sessions.

2014 had the largest SciMed attendance with almost double the number of posters (25) on display compared to previous years. Five IRB-approved studies were performed in the days leading up to the SciMed and Family sessions. Matt provided a summary of the Conference to the trade paper, *Congenital Cardiology Today*, which is read by many pediatric cardiologists. Videos of many of the SciMed speakers, including the four poster winners, are available on BSF’s website, where it provides an extremely valuable resource for researchers. The R13 NIH grant for the Conference, which totaled \$26,000 in funds, was supported by NHLBI (primary), NCATS (ORDR is part of NCATS), and NICHD.

2016 Conference

Lindsay reported that she has completed a venue comparison for the 2016 Conference. The board reviewed the venue comparison and after a thorough discussion, it was proposed that the board authorize Lindsay to move forward with finalizing the negotiations with the Hilton Clearwater Hotel to secure this venue for the 2016 Conference.

VOTED: That the Board of Directors authorize Lindsay to move forward with finalizing the negotiations with the Hilton Clearwater Hotel to secure this venue for the 2016 Conference.

5. Discussion – Fundraising

Lindsay reported that fundraising activity has been quite active with the dedicated help from Sandra Stevens in this area (increased appeals, focus on donor retention, a new online payment processor; increased grassroots fundraising). Still to come in 2014 are plans for #GivingTuesday and the year-end appeal(s).

6. Update – Family Services & Awareness

Shelley Bowen reported that we have seen an increase in the number of diagnosed cases over the past few months.

Shelley reported that the 2014 Conference videos have been shared with other agencies such as the Non-Compaction Cardiomyopathy Support Group, Cincinnati Children’s Hospital, and the Pediatric Cardiomyopathy Foundation, which have been favorably received. Families have shared the link to these videos with the doctors who are caring for their children. The videos have also been an invaluable educational tool for new families who have recently joined our group. Dr. Maryanne Chrisant at Joe DiMaggio Children’s Hospital has not only viewed the videos, but has also distributed the link to her colleagues.

Shelley reported that she has approached Dr. Bob Gajarski, chair of the steering committee for the Pediatric Heart Transplant Study (PHTS) to request that BTHS be added as one of the diagnostic etiologies in the PHTS database. The PHTS is the largest repository of pre-transplant and transplant data for children (nearly 3,000) in the world. Dr. Gajarski and his committee have approved this request. When the database goes live, it will then be possible for contributors at participating centers around the world to enter the BTHS diagnosis for those who are already enrolled in the PHTS and for those who will be enrolled in the future.

7. Update – Barth Syndrome Registry & Repository

BRR 2.0

Shelley reported that the new Barth Syndrome Registry and Repository was opened on August 18. There are 32 participants to date. All participants have been asked to provide documentation to confirm the BTHS diagnosis. Weekly announcements to recruit enrollment in the registry have gone out on Facebook and on the listserv.

BRR 1.0

Matt reported that he spoke to Barry Byrne about the status of the biological samples of the BRR, and Barry will have his staff make up an inventory of what is available so it can be advertised for researchers to easily use.

8. Update – Science & Medicine

Research Grant Program

Two “Request for Applications” were advertised for the 2014 cycle: BSF-01, Depression in Barth Syndrome, and BSF-02, Impact of Testing Positive as a Barth Syndrome Mutation Carrier. These RFA additions to the BSF Research Grant Program were discussed at the SMAB meeting and are a direct consequence of developments at the 2014 Conference. Twenty-one letters of intent were received by the deadline of September 1st —11 Development and 10 Idea applications.

Bezafibrate Initiative

Matt reported that per the board's authorization, BSF contracted with Cincinnati Children's Hospital (Dr. Zaza Khuchua) and New York University (Drs. Mindong Ren and Colin Phoon) to pre-clinically test bezafibrate on the knockdown mouse model of BTHS.

Drug Discovery/Development

Matt proposed that it may be a good idea to think about a "Drug Development" capacity for BSF; to at least separate out those expenses that cannot be properly handled by BSF's Research Grant Program but that are vital to the goals of BSF. There are several examples of groups like BSF fostering drug development. Expenditures for individual drug development programs would have an endogenous fundraising appeal that could be exploited separately from the usual general appeals of BSF.*

9. Update – Board Development

Susan Osnos, Chair of the Board Development Committee, led a discussion about the need to identify and cultivate potential board candidates. It was proposed that the Board authorize Susan to move forward and invite the two named candidates at this meeting to serve on the board for a three-year term. The Board Development Committee will also interview additional potential candidates and will provide a detailed summary at the board's November meeting.*

It was also suggested that the Board Development Committee cultivate new members to serve on this committee.

10. Review – November Face-to-Face Board Meeting

Lindsay reported that she is working with Marc to prepare for the November board meeting which will be held November 14-16, 2014 in Wellesley, MA. The board thanks Susan McCormack for offering to host this meeting at her home.

11. Discussion Awareness Opportunity

Kevin Woodward reported that he has secured an opportunity for BTHS to be featured in the **BioProcess International Magazine**, a monthly, controlled-circulation magazine devoted to the development, scale-up, and manufacture of biotherapeutics and biodiagnostics. The article will be featured in the May 2015 issue.

Adjournment

The meeting was adjourned at 11:20 pm ET. The next Board meeting is scheduled for November 14-16, 2014 in Wellesley, MA.

Respectfully submitted,



Susan A. McCormack
Secretary