



# MINUTES

Barth Syndrome Foundation, Inc.  
Board of Directors Meeting  
April 9, 2018

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**Members in Attendance:**

David Axelrod, MD	Board Member
Megan Branagh	Board Member
Nicole Derusha-Mackey	Board Member
B.J. Develle	Board Member
Susan A. McCormack	Secretary, Board Member
Susan Osnos	Board Member
John Wilkins	Board Member
Kevin Woodward	Treasurer, Board Member
Stephen B. McCurdy	Chairman <i>Emeritus</i>

**Members Not in Attendance**

Marcus E. Sernel	Chairman
Matthew Blumenthal	Board Member
Florence Mannes	Board Member
Catharine Lynne Ritter	Board Member

**Invited Guests:**

Shelley Bowen, Director, Family Services & Awareness  
Kate McCurdy, *Emerita*, SMAB  
Lynda Sedefian, Executive Assistant  
Matt Toth, PhD, Science Director

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

**Agenda Items:**

1. Ratification of Minutes
2. Review & Discussion – 2018 Budget
3. Review & Discussion – Financials
4. Update & Discussion – 2018 Conference
5. Update & Discussion – Externally-led Patient-Focused Drug Development Meeting
6. Update & Discussion – Science/Medicine
7. Update & Discussion – New Executive Director
8. Update & Discussion – General Data Protection Regulation (GDPR)
9. Update – Board of Directors Roster

The meeting, held via GoToMeeting, was called to order by Susan McCormack, on Monday, April 9, 2018, at 12:00 pm ET.

**1. Ratification of Minutes**

The January 26, 2018 Board minutes, as submitted on this date.  
The February 13, 2018 Board minutes, as submitted on this date.  
The March 13, 2018 Executive Committee minutes, as submitted on this date.

**2. Review & Discussion – 2018 Budget**

Kevin Woodward reported that he has been working with Susan McCormack and Natalie Cohn, BSF Controller, on finalizing the 2018 consolidated budget. Kevin provided a high-level overview of the consolidated budget. The Board engaged in a discussion.

**VOTED:** To accept the 2018 consolidated budget, with amendments made on this date.

**3. Review & Discussion - Financials**

Kevin Woodward provided an overview of the 2018 financial statements through February 28, 2018, which reflected the following:

*Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2018 – 02/28/2018*

Total Revenues of \$94,426.

Total Expenses of \$77,000; and an Excess of Revenue over Expenditures of \$17,427.

Total Current Assets	\$3,928,831
Total Current Liabilities	\$ 198,736
<b>Total Fund Balance</b>	<b>\$3,730,096</b>

Susan McCormack reported that the 2017 audit is nearly complete and that Natalie Cohn, BSF Controller, has been working with Dorfman Abrams Music LLC to provide all requested documentation. Susan reported that the auditor will be invited to join members of the Board of Directors to present an overview of the 2017 Audited Financial Statements and Form 990 at a future meeting.\*

**4. Update & Discussion – 2018 Conference**

Shelley Bowen provided an update on conference planning for BSF’s 2018 conference. Planning is well under way. To date, registration is at an all-time high and the room block is nearly 90% filled. A block of rooms has been reserved at a near-by hotel, if needed.

**5. Update & Discussion – Externally-led Patient-Focused Drug Development Meeting (EL-PFDD)**

Susan McCormack informed the Board that the FDA has approved the EL-PFDD meeting on Barth syndrome, scheduled for Wednesday, July 18, 2018, during BSF’s conference. The Board engaged in a discussion regarding the planning of this meeting. Shelley Bowen thanked Kate McCurdy and Susan McCormack for taking the lead on this accomplishment.

**6. Update & Discussion – Science/Medicine**

Matt Toth provided an update on science and medicine initiatives, including the following:

***Research Grant Program***

Matt Toth reported that the five research grant awardees for the 2017 cycle (Drs. Amulic, van der Laan, Greenberg, Epanand, and Phoon) have accepted their awards and several have received their first checks.

***2018 Conference***

Matt Toth reported that 34 speaker abstracts for the SciMed sessions have been received. The SciMed Conference Steering Committee (Drs. Schlame, Strauss, Cade, Hatch, and Vernon) have chosen 21 abstracts. Those applicants not chosen to be speakers will be offered a poster presentation slot. As we did in 2016, the

\*Items needing follow-up

SMAB will choose four poster presenters at the Thursday afternoon poster session to speak at the Friday SciMed sessions.

#### ***Healx/Pu Collaboration***

Matt Toth reported that the BSF Board approved the expenditure for the next phase of the collaboration with Dr. Pu and Healx. Healx is producing a second written agreement with BSF for this next phase of the collaboration for BSF Board approval.\*

#### ***Stealth/Adelphi Values***

Matt Toth reported that after the Board's approval to fund the study on older BTHS individuals, Adelphi Values engaged Shelley Bowen and himself to develop the protocol based on their previous experiences at the 2016 BSF conference. Matt will submit an amendment to the existing WIRB approval of the BRR2.0 for this project.

Matt Toth reported that he and Shelley Bowen were panelists at a webinar given by Stealth to update the BSF community about TAZPOWER on March 21, 2018.

#### ***BRR2.0***

Matt Toth reported that Invitae, the company that hosts the BRR2.0 registry, is adding two sets of questions (QOL and heart transplant) to the existing database. The BSF Board approved of the expenditure to add these questions.

#### ***Scientific & Medical Advisory Board (SMAB)***

Matt Toth informed the Board that Drs. Michio Hirano and Brian Feingold have accepted the Board's invitation to serve on the SMAB for a four-year term.

Dr. Feingold is Medical Director of the Pediatric Heart Failure and Transplantation Programs at the Children's Hospital of Pittsburgh of UPMC. He received his medical degree from the University of Pittsburgh and completed a residency in pediatrics at the University of Massachusetts. He then returned to Pittsburgh for pediatric cardiology fellowship training and advanced training in pediatric heart failure and transplantation. Dr. Feingold holds a master's degree in clinical research from the University of Pittsburgh, where he is currently an Associate Professor of Pediatrics and Clinical and Translational Science. His research interests are in pediatric transplantation outcomes and pediatric heart failure, including various forms of cardiomyopathy such as non-compaction. He leads a team that cares for multiple boys with Barth syndrome.

Dr. Hirano is a Professor of Neurology at the Columbia University Medical Center (CUMC) in New York City. He has both clinical and research responsibilities and serves as Chief of the Division of Neuromuscular Disorders, Co-Director of the CUMC Center Muscular Dystrophy Association Clinic, Director of the H. Houston Merritt Center for Muscular Dystrophy and Related Diseases, and Medical Director of the Laboratory of Molecular Genetics/Laboratory of Metabolic and Mitochondrial Disease. His specialties include treating patients with mitochondrial diseases, myopathies and other neuromuscular disorders, and he also conducts research into a number of these disorders in order to advance what is known about them.

The Board expressed their sincere gratitude to Dr. Mark Tarnopolsky, whose term ended in early 2018, as a member of the SMAB.

#### **7. Update & Discussion – New Executive Director**

Susan McCormack informed the Board that Emily Milligan has accepted the Board's offer to serve as Executive Director, commencing May 21, 2018. The Board extended its appreciation for Emily's willingness to devote her time and resources to BSF.

#### **8. Update & Discussion - General Data Protection Regulation (GDPR)**

John Wilkins informed the Board that BSF has received notification from its affiliate, Barth Syndrome Trust, that the European Union's General Data Protection Regulation (GDPR) comes into force in the UK in May 2018.

This new regulation was designed to harmonize data privacy laws across Europe, to protect and empower all EU citizens' data privacy and to reshape the way organizations across the region approach data privacy. The GDPR not only applies to organizations located within the EU, but it will also apply to organizations located outside of the EU if they offer goods or services to, or monitor the behavior of, EU data subjects. John has taken the lead on this task and attended a webinar on March 15, 2018.

It was recommended that BSF seek advice from outside counsel on this issue.\*

**9. Board of Directors' Roster**

Susan McCormack informed the Board that Marc Sernel and Susan Osnos's terms on the Board will expire, commencing on this date. The Board expressed their deepest appreciation to Marc and Susan for their service over the years.

Susan McCormack reported that Susan Osnos has accepted BSF's Publications Team's invitation to serve on this committee.

Susan McCormack reported that, following the commencement of this meeting, she will serve as Chair of the Board, and that John Wilkins will serve as Secretary.

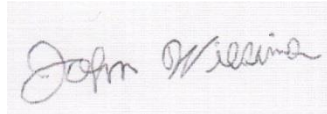
After the meeting concluded, it was noted that three Board members' terms had expired at the April Board meeting: (1) David Axelrod; (2) Matthew Blumenthal; and (3) Florence Mannes. The Board voted, via email on May 7<sup>th</sup> and May 14<sup>th</sup>, to retroactively reinstate all three Board members for another three-year term.

**VOTED:** To re-elect the above-named Board members for an additional three-year term, commencing on May 7, 2018 (Axelrod and Mannes) and May 14, 2018 (Blumenthal). Said terms will run through 2021.

**Adjournment**

The Board of Directors adjourned the meeting at 2:10 pm ET. The next Board meeting will be held face-to-face during BSF's 2018 conference (date TBD). The next Executive Committee meeting is scheduled for Tuesday, June 19, 2018 @ 12:00 pm ET.

Respectfully submitted,



John Wilkins  
Secretary