Barth Syndrome Foundation, Inc.
Board of Directors Meeting
April 18, 2012

Members in Attendance:

Stephen B. McCurdy	Chairman
Lindsay Groff, Executive Director	Board Member, *ex-officio*
David Axelrod, MD	Board Member
Randy Buddemeyer	Treasurer, Board Member
Michaela Damin	Board Member
Stephen Kugelmann	Board Member
Susan A. McCormack	Board Member
Katherine R. McCurdy	Board Member
Susan Osnos	Board Member
John Wilkins	Board Member
Susan V. Wilkins	Board Member

Members Not In Attendance

Marcus E. Sernel	Corporate Secretary, Board Member

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.*

The meeting was called to order by the Chairman on Wednesday, April 18, 2012 at 8:00 PM EDT.

Barth Registry & Repository - Update
Lindsay Groff provided a detailed overview of her findings while researching different models and methods of patient databases and repositories. The Board engaged in a discussion regarding roles and responsibilities of the key players, as well as costs, associated with operating a medical database and repository.

After discussion, and upon **Motion** duly made and Seconded, it was:

> **VOTED:** To authorize Lindsay and her sub-committee to proceed with the plan to transfer the Barth Registry & Repository (BRR) in-house under a Western IRB, with Matthew Toth as the PI, and to engage PatientCrossroads as the registry platform.

The Board expressed their sincere gratitude to Lindsay and her sub-committee for providing clear and concise supporting documents for a unanimous decision on how to move forward.

ADJOURNMENT

The meeting was adjourned at 10:30 PM EDT. The next Board meeting is scheduled for Sunday, April 29, 2012 @ 3:00 PM EDT via teleconference.

Respectfully submitted,

Stephen B. McCurdy

Stephen B. McCurdy
Chairman

2012 Meeting Dates:

<u>Board of Directors</u>

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)**

<u>Executive Committee</u>

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