



**Barth Syndrome Foundation, Inc.
Board of Directors Meeting
February 25, 2012**

Members in Attendance:

Stephen B. McCurdy	Chairman
Lindsay Groff, Executive Director	Board Member, <i>ex-officio</i>
David Axelrod, MD	Board Member
Randy Buddemeyer	Treasurer, Board Member
Michaela Damin	Board Member
Stephen Kugelmann	Board Member
Katherine R. McCurdy	Board Member
Susan Osnos	Board Member
Marcus E. Sernel	Corporate Secretary, Board Member
John Wilkins	Board Member
Susan V. Wilkins	Board Member

Board Members Not in Attendance

Susan A. McCormack	Board Member
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Additional Invitees

Valerie (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. Decision – Vote to Accept Minutes
2. Decision – Barth Syndrome Registry & Repository (BRR)
3. Other

The meeting was called to order by the Chairman on Saturday, February 25, 2012 at 10:00 AM EST.

1. Ratification of Minutes

The Board approved the January 24, 2012 Board minutes as submitted on this date.

2. Barth Syndrome Registry & Repository (BRR)

Per the Board's direction, a sub-committee consisting of Lindsay Groff (chair), Kate McCurdy, Shelley Bowen, and Matt Toth were assigned the task of (1) evaluating the BRR in its current state; (2) identifying best practices of leading medical database platforms; and (3) determining options and a plan of action for improving the BRR. After a presentation regarding the current state of the BRR and review and discussion regarding the potential options going forward, it was:

VOTED: Accept the recommendations of this sub-committee and authorize them to move forward to apply to the National Institutes of Health (NIH), [Office of Rare Diseases Research RFI](#) to be considered for participation in the Global Rare Diseases Patient Registry and Data Repository (GRDR). The goal of the GRDR is to enable data analysis within and across many rare diseases and to facilitate clinical trials and other studies.

3. Other Items

Revised 2012 Consolidated Budget

The Board of Directors reviewed the revised 2012 consolidated budget prepared by Lindsay Groff. Following this discussion it was:

VOTED: Accept the revised 2012 consolidated budget as submitted on this date.

Decision – Todd Cade Letter of Request

Matt Toth presented an overview of Dr. Todd Cade’s letter of request to complete his 2009 BTBS research study. After discussion, it was:

VOTED: Approve Dr. Todd Cade’s letter of request to complete his 2009 BTBS research study for a net expense of \$879.71 to BSF.

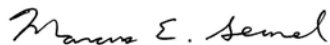
MODDERN Cures Act of 2011

Stephen McCurdy provided an overview of the National Health Council’s MODDERN Cures Act of 2011. After discussion, it was decided that several outstanding questions should be evaluated before deciding whether to support this legislation.

ADJOURNMENT

The meeting was adjourned at 12:30 PM EST. The next Board meeting is scheduled for Sunday, April 29, 2012 @ 3:00 PM EST via teleconference.

Respectfully submitted,



Marcus E. Sernel
Corporate Secretary

2012 Meeting Dates:

Board of Directors

Tuesday, January 24, 2012	Teleconference @ 8:00 PM EST
Saturday, February 4, 2012	Teleconference @ 12:00 PM EST
Sunday, April 29, 2012	Teleconference @ 3:00 PM EST
Sunday, June 24, 2012	Face-to-Face (Conference)
Tuesday, September 11, 2012	Teleconference @ 8:00 PM EST
November/December, 2012	Face-to-Face (TBD)

Executive Committee

Tuesday, March 13, 2012	Teleconference @ 8:30 PM EST
Tuesday, May 15, 2012	Teleconference @ 8:30 PM EST
Tuesday, July 17, 2012	Teleconference @ 8:30 PM EST
Tuesday, October 16, 2012	Teleconference @ 8:30 PM EST