

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
September 16-18, 2011

The Board of Directors of the Barth Syndrome Foundation, Inc. (BSF) met on September 16-18, 2011, in Greenwich, Connecticut.

Board Members in Attendance

Stephen B. McCurdy	Chairman
Randy Buddemeyer	Treasurer, Board Member
Michaela Damin	Board Member
Stephen Kugelmann	Board Member
Susan A. McCormack	Board Member
Katherine R. McCurdy	Board Member
Susan S. Osnos	Board Member
John Wilkins	Board Member
Susan V. Wilkins	Board Member

Board Members Not in Attendance

Valerie “Shelley” Bowen	President, Board Member
Marcus E. Sernel	Corporate Secretary, Board Member

Additional Invitees

Lynda Sedefian, Executive Assistant
Matthew J. Toth, PhD, BSF Science Director
Debbie Duncan
Lindsay Groff

Agenda Items:

1. Financials
2. Ratification of Minutes
3. Executive Director Interviews
4. Board Development
5. Staff Compensation & Benefits
6. Science & Medicine Update
7. Barth Registry & Repository (BRR) Update
8. 2012 International Scientific, Medical & Family Conference
9. Family Services Update
10. Barth Syndrome Trust Update

The meeting was called to order by the Chairman on Friday, September 16, 2011 at 1:00 PM EST.

1. Financial Statements

Steve McCurdy provided an overview of the following reports: 1) 2010 vs. 2011 ALL gift/donation comparison; 2) 2010 vs. 2011 gift/donation comparison by solicitor.

Steve also provided an overview of the September 2011 year-to-date preliminary financial statements, which reflected the following:

Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2011 – 08/31/2011

Total Revenues of \$273,084; including unrestricted donations of \$194,693.

Total Expenses of \$592,274; for a Net Deficit of \$319,190.

Total Current Assets	\$ 1,839,266
Total Current Liabilities	\$ 247,375
Total Liabilities & Fund Balance	\$ 1,839,266

Steve also presented a comparison review of the 2011 preliminary consolidated budget vs. 2011 budget. The Board engaged in a conversation regarding (1) maximum deficit allowable; and (2) board fund-raising targets.

2. Ratification of Minutes

The Board approved the April 9-10, 2011 Board minutes, as submitted on this date.

The Board accepted the May 24, 2011 Executive Committee minutes, as amended on this date.

3. Executive Director Search

Steve McCurdy welcomed candidates Lindsay Groff and Debbie Duncan to separate portions of the Board meeting to conduct final interviews for the Executive Director position. The Board meeting reconvened as each candidate departed the meeting.

Following a lengthy discussion, and upon Motion duly made and Seconded, it was:

VOTED: That the Board of Directors hire Lindsay Groff as its new Executive Director, pending formal acceptance of the offer.

4. Board of Directors Development

The Board of Directors is very pleased to announce that David Axelrod, M.D., Pediatric Cardiologist, has accepted BSF's offer to serve on the Board of Directors. Following a discussion, and upon Motion duly made and Seconded, it was:

VOTED: That the Board of Directors elect David Axelrod, M.D. as a member of the Board of Directors for a 3-year term commencing on September 16, 2011. Said term will run thru April 2014.

5. Compensation & Benefits Discussion

Steve McCurdy reviewed a Professional Employer Organization (PEO) Analysis provided by Ellen Bruno. Following a discussion, and upon Motion duly made and Seconded, it was:

VOTED: That the Board of Directors adopt a policy wherein BSF will contribute 50% of the cost of individual health coverage plans for exempt employees. Employees may elect individual or family coverage.

Kate McCurdy reviewed annual employee performance evaluations and compensation packages with Lynda Sedefian, Executive Assistant and Matt Toth, Science Director.

6. Science & Medicine Update

Scientific & Medical Advisory Board (SMAB)

Kate McCurdy reported that Drs. Barry Byrne and Gerald Cox's 4-year term of serving on the SMAB is due to expire in November 2011. Following a discussion, and upon Motion duly made and Seconded, it was:

VOTED: That the Board of Directors invite Drs. Barry Byrne and Gerald Cox to serve an additional 4-year term on the SMAB. Said term will run through November 2015.

The Board of Directors will continue to cultivate new members to serve on BSF's SMAB to incorporate a diverse group of BTHS experts representing the various research and clinical specialties that are encompassed by the many facets of Barth syndrome, including, but not limited to, biochemistry, genetics, cardiology, neurology, hematology, and metabolic disorders.

Kennedy Krieger Institute (KKI)

Kate McCurdy reviewed the short-term and long-term goals that have been outlined for Dr. Hilary Vernon, Assistant Professor, Johns Hopkins University, in support of BSF and KKI's collaboration on Barth syndrome.

Research Grant Program

Matt Toth reported on progress that is being made in BTHS research as a direct result of BSF funding. To date, BSF has given 54 awards (US \$2 million) to 34 PIs yielding 58 publications. Additionally, BSF grant awardees continue to seek and receive funding from the National Institutes of Health (NIH) to continue on with their research focusing on Barth syndrome. This has been a goal of BSF since the birth of this program.

Scientific Collaboration

Matt and Kate reported on significant meetings held to advance progress:

- Genetic Diseases of Children—NY State Dept. Health—NYC (March 8-9, 2011)
- Teleconference to discuss potential future BTHS clinical trials (May 6, 2011)
- Teleconference to discuss BRR (May 6, 2011)
- Mitochondria Biology Symposium—NHLBI—NIH (May 16-17, 2011)
- KKI visit—Johns Hopkins—BSF & KKI collaboration on BTHS (May 20, 2011)
- NHLBI-PIO meeting—NHLBI—Bethesda (May 23-24, 2011)
- Meeting to discuss treatment guidelines, research, and 2012 Conference—NYU (June 19, 2011)
- Teleconference with members of Centers for Disease Control (CDC) to discuss newborn screening potential (August 19, 2011)

Tafazzin Knockdown Mouse Model of BTHS

Matt Toth reported that the *Tafazzin* Knockdown Mouse model, a vital tool for the advancement of BTHS research, has now been distributed to 7-8 laboratories internationally. Matt also reported that the knockdown mouse model will soon be available for distribution by Jackson Laboratory. An announcement will be made on BSF's website regarding this resource in the near future.

7. Barth Registry & Repository (BRR) Update*

Matt Toth reported on ongoing issues of concern regarding the BRR. A discussion ensued and the Board asked Matt to contact Amy Roberts to set up a face-to-face meeting to discuss these issues.

A discussion ensued regarding possible candidates to invite to serve on the BRR Advisory Board.

*Items needing follow-up.

8. 2012 Scientific, Medical & Family Conference*

Kate McCurdy led an in-depth conference planning discussion focusing on the Family part of the meeting – the clinic/consultations portion as well as the Family, Youth and Sibling Sessions. It was agreed that the goals of the Family side of BSF's 2012 Conference are: 1) education; 2) fellowship; and 3) participation (in research and BSF). It was agreed that the newly hired Executive Director would be the chairperson of the Conference Steering Committee and will oversee sub-committees.

Matt Toth reported that the R13 NIH grant application has been filed and that a decision is expected in February 2012. Matt also provided an overview of the draft agenda outlined for the Scientific & Medical Sessions.

9. Family Services – Update

John Wilkins reported on the phone log of calls received on BSF's phone line. John also reported that he has held a couple of teleconferences with the older BTHS guys trying to encourage their participation. John would now like to bring in some of the teenagers for their input and participation.

Lynda Sedefian reported on the September 2011 numbers contained in the Family Registry. A discussion ensued on how best to differentiate the groups/categories that BSF would like to track within this registry. Lynda will work with members of the Family Services team on this task.

10. International Update

Barth Syndrome Trust

Michaela Damir reported that the next NHS Barth Syndrome Clinic is scheduled for September 29-30, 2011, and that the clinic continues its ongoing success offering expert advice to families. A family gathering is scheduled for October 1st.

Michaela also said that she is working with the Bristol Service to create and distribute Quality of Life surveys and customized surveys on the NHS clinic to ensure that the Service continues to be a patient-led clinic with families having a strong voice.

Michaela announced that she has been in contact with two newly diagnosed families in her region (boys 5 months and 9 years of age).

Michaela also reported that she has welcomed Suzanne Green and Helen Coleman as trustees of the Barth Syndrome Trust's Board.

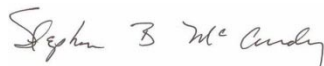
Barth France*

Michaela Damir reported that Madeleine Egueur from Belgium and Florence Mannes (Chair, Barth France) are in the process of creating a brochure for French speaking families using information taken from BSF and BST's website and healthcare professional brochure. Members of BSF's Publications Team will also be involved in this process.

ADJOURNMENT

The meeting was adjourned on Sunday, September 18, 2011 at 2:00 PM EST. The next Board meeting is scheduled for Tuesday, November 15, 2011, via teleconference.

Respectfully submitted,



Steve McCurdy
Acting Corporate Secretary

**Items needing follow-up.*