



Barth Syndrome Foundation, Inc.
Board of Directors Meeting
June 23, 2016

Members in Attendance:

Marcus E. Sernel	Chairman
David Axelrod, MD	Board Member
Randy Buddemeyer	Treasurer, 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

Matthew Blumenthal	Board Member
Florence Mannes	Board Member
Catharine Lynne Ritter	Board Member

Invited Guests:

Katherine McCurdy, *Emerita*, SMAB
Lynda Sedefian, Executive Assistant
Matthew J. Toth, PhD, Science Director
Anthony Aiudi, Program Lead, Stealth BioTherapeutics
Jim Carr, VP Clinical Development, Stealth BioTherapeutics
Doug Weaver, Medical Monitor, Stealth BioTherapeutics
David Schubert, VP Regulatory and Quality, Stealth BioTherapeutics
Aashita Parikh, Senior Specialist Regulatory Affairs, Stealth BioTherapeutics
Olga McGlashing, Program Manager, Stealth BioTherapeutics
Elizabeth Farley, Director, Patient Resources, Stealth BioTherapeutics
Gene Kelly, Senior Director, Commercial, Stealth BioTherapeutics
Chad Gwaltney, Gwaltney Consulting, Independent Consulting (working with Adelphi on the patient interviews)
Nate Cahill, Patient Interview Lead, Adelphi Values
Dr. Hilary Vernon

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

Agenda Items:

1. Stealth BioTherapeutics (Stealth)

The meeting, held via teleconference, was called to order by the Chairman on Thursday, June 23, 2016 at 8:00 pm ET. Marc provided an introduction to the Board about Stealth Biotherapeutics before guests from Stealth joined the call. Marc outlined three items that needed to be decided by BSF at this meeting: 1) permitting Stealth to present at the Scientific and Medical Advisory Board (SMAB) meeting at the July BSF Conference; 2) permitting Stealth to present a poster at the July BSF Conference; and 3) permitting interviews to be conducted by Adelphi Values at the July BSF conference, on behalf of Stealth to gather patient-centered outcomes for a Barth syndrome clinical trial.

Marc then welcomed members of the Stealth BioTherapeutics team and thanked them for taking the time to join this meeting.

Anthony Aiudi of Stealth, who is the project lead, introduced Jim Carr who provided some background information on recent clinical trials. Anthony Aiudi then spoke about the current MMPOWER clinical study looking at skeletal muscle myopathy in 36 individuals with mitochondrial disease. This study was coordinated with the United Mitochondrial Disease Foundation (UMDF). Nate Cahill from Adelphi Values then spoke about what they wanted to accomplish at the July BSF Conference. Anthony Aiudi concluded that Stealth is very excited for this collaboration.

At this time all members of the Stealth community left the meeting.

The BSF Board discussed the situation and voted the following:

Marc reported that Stealth requested a meeting with BSF's SMAB at the SMAB meeting on Saturday, July 23, 2016.

VOTED: To authorize Stealth to meet with the SMAB on Saturday, July 23, 2016.

Marc reported that Stealth requested an opportunity to present some of their results at the BSF Conference.

VOTED: To authorize Stealth to present a poster at the Poster Sessions of BSF's July Conference.

Marc reported that Stealth requested that a third party provider, Adelphi Values, be allowed at the Conference to interview BTHS individuals (and if too young, their caretakers), about patient-centered aspects of what it is like to live with Barth syndrome. This data collection is pursuant to the FDA directive to input the patient's voice in any drug development program.

VOTED: To authorize Adelphi Values to conduct interviews of affected individuals and caretakers at BSF's July Conference and to share the results with BSF.

Adjournment

The Board of Directors adjourned the meeting at 10:10 pm ET. The next Board meeting is scheduled for Wednesday, July 20, 2016 at 6:00-9:00 pm ET in Clearwater, FL. The next Executive Committee meeting is scheduled for Tuesday, September 27, 2016 at 8:00 pm ET.

Respectfully submitted,



Susan A. McCormack
Secretary
