



# MINUTES

Barth Syndrome Foundation, Inc.  
Board of Directors Meeting  
January 26, 2018

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**Members in Attendance:**

Marcus E. Sernel	Chairman
David Axelrod, MD	Board Member
Matthew Blumenthal	Board Member
Megan Branagh	Board Member
Nicole Derusha-Mackey	Board Member
B.J. Develle	Board Member
Florence Mannes	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>
Lindsay Groff	Board Member, <i>ex-officio</i>

**Members Not in Attendance/Partial Attendance**

Catharine Lynne Ritter	Board Member
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**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 – Financials
3. Review & Discussion – Fundraising
4. Update & Discussion – 2018 Conference
5. Update & Discussion – Board Leadership Development
6. Update & Discussion – Science/Medicine
7. Update – Search Committee Update on Executive Director Position

The meeting, held via GoToMeeting, was called to order by the Chairman on Friday, January 26, 2018, at 12:00 pm ET. Marc welcomed Megan Branagh who was elected to serve on BSF's Board of Directors commencing January 1, 2018, for a three-year term.

**1. Ratification of Minutes**

The October 18, 2017 Board minutes, as submitted on this date.  
The December 19, 2017 Executive Committee minutes, as submitted on this date.

**2. Review & Discussion - Financials**

Lindsay Groff provided an overview of the year-end 2017 financial statements, which reflected the following:

*Preliminary Statement of Revenue and Expenditures All Funds – 01/01/2017 – 12/31/2017*

Total Revenues of \$1,084,995, including donations of \$865,235; the balance of \$219,760 is realized plus unrealized investment income.

Total Expenses of \$922,045; and an Excess of Revenue over Expenditures of \$162,950.

Total Current Assets	\$3,976,374
Total Current Liabilities	\$ 235,870
<b>Total Fund Balance</b>	<b>\$3,740,504</b>

Lindsay reported that overall donations were below budget in 2017. However, BSF ended fiscal year 2017 ahead of budget due to revenues benefitting from strong investment earnings in 2017.

Lindsay will provide the Board with a draft consolidated budget for 2018 prior to her departure on February 9, 2018.\*

**3. Review & Discussion - Fundraising**

Lindsay Groff provided a contribution analysis of 2016 vs. 2017, and the impact on revenue.

Lindsay reported that on February 9, 2018, the New York Islanders will host the second #BarthNight, and plans are being finalized. Devin will be featured that evening through a PSA, on the jumbotron, and in other ways. We plan to raise awareness and seek donations in support of BSF.

**4. Update – 2018 Conference**

Shelley Bowen provided an update on conference planning for BSF’s 2018 conference. Planning is well under way, and registration is open as is the ability to reserve a hotel room. Many have already done so; hotel bookings are ahead of schedule.

Kevin Woodward provided a preliminary conference budget for review.

Matt Toth reported that the R13 application to the National Institutes of Health (NIH) for funding of the SciMed sessions of the conference was filed on December 7, 2017. BSF’S website and current newsletter advertise a call for speaker abstracts and for poster abstracts at the July conference. Emails, listserv postings, and website advertisements for speaker abstracts, poster abstracts, and scholarships to the 2018 BSF conference have been made.

**5. Update & Discussion – Board Leadership Development**

Susan Osnos reviewed the term limits of the current Board of Directors. Marc Sernel and Susan Osnos’s terms will end in April 2018. At that time, Susan McCormack, currently serving as Vice-Chair and Secretary of the Board, will fill the role of Chairperson of the Board. The Board discussed the role of Secretary and who will fill that position commencing in April.

**VOTED:** The Board voted to elect John Wilkins as Secretary of the Board of Directors, commencing in April 2018.

\*Items needing follow-up

Marc Sernel recommended that the Board set aside a material amount of time to discuss board development at its next meeting.\*

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

Matt Toth provided an update on science and medicine initiatives, including an update on BSF's Research Grant Program, Healx, Stealth/Adelphi Values, and the BRR2.0.

##### ***Research Grant Program***

Matt Toth reported that thirteen applications for the 2017 BSF research grant program were submitted. Seven of the applicants are new to the grant program and five are in the young investigator class. The teleconference to discuss the applications was held on Wednesday, January 24, 2018. The BSF Board meeting to discuss the applications is scheduled for February 13, 2018.

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

Matt Toth reported that on November 28, 2017, Matt met with Dr. Pu and several members of Healx to discuss the next steps in the collaboration. Matt proposed that the Board of Directors decide on the Healx-Pu proposal (second phase) to pursue further testing of identified drugs in BTHS iPS cells. This item has been placed on the agenda for discussion at the next Board meeting.\*

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

Matt Toth reported that the TAZPOWER clinical trial has been under way since May 2017, and Dr. Vernon reports that everything is on track. On January 11, 2018, Shelley Bowen and Matt Toth met with Tracey Wall of Stealth. One issue that was discussed was the potential support of Stealth for the Adelphi proposal (Jonathan Stokes) to study the health of older BTHS individuals. This item has been placed on the agenda for discussion at the next Board meeting.\*

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

WIRB has approved of the changes to the BRR2.0 which includes: updating some of the registry details; inclusion of questions for registrants with heart transplants; and the inclusion of quality of life questions from the TAZPOWER clinical trial plus the PROMIS fatigue questionnaire. WIRB has also certified the BRR2.0 for another year.

Invitae, the company that hosts the BRR2.0 registry, provided Shelley Bowen and Matt Toth with a quote for adding two sets of questions (QOL and heart transplant) to the existing database. This addition is in conjunction with the work of Drs. Feingold and Taylor who are pursuing a survey of the experiences of heart transplantation in the BSF community. This item has been placed on the agenda for discussion at the next Board meeting.\*

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

Kate McCurdy informed the Board that the terms of six SMAB members expire in early 2018. One of these, Dr. Jeffrey Towbin, unfortunately is no longer able to give BSF the time that is required to serve on our SMAB.

**VOTED:** The Board voted to re-elect five SMAB members whose terms expire in early 2018.\*

The Board expressed their sincere appreciation for Dr. Jeffrey Towbin's immense contributions to BSF over the years. We are so grateful that he has been a SMAB member since its founding in 2001, and that he has helped get us where we are today.

After further discussion, the Board agreed to allow Kate McCurdy to invite two new prospective members to serve the SMAB, commencing in February 2018.\*

**VOTED:** The Board voted to allow Kate McCurdy to invite two new prospective members to serve on the SMAB, commencing in April 2018.

7. **Update – Search Committee Update on Executive Director Position**

Susan McCormack informed the Board that the search firm, Arthur Diamond, has proposed a number of highly-qualified candidates for the role of BSF Executive Director. The search committee is currently in the process of reviewing resumes and will conduct interviews soon.\*

**Adjournment**

The Board of Directors adjourned the meeting at 1:50 pm ET. The next Board meeting is scheduled for Tuesday, February 13, 2018 @ 12:00 pm ET. The next Executive Committee meeting is scheduled for Tuesday, March 13, 2018 @ 12:00 pm ET.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Susan A. McCormack". The signature is fluid and cursive, with the first name "Susan" and last name "McCormack" clearly distinguishable.

Susan A. McCormack  
Secretary