



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
January 14, 2014

Members in Attendance:

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

Members Not in Attendance:

Susan Osnos	Board Member
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Additional Invitees

Stephen B. McCurdy	Chairman <i>Emeritus</i>
Matthew J. Toth, PhD, BSF Science Director	
Shelley Bowen, Director, Family Services/Awareness	
Lynda Sedefian, Executive Assistant	
Kevin Woodward	

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

Agenda Items:

1. Review and acceptance of Minutes
2. Review – 2013 Year-End Financials
3. Review – 2013 Fundraising & Development
4. Update – 2014 Conference
5. Review – Board Terms & Succession Planning
6. Update - Barth Registry & Repository
7. Update – Science & Medicine
8. Update – Staff Evaluations/Reviews

The meeting, held via teleconference, was called to order by the Chairman on Tuesday, January 14, 2014 at 8:00 pm ET. Marc welcomed Kevin Woodward who was elected to serve on BSF's Board of Directors commencing April 2014 for a three-year term. Kevin joined the meeting as a guest of the Board and in an unofficial (non-voting) capacity for this meeting.

1. Review and acceptance of minutes

The board approved the September 19, 2013 board minutes, as amended on this date.

The board approved the October 30, 2013 executive committee minutes, as amended on this date.

The board approved the November 16-17, 2013 board minutes, as amended on this date.

Review – 2013 Year-End Financials

Randy Buddemeyer, BSF Treasurer, provided an overview of the 2013 year-end budget comparison preliminary financial statements, which reflected the following:

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2013 – 12/31/2013

Total Revenues of \$821,661; including unrestricted donations of \$794,766.

Total Expenses of \$794,947; and a Total Fund Balance of \$1,846,061.

Total Current Assets	\$ 1,906,799
Total Current Liabilities	\$ 60,738
Total Fund Balance	\$ 1,846,061

The board indicated its gratitude to Lindsay Groff, the rest of the staff, and all board members for their commitment to reach our revised 2013 year-end goal of ending the year with a net surplus. This goal was achieved as a result of both increased fundraising efforts and reduced expenses.

Update – 2013 Audit

Lindsay reported that BSF’s 2013 audit is underway. Lindsay and Ellen have been working with Gray, Gray & Gray, LLP and have provided all requested documentation.

Review – 2014 Budget

Lindsay provided an overview of the 2014 preliminary consolidated budget comparison report. The budget was approved as presented.

2. Review – Fundraising & Development

Lindsay provided a review of 2013 fundraising efforts. In 2014, we have set an aggressive goal to raise \$1million dollars, which we hope to achieve through applying a strategic plan to fundraising with specific metrics. This will be achieved, in part, by using a new donor management software platform and the hiring of a development director/project manager.

Lindsay reported that she has enrolled in the Principles & Techniques of Fundraising Course at Indiana University scheduled for March 24-27, 2014. In the meantime, Lindsay continues the search for a development director/project manager.

3. Update – 2014 Conference

Lindsay reported that Conference planning is in full swing. The Conference Steering Committee meets on a monthly basis to discuss all aspects of the conference: registration, sessions, clinics, childcare, social events, sponsorships, AV, and more. Registration will open in late January.

Science & Medicine

Matt Toth, BSF Science Director, reported on the planning of the Scientific/Medical Session of the 2014 Conference. The Conference Steering Committee is in the process of finalizing the speaker agenda.

Family Sessions

Shelley Bowen reported on the planning of BTHS clinics that will be held during the conference for the purpose of collecting clinical data to support research.

Varner Award for Pioneers in Science and Medicine

John Wilkins proposed that the 2014 Varner Award for Pioneers in Science and Medicine be awarded to Iris Gonzalez, PhD, Molecular Diagnostics Lab (retired), A.I. DuPont Hospital for Children, Wilmington, Delaware. Iris serves on BSF’s Scientific & Medical Advisory Board and has been committed to BSF since its inception. Iris is also a grant recipient of BSF’s Research Grant Program and is the author of numerous journal articles

relevant to the genetics of Barth syndrome. The board was in agreement that Iris is well-deserving of receiving this award.

VOTED: That the Board of Directors accept John’s proposal to award the 2014 Varner Award for Pioneers in Science and Medicine to Iris Gonzalez, PhD. This award will be presented to Iris at BSF’s 2014 Conference.

4. Board Terms & Succession Planning

Marc reviewed the term limits of the current Board of Directors, and discussed the fact that BSF By-Laws contained term limits that were more stringent than required by National Health Council and other applicable guidelines. After a discussion, and per a board consensus, it was proposed to amend BSF’s By-Laws to reflect that the board term limits will be increased from up to **two** to up to **three** consecutive 3-year terms, consistent with the National Health Council standards.

VOTED: That the Board of Directors amend the By-laws to reflect that the board term limits will be increased from up to **two** to up to **three** consecutive 3-year terms.

Further discussion was had about turnover on the Board and the need to identify and cultivate new potential board candidates.*

5. Update – Barth Registry and Repository

BRR 1.0

Matt reported that the modified Statement of Work has been submitted to the University of Florida for final review/approval for the maintenance of BTHS biological specimens it currently houses.

BRR 2.0

Matt reported that the GRDR continues to experience delays in going “live.” After a lengthy discussion, it was proposed that BSF implement a contract with Patient Crossroads to host and maintain BSF’s database. It is BSF’s intention to roll this database into the GRDR database once operational.

VOTED: That the Board of Directors approve the finalization of an agreement with Patient Crossroads to host and maintain BSF’s database.

6. Update – Science & Medicine

Bezafibrate Initiative

Matt reported that the FDA had raised certain questions about the bezafibrate clinical trial, including but not limited to the need to repackage certain information. Matt has had several conversations with key people involved with this initiative and is in the process of drafting a response to the FDA. Matt will keep the Board updated on future developments and strategy to eventually obtain FDA approval of bezafibrate clinical trial.

BTHS Pluripotent Stem Cell Lines

Matt reported that there is a delay in the availability of BTHS pluripotent stem cell lines housed at Coriell Institute for Medical Research. In order to increase research interest, BSF is offering to reimburse 90% of the cost of induced pluripotent stem cells obtained from Barth syndrome individuals that are available at Coriell (list price of US \$750). Matt will keep the board informed as to when these cell lines become available.*

Research Grant Program

Matt reported on the applications received for the 2013 research grant cycle. The Scientific and Medical Advisory Board (SMAB) will meet on January 29, 2014 to review the grant applications received for the 2013 cycle. The BSF Board of Directors will meet on February 11, 2014, and Matt will present a summary of the grants received and the SMAB's recommendations. BSF affiliate board members will be invited to participate in this meeting. The BSF Board will then vote on grant funding for the 2013 research grant cycle.

Update - Scientific and Medical Advisory Board (SMAB)

Kate McCurdy reported that, per the approval of the board, invitations were sent to those members whose terms expired at the end of 2013 to enlist in another 3-year term. Please join us in thanking Drs. Michael Schlame, Miriam Greenberg, Grant Hatch, Ronald Wanders, and Jeffery Towbin for accepting an additional 3-year term. We truly appreciate their dedication and contributions.

Kate also reported that Marc Tarnopolsky, Professor, Department of Pediatrics, Department of Medicine, McMaster University, has accepted the board's invitation to serve on the SMAB for a 3-year term commencing January 1, 2014. Please join us in welcoming Dr. Tarnopolsky.

Kate also provided an overview of succession planning for the Scientific and Medical Advisory Board.

7. Update – Staff Evaluations/ Reviews

Marc reported that the Organizational Development Committee has begun the process of employee performance evaluations. A joint meeting will be scheduled with the Board of Directors and Organizational Development Committee for final review of employee performance evaluations and compensation packages.

Adjournment

The meeting was adjourned at 10:45 pm ET. The next Board meeting is scheduled for Tuesday, February 11, 2014 at 7:00 pm ET.

Respectfully submitted,



Susan A. McCormack
Secretary