



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
June 23, 2014

Members in Attendance:

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

Members in Attendance via GoToMeeting:

David Axelrod, MD	Board Member
Stephen B. McCurdy	Chairman <i>Emeritus</i>
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. Update – Science & Medicine
6. Review – Board Development
7. Other

The meeting, held at the Hilton Clearwater Beach Hotel, Clearwater, FL, was called to order by the Chairman on Monday, June 23, 2014 at 8:30 am ET.

1. Review and acceptance of minutes

The board approved the January 14, 2014 board minutes and amended by-laws, as amended on this date.
The board approved the February 11, 2014 board minutes, as amended on this date.
The board approved the April 10, 2014 board minutes, as amended on this date.

2. Review - 2014 Year-to-Date Financials

Randy Buddemeyer, BSF Treasurer, and 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 \$208,007; including unrestricted donations of \$185,678.

Total Expenses of \$728,591; and a Total Fund Balance of \$1,302.461.

Total Current Assets	\$ 1,605,972
Total Current Liabilities	\$ 303,511
Total Fund Balance	\$ 1,302.461

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 have sponsored the 2014 Conference, making it a truly collaborative, international affair.

- Barth France
The first French clinic in Paris next September 15, 2014. Many different appointments are planned with many different doctors (Jean Donadieu, Pr Bonnet, et al.).
- South Africa
We received notice that the South African Affiliate will officially cease operation. The remaining funds in the bank account will be sent to BSF.
- Italy
We are still in discussions with our contacts in Italy about the possibility of creating an affiliate.

Awareness

Each family member will be given the blue awareness bracelets at the conference as well as several healthcare brochures to share with their child’s doctor(s).

Fundraising

Lindsay reported that fundraising activity this year has been mostly dedicated to the 2014 Conference. We sent a direct mail appeal to 692 people. We applied communication principals learned at the IUPUI fundraising course in Indianapolis. In addition, John Wilkins, Susan McCormack, and Kevin Woodward sent personalized direct mail appeals to their community and friends.

Publications/Communications

Lindsay reported that Lynda Sedefian and the Publications Team produced three remarkable publications in the last few months: the annual report, the newsletter, and the conference program.

4. Update - Conference Overview

Lindsay reported that the 2014 Conference has been thoughtfully orchestrated by all members of the staff and several key volunteers. As in prior years, planning takes up a majority of staff time in the months preceding the big event. The 2014 Conference Steering Committee members are: Shelley Bowen, BJ Develle, Lois Galbraith, Lindsay Groff, Lynda Sedefian, Matt Toth, John Wilkins, and Kevin Woodward. Each member tackled a specific area. Combining all of the pieces, the group built from 2012’s success to create a spectacular 2014 Conference. The Board expressed its appreciation to the staff and volunteers for their hard work on the 2014 Conference.

This conference offers more clinics and consultations than seen in 2012, including a multi-disciplinary study and research on: psychosocial functioning, sensory and feeding issues, impact on parents of a child with disabilities, and severe chronic neutropenia. There are consultations around: genetics, metabolism and nutrition, vital signs, and labs. In addition, there are several small group meetings to address the needs of the community.

All plans for SciMed sessions of the 2014 BSF Conference have been completed and implemented. Details of the agenda are contained in the Conference Program. We have scheduled 22 speakers and 26 poster presentations (a large increase compared to 2012) over the two days of the SciMed sessions. Four poster presenters will be chosen to give a short talk about their work on Friday morning of the SciMed sessions. The NIH R13 application for the Conference has received an outstanding score, but we are still waiting to hear about funding decisions from the Institutes.

5. Update – Science & Medicine

BRR 2.0

Lindsay and Matt Toth reported that, due to other priorities such as the Conference planning and the fact that Patient Crossroads has a queue with restrictive time slots for implementation, the BRR 2.0 will go live in July to allow enough time to properly prepare the BSF community. Shelley Bowen and Matt Toth will address the families at the conference to inform them of this news.

Clinic at Kennedy Krieger Institute (KKI)

Lindsay provided an update from Becky McClellan at KKI: “The remaining 2014 dates are: 9/2/14, and 11/4/14. Aside from some weather complications this past March I would say that attendance has been doing well.”

Open-Access Articles Relevant to Barth Syndrome

The Wang et al., 2014 *Nature Medicine* publication was highlighted on the BSF website in mid-May, and an Open Access-like option was purchased so that anyone visiting our website could read the publication online. There was a considerable amount of scientific press reporting about this work and these press articles are also hyperlinked on our website.

Matt also reported that a manuscript by the Bristol group (Colin Steward, Ann Bowron, and others) that deals with an almost normal cardiolipin amount in several BTHS individuals from the UK has been accepted by the *Journal of Inherited Metabolic Disease*. BST and BSF will co-fund (\$3,000 total) the Open Access availability of this publication. Matt believes this publication is important and that it should be advertised to the research community and to other groups using the Open Access portal.

2013 Research Grant Cycle

Matt reported that, in response to the invitation from BSF to demonstrate further evidence in support of his grant proposal, Dr. Michael Chin has submitted more data to supplement his 2013 BSF Research Grant application. The SMAB has been apprised of the supplementary data and five SMAB members (Drs. Strauss, Gonzalez, Kelley, Ren, and Schlame) have voted to approve an Idea grant for Dr. Chin as a belated 2013 BSF research grant. Matt recommends awarding Dr. Chin a BSF Idea Research Grant (\$50,000) along the lines outlined in Dr. Chin’s 2013 application and which is consistent with current SMAB recommendations.

VOTED: To fund the following IDEA Grant application in the amount of US \$50,000 from the 2013 grant application submissions.

Michael T. Chin, MD, PhD, Associate Professor
University of Washington, Seattle, WA
“*Tafazzin* enzyme replacement therapy in a mouse model of Barth syndrome”
Award—US \$50,000 over 1 or 2-year period

Update - Bezafibrate Initiative

Matt reported on the status of the bezafibrate initiative. The Research Service Agreements (\$50,000 each) with Cincinnati Children’s Medical Center (Dr. Zaza Khuchua) and with New York University School of Medicine (Drs. Colin Phoon and Mindong Ren) have been completed. Work is progressing with the object of showing positive evidence that bezafibrate treatment could be useful as a therapy for Barth syndrome individuals using the *tafazzin* knockdown mouse model of BTHS. The funds have been received and the animal colonies are being expanded. Results are expected in 9 months. The conclusions from this work will allow BSF to make a better decision about committing substantial resources for a bezafibrate clinical trial/study.

6. Update - Board Development

Susan Osnos, Chair of the Board Development Committee, provided the Board with an update regarding the Committee’s ongoing efforts. Susan encouraged the Board to continue the search for suitable Board members. It is the Board’s goal to add three to five new board members by April 2015.

Adjournment

The meeting was adjourned at 11:30 am ET. The next Board meeting is scheduled for Tuesday, September 16, 2014 @ 8:00 pm ET via teleconference.

Respectfully submitted,



Susan A. McCormack
Secretary