

MINUTES
Barth Syndrome Foundation, Inc.
Board of Directors Meeting
February 7, 2022

Members in Attendance:

Kate McCurdy	Board Member, Chair
Emily Milligan	Board Member <i>ex officio</i> , Executive Director
Kevin Woodward	Board Member, Treasurer
Jamie Baffa	Board Member, Secretary
Florence Mannes	Board Member
Michelle Florez	Board Member
Nina Russell, MD	Board Member
Brandi Dague	Board Member
B.J. Develle	Board Member
Megan Branagh	Board Member
Andrew Buddemeyer	Board Member
Maryanne Chrisant, MD	Board Member

Invited Guests

Shelley Bowen	Director of Family Services, BSF
Brett Smith	Operations and Communications, BSF
Erik Lontok	Director of Research, BSF
Melissa Huang	Clinical Research Coordinator, BSF

Members in Not Attendance:

Peter van Loo	Board Member
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AGENDA

1. *Discussion on 2022 BSF Conference*

The meeting, held via Zoom, was called to order by Kate McCurdy on Monday, February 7, 2022 at 4:01 p.m. ET.

1. Discussion on 2022 BSF Conference
 - a. Kate opened by reiterating the importance that while we want to present a united front regarding any decisions, we want everyone to share their honest opinions and be willing to disagree during board meetings

- b. Emily thanked everyone for making the time for this ad hoc meeting and shared that the Conference committee has been very focused on whether or not we should still have a conference
- c. BSF polled families, researchers, and clinicians, and found a near even split between those who were committed to attending the conference in person, those who definitely would not attend the conference in person, and those who were undecided at this time.
- d. Given the uncertainty and divergent opinions of our community, we need to consider what is the most responsible path forward
- e. The goal for this meeting is to make a decision regarding the conference
- f. Emily reviewed the four options on the table
 - i. Maintain seven-day, in-person event at an approximate cost of \$300k
 - ii. Switch to a three-day, in-person event in Clearwater focused on our families and the community at an approximate cost of \$200k
 - iii. Cancel the conference in Clearwater and offer three to five smaller gatherings at a to be determined cost
 - iv. Cancel all in-person events for 2022 and shift to virtual
- g. Kate and Emily then opened up the floor and discussion followed
- h. Following the discussion, the board voted on four proposals
 - i. **APPROVED:** Decision to postpone the existing Hilton Clearwater contract to 2023
 - ii. **APPROVED:** Commitment from BSF and its affiliates to plan smaller gatherings for families to meet and spend time together
 - iii. **APPROVED:** Decision to host a global, virtual science and medicine meeting
 - iv. **APPROVED:** Commitment to explore creative ways to continue doing clinical research even during these times; possible options to consider include folding research into smaller gatherings and/or hosting an event near Johns Hopkins and the Barth Clinic
- i. Kevin and Kate shared final thoughts on how important it is to gather, and that we will lean on our medical experts to identify the right health and safety protocols
- j. Emily forecasted that staff will move its focus to communicating this decision with the BSF community

2. Adjournment

- a. Kate McCurdy adjourned the meeting at 5:07 p.m. ET

Respectfully submitted,

Jamie Baffa – Secretary