



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting
August 23, 2019

Members in Attendance

Susan A. McCormack	Chair, Board Member
Megan Branagh	Board Member
Brandi Dague	Board Member
Nicole Derusha-Mackey	Board Member
Michelle Florez	Board Member
Florence Mannes	Board Member
Stephen B. McCurdy	Chairman <i>Emeritus</i>
Emily Milligan	Board Member, <i>ex-officio</i>
John Wilkins	Secretary, Board Member
Kevin Woodward	Treasurer, Board Member

Members Not in Attendance

David Axelrod, MD	Board Member
B.J. Develle	Board Member
Matthew Blumenthal	Board Member

Invited Guests

Jennifer Farmer, MS, CGC, Executive Director, Friedreich's Ataxia Research Alliance (FARA)
Kate McCurdy, SMAB, *Emerita*

Staff in Attendance

Shelley Bowen, Director, Family Services & Advocacy
Erik Lontok, PhD, Director of Research
Lynda Sedefian, Executive Assistant

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

Agenda Items:

1. Education Session – Patient Registries
2. Discussion – Patient Registries
3. Discussion & Vote – Conference Software
4. Update – Blackbaud
5. Update – Gene Therapy
6. Other

The meeting, held via GoToMeeting, was called to order by Ms. McCormack, on Friday, August 23, 2019, at 1:30 pm ET. Ms. Milligan introduced Dr. Erik Lontok, Director of Research, to the Board and welcomed him to BSF. Dr. Lontok joined BSF on August 19, 2019. Ms. Milligan also introduced Jennifer Farmer, MS, CGC, Executive Director of FARA, who was invited to this meeting as a follow-up from the Portfolio Review Meeting that was held on June 19, 2019, to provide an overview of FARA's experience on the evolution of 15 years of building FARA's two registries.

1. **Education Session – Patient Registries**

Ms. Farmer provided an overview of the history of FARA's two registries (physician entered and patient reported registries), the associated costs required to launch and sustain both registries, and the role each of the registries has played in advancing FARA's mission.

The Collaborative Clinical Research Network in Friedreich's Ataxia (CCRN in FA), funded by FARA, is an international network of clinical research centers that work together to advance treatments and clinical care for individuals with Friedreich's ataxia. Specifically, the CCRN in FA has an established infrastructure that supports the following:

- Facilitation in recruitment and planning of clinical trials
- Natural history and outcome measures in FA
- Partnership for new clinical studies to support the advancement of novel interventions

FARA is in the process of partnering with Critical Path Institute to evolve this physician-entered registry into a Clinical Data Interchange Standards Consortium (CDISC) format as required by FDA.

FARA's Global Patient Registry is a patient recruitment and communications tool for both academic and industry-sponsored clinical research studies and trials. This registry was created to serve the patient, physician, and research communities.

The Board thanked Ms. Farmer for being so giving of her time and experience. At this time, Ms. Farmer exited the meeting.

2. **Discussion – Patient Registries**

Ms. Milligan provided a summary of Ms. Farmer's presentation. The Board engaged in a discussion regarding:

- Goals of BSF's registry
- Cost-benefit tradeoffs of a clinically reported registry vs. a patient reported registry
- Critical data elements BSF needs to collect to achieve necessary outputs and high ROI
- Information gathering from end-users

3. **Discussion & Vote – Conference Software**

Ms. Milligan informed the Board that the Conference Steering Committee performed extensive due diligence in evaluating different platforms for conference registration and coordination. Cvent was the one platform in the market that presently fulfills BSF's business and functionality

requirements. Ms. Milligan negotiated down the contract price, presenting an SOW with \$9,210 in cost-savings to BSF. Benefits include:

- Provides attendees with a quick and easy check-in process
- Mobile friendly
- Banner/Sponsor features
- Ability to push notifications to attendees
- On-line store
- GDPR compliance
- Ability to configure languages
- Ability to upload bios/photos of presenters

VOTED: To allow a 3-year budget of \$12,674 (plus user overage fees as detailed in the SOW) and grant permission for Ms. Milligan to sign the contract with Cvent which will cover BSF's 2020 and 2022 conferences.

4. Update - Blackbaud

Ms. Milligan provided a brief overview of the status of Blackbaud/Luminate Online.

- Luminate Online has been implemented
- Breakthroughs4Barth campaign very successful. Ms. Milligan thanked the Board for their \$10,000 match!
- Fundraising Committee testing TeamRaiser platform which will enable constituents to more easily generate personal fundraising campaigns.

Ms. Milligan will keep the Board informed of progress bringing over historical data from Bloomerang.

5. Update - Gene Therapy

Ms. McCormack informed the Board that a working group has been established to focus on BSF's plan moving forward for gene therapy. This working group includes Emily Milligan, Susan McCormack, Erik Lontok, Steve McCurdy, Kate McCurdy, and Marc Sernel.

Adjournment

The meeting was adjourned at 3:50 pm ET. The next Board of Directors meeting is scheduled for Saturday, October 19, 2019 @ 11:00 am ET. The next Executive Committee meeting is scheduled for Thursday, September 12, 2019 @ 12:00 pm ET.

Respectfully submitted,



John Wilkins
Secretary