

MINUTES
Barth Syndrome Foundation, Inc.
Board of Directors Meeting
April 27, 2023

Members in Attendance:

Andrew Buddemeyer	Board Member
BJ Develle	Board Member
Emily Milligan, MPH	Board Member <i>ex officio</i> , Executive Director
Florence Mannes	Board Member
Jamie Baffa	Board Member, Secretary
Kate McCurdy	Board Member, Chair
Mark Greene	Board Member, Treasurer
Megan Branagh	Board Member
Michelle Florez	Board Member
Miriam Greenberg, PhD	Board Member
Nina Russell, MD	Board Member
Kevin Woodward	Board Member, Outgoing Board Treasurer

Invited Guests

Bill Belscher	Audit Committee, Chair
Brett Smith	Operations and Communications, BSF
Edward Baltazar	Dorfman Abrams Music
Emily Madalinski	Development and Stewardship, BSF
Erik Lontok, PhD	Director of Research, BSF
Melissa Huang, PhD	Clinical Research Coordinator, BSF
Natalie Cohn	Controller
Palmer Lummis	Audit Committee
Shelley Bowen	Director of Family Services, BSF

Members in Not Attendance:

Brandi Dague	Board Member
Maryanne Chrisant, MD	Board Member
Peter van Loo	Board Member

The meeting, held via Zoom, was called to order by Kate McCurdy on Thursday, April 27th at 12:03 p.m. ET.

1. Welcome
2. Vote: February and March Minutes / Offline Votes
 - a. Jamie Baffa asked for final input on February and March minutes

- b. **APPROVED:** February and March minutes as proposed
 - c. Kate McCurdy reminded board members to sign Annual Disclosures
 - d. Record of offline votes
 - i. Barth Syndrome Trust will not contribute to grants this year due to revenue shortfalls
 - ii. Barth Syndrome Canada will contribute \$25,000 (USD) to help fund the grant for Elucidating Cardiolipin Immune Dysfunction in Barth Syndrome (Kate Schroder, PhD at University of Queensland)
 - iii. Three individuals have been approved for additional three-year terms to the board and one individual was approved as board treasurer
 - 1. **APPROVED:** BJ Develle
 - 2. **APPROVED:** Jamie Baffa
 - 3. **APPROVED:** Nina Russell, MD
 - 4. **APPROVED:** Mark Greene as Treasurer
3. Service Appreciation, Transition of Treasurer
- a. Kate recognized Kevin Woodward, who is departing the board due to term limits, and shared appreciation for lending his talents and support over the past nine years; Kevin will remain a member of the BSF Finance and Investments Committee
 - b. Kate expressed further appreciation for Grant Hatch PhD, a devoted member of the SMAB since 2001, who is retiring
4. Vote: Jonathan Stokes' Board Candidacy
- a. Emily Milligan shared background on Jon Stokes including his position at AbbVie in which he focuses on including patient voices in drug development and his work to support the BSF community, especially his work with older affected individuals
 - b. **APPROVED:** Jonathan Stokes to join the board for a three-year term, effective immediately.
5. Treasurer's Update
- a. Mark Greene reviewed the audited 2022 balance sheet
 - i. Noted a decline in net assets from \$5.7 million to \$5.0 million due to unrealized losses, driven by a weak stock market (BSF has already recouped ~20% of 2022 losses in Q1 2023)
 - ii. Total revenue rose nearly 23% year over year
 - iii. Total expenses rose nearly 40%, driven by intentional strategic investments in research and development
6. Discussion and Vote: 2022 Financials and Audit Report; Ed Baltazar reviewed the independent auditors' report

- a. Noted that the auditors' statement was updated several years ago and that this year's is similar to the previous
 - b. \$27,183 in deferred revenue that has carried over, initially intended for the conference
 - i. Expectation for this to resolve in 2023
 - c. Natalie Cohn noted that the general fund was even, and that extra expenses were largely drawn from restricted funds
 - d. Added a line of "Contributions of nonfinancial assets" to capture in-kind legal fees
 - i. Kate clarified that this reflects work that Kirkland & Ellis has done pro-bono for BSF valued at \$77,451
 - e. Mark asked how BSF compares to other non-profits regarding its percentage of revenue applied to services (74%)
 - f. Ed noted that the BSF is well within the expected range and there is nothing found that would suggest BSF should rethink its approach
 - g. Pandemic note will likely fall off financial statements after 2022
 - h. Mark noted that there is a convertible promissory note in the investment portfolio, which is an investment in Research and Development distinct from our financial investment portfolio
 - i. Treating as a financial investment based on the contract structure, recognizing it may be handled differently in the future
 - i. Ed then reviewed the governance report
 - i. Audit went smoothly, no significant concerns
 - j. Kate highlighted three likely revisions
 - i. Located in Larchmont, NY, not New York, NY
 - ii. Note number seven should be updated to \$25,000
 - iii. Asked that we review the breakdown of how BSF allocates the in-kind legal donation across administrative and research
 - k. **APPROVED:** 2022 Audit Report, pending minor revisions noted above
7. Barth Syndrome Awareness Day
- a. Emily shared the reasoning behind the decision for advocating for April 5 as Barth Syndrome Awareness Day in the US (the 4.5 gene is causative)
 - b. Seven members of the US House of Representatives are sponsoring / co-sponsoring a bipartisan formal resolution to make April 5 Barth Syndrome Awareness Day in perpetuity
 - i. Rep. Paul Tonko (NY-20)
 - ii. Rep. Ralph Norman (SC-5)
 - iii. Rep. Gus Bilirakis (FL-12)
 - iv. Rep. Neal Dunn (FL-2)

- v. Rep. Nancy Mace (SC-1)
 - vi. Rep. Doris Matsui (CA-7)
 - vii. Rep. William R. Timmons IV (SC-4)
- c. Acknowledged with gratitude the families who have and continue to advocate with their legislators
 - d. Reviewed communication data and metrics, noting the importance of giving everyone multiple ways to engage and support the effort to establish Barth Syndrome Awareness Day
 - e. Kate encouraged the board to take supporting actions when opportunities arise
 - f. Emily acknowledged the importance of Lynda Sedefian in meeting with Rep. Paul Tonko
8. Vote: Communication Consultant
- a. The board had set aside funds to hire an external consultant to evaluate and make recommendations for how BSF can improve its communication
 - b. Jamie had connected Emily with a colleague, Jessica Lee, with expertise in organizational communication and experience working with non-profits
 - c. Jessica shared a proposal for \$12,000, that will require minor revisions before being final
 - d. Kate reinforced the value of doing this work especially in a globally dispersed, virtual community
 - e. **APPROVED:** Scope of work from Jessica Lee up to \$15,000 following revisions
 - f. Jamie abstained for voting due to potential conflict of interest since he and Jessica work for the same firm
 - g. Andrew Buddemeyer also abstained
9. Vote: Modification to BSF's Mission Statement
- a. Recommended to make the word "treatment" plural in BSF's mission statement to acknowledge BSF's pursuit of multiple lines of treatment, since Barth syndrome (BTHS) is a multi-system disorder with many clinical components which may not be improved by a single treatment, since the details of some aspects of BTHS can change over time so various treatments may be more or less relevant in any given period, and since no one treatment will likely work for every affected individual
 - b. **APPROVED:** Mission statement to now read "Saving lives through education, advances in treatments, and finding a cure for Barth syndrome."
10. Update and Vote: Strategic Initiatives Program (SIP) / Barth Syndrome Foundation Gem Prize
- a. Erik Lontok, PhD reviewed the BSF Seed Grant Program and how it connects to the Strategic Initiatives Program
 - b. Proposed Gem Prize, designed to garner wider engagement of existing researchers and novel data scientists while driving use of BSF's Tafazzin Human Variants Database

- c. Gem Prize would be overseen seen by the Gem Prize Organizing and Review Committee (ORC) composed of Iris Gonzalez, PhD, BSF staff, subject matter expert(s), and an affected individual or family / caregiver, and would be tasked with two objectives:
 - i. Define the Gem Prize recipient's selection criteria and programmatic metrics of success, as well as announcement, dissemination, and management of the Gem Prize's intake, review, and selection of submissions
 - ii. Identification of a technically proficient individual who both cares and understands the value of the *database* as a research resource
- d. Source of funding would be the Varner Fund and the prize would be \$10,000
- e. Discussion about if we should target early career investigators
- f. Kate proposed that we amend the name to be the Iris Gonzalez, PhD Prize as a way of honoring her contributions
- g. **APPROVED:** Launch of the Iris L. Gonzalez, PhD Prize

11. Vote: Virtuous to Replace Blackbaud CRM

- a. Emily reviewed BSF's history with Blackbaud and the proposal to adopt a new CRM to align with BSF's needs
- b. Recommendation is to migrate to Virtuous with an expected implementation cost of up to \$26,000
- c. **APPROVED:** BSF to transition from Blackbaud to Virtuous for our CRM
- d. Florence Mannes abstained

12. Adjournment

- a. Kate summarized the meeting by saying that there is a lot of positive evolution and progress that is occurring at BSF right now. Today we voted on a number of changes to various aspects of our organization, our infrastructure and our programs that will put us in even better stead for the future. Kate said there is a lot going on and she appreciates each of the members of the staff and the board for their leadership, participation and good work. She adjourned the meeting at 1:59 p.m. ET

Respectfully submitted,

Jamie Baffa – Secretary