



Barth Syndrome Foundation, Inc.
Board of Directors Meeting
July 20, 2016

Members in Attendance:

Marcus E. Sernel	Chairman
Matthew Blumenthal	Board Member
Randy Buddemeyer	Treasurer, Board Member
Florence Mannes	Board Member
Susan A. McCormack	Secretary, Board Member
Susan Osnos	Board Member
John Wilkins	Board Member
Kevin Woodward	Board Member
Lindsay Groff, Executive Director	Board Member, <i>ex-officio</i>
Stephen B. McCurdy	Chairman <i>Emeritus</i>

Members Not in Attendance

David Axelrod, MD	Board Member
Catharine Lynne Ritter	Board Member

Invited Guests:

Lynda Sedefian, Executive Assistant
Michaela Damin, Chair, Barth Syndrome Trust
Helen Coleman, Secretary, Barth Syndrome Trust
Susan Hone, President, Barth Syndrome Foundation of Canada
Lynn Elwood, Board Director, Barth Syndrome Foundation of Canada
Paola Cazzaniga, President, Association Barth Italy
Professor Amelia Morrone, Translator, Association Barth Italy

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

Agenda Items:

1. Ratification of minutes
2. Review & Discussion – Finances
3. Update – Fundraising
4. Update – Affiliate activities
5. Update – Science/Medicine
6. Board development

The meeting, held face-to-face in Clearwater Beach, Florida, was called to order by the Chairman on Wednesday, July 20, 2016 at 6:00 pm ET. Marc welcomed members of BSF's affiliates who were invited to join the meeting to provide updates.

1. Ratification of Minutes

The board approved the April 14, 2016 Board minutes, as submitted on this date.

The board approved the May 10, 2016 Executive Committee minutes, as submitted on this date.

The board approved the June 23, 2016 Board minutes, as submitted on this date.

*Items placed on the November 1, 2016 board meeting.

2. **Review & Discussion – Finances**

Randy Buddemeyer provided an overview of the May 2016 comparison financial statements, which reflected the following:

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2016 – 05/31/2016

Total Revenues of \$287,370, including unrestricted donations of \$247,134; the balance of \$40,236 is temporarily restricted (Science/Medicine, Varner, and Will McCurdy Funds).

Total Expenses of \$696,302; and a Deficiency of Revenue over Expenditures of \$408,932.

Total Current Assets	\$3,612,548
Total Current Liabilities	\$ 371,454
Total Fund Balance	\$3,241,094

3. **Update – Fundraising**

Lindsay Groff provided a review of year-to-date fundraising activities, metrics, and the impact on revenue. Regarding fundraising for the conference, Lindsay reported that Dr. Miriam Greenberg helped BSF with soliciting donations from corporations. Felicia Ganote wrote the grants necessary to receive funding from the leads generated by Dr. Greenberg. The conference direct mail appeal also performed well, as did the sponsorship packages and onsite activities. Several families sent an appeal directly to their friends and family.

Future direct mail appeals will be sent in the fall/winter, including e-appeals. Lindsay noted that she recently presented a webinar on fundraising with Global Genes. In addition, a major donor event will be held in Boston on October 24, 2016, the first of its kind.

4. **Update – Affiliate activities**

Association Barth France

Florence Mannes provided an update on Association Barth France activities. Florence reported that (1) a booklet was designed and produced for young children to better understand Barth syndrome; and (2) two scientists from France who are performing research on Barth syndrome will be attending the French National Institute of Health and Medical Research (INSERM) meeting in France in late September 2016.

Barth Syndrome Trust

Michaela Damin provided an update on Barth Syndrome Trust activities. Michaela reported that (1) the Bristol team is working on ways to improve communication between BTHS clinics/clinicians; (2) the UK bezafibrate trial is scheduled to begin July/August of 2017; (3) Barth Syndrome Trust received a grant from Jeans for Genes; (4) Michaela also submitted a grant to Global Genes to sponsor an activity weekend in the UK; (5) Michaela has been invited to speak at the Global Genes meeting in London in 2017; (6) Barth Syndrome Trust received funding from the National Institute of Health Research (NIHR) for the production of bezafibrate pills.

Association Barth Italy

Paola Cazzaniga provided an update on Association Barth Italy activities. Paola reported that (1) September 2016 will mark Barth Italy's 1-year anniversary as an affiliate of BSF; (2) there are 10 families for whom the affiliate provides support; (3) Barth Italy held several successful grassroots fundraisers; (4) Barth Italy provided financial support for two physicians to attend BSF's 2016 Conference.

Barth Syndrome Foundation of Canada (BSFCa)

Susan Hone provided an update on Barth Syndrome Foundation of Canada activities. Susan reported that (1) 2016 has been difficult, due to health issues, with three of their board members; (2) BSFCa's recent mail campaign brought in \$7,000; (3) BSFCa's Annual General Meeting and Family Outreach will be held in September 2016; (4) BSFCa partially funded a 2015 grant to Robin Duncan, Assistant Professor, University of

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Waterloo, Waterloo, Canada (A new enzyme and pathway in cardiolipin synthesis); (5) BSFCa has been in contact with one new family for whom BSFCa is providing support.

Marc Sernel thanked the affiliate leads for their very informative updates. At this time the affiliate leads adjourned.

5. Update – Science/Medicine

Marc provided an overview of science and medicine initiatives. Marc reported that BSF's board met with members of Stealth Biotherapeutics in June at which time the board: 1) permitted Stealth to present at the Scientific and Medical Advisory Board (SMAB) meeting at the 2016 BSF Conference; 2) permitted Stealth to present a poster at the 2016 BSF Conference; and 3) permitted interviews to be conducted by third party, Adelphi Values, at the 2016 BSF Conference, on behalf of Stealth to gather patient-centered outcomes for a Barth syndrome clinical trial.

Marc reported that Dr. Michael Chin received an R01 grant from the National Institutes of Health to continue his research on Barth syndrome.

6. Board Development

Susan Osnos provided an update on proposed candidates for board membership. After a discussion, board members were assigned the task of engaging in a preliminary conversation with the proposed candidates to assess their interest in BSF and its mission.

7. Other

Steve McCurdy proposed that the Board of Directors consider forming an ad hoc advisory council of sorts for the purpose of advising on developing treatments for Barth syndrome.*

John Wilkins thanked BSF staff for organizing BSF'S 2016 Conference. John also thanked the many volunteers who helped in the planning of the conference as well as onsite volunteering.

Adjournment

The Board of Directors adjourned the meeting at 9:45 pm ET. The next Board meeting is scheduled for Tuesday, November 1, 2016 at 8:00 pm ET, via GoToMeeting. The next Executive Committee meeting is scheduled for Tuesday, September 27, 2016 at 8:00 pm ET, via teleconference.

Respectfully submitted,



Susan A. McCormack
Secretary

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