



MINUTES

Barth Syndrome Foundation, Inc.
Board of Directors Meeting 23 June
2020

Members in Attendance:

Kate McCurdy	Chair, Board Member
Jamie Baffa	Board Member
Megan Branagh	Board Member
Brandi Dague	Board Member
Nicole Derusha-Mackey	Secretary, Board Member
B.J. Develle	Board Member
Michelle Florez	Board Member
Florence Mannes	Board Member
Emily Milligan	Board Member, <i>ex-officio</i>
Nina Russell	Board Member
Peter van Loo	Board Member
Kevin Woodward	Treasurer, Board Member

Members Not in Attendance

David Axelrod, MD	Board Member
Matthew Blumenthal	Board Member

Invited Guests

Shelley Bowen	Director of Family Services, BSF
Erik Lontok	Director of Research, BSF
Brett Smith	Operations & Communications Lead, BSF

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

Agenda Items:

1. **Welcome**
2. **Vote on approval of April 2020 Board minutes**
3. **Vote on Board members**
4. **Vote on committee members**
5. **Discussion: Treasurer Update**
6. **Vote: Nathan Alder Grant Proposal**
7. **Presentation: Family Services Program Focus**
8. **Discussion: Family Services**
9. **Announcement/Other business**

The meeting, held via Goto Meeting, was called to order by Kate McCurdy, on Tuesday June 23, 2020 at 12 noon ET.

1. Welcome

- a. KM welcomed everyone and called the meeting to order at 12:05pm

2. Vote on approval of April 2020 Board minutes

- a. Minutes approved as modified.
- b. UCLA Seizures and Stroke Study in BTHS (officially called the Barth Syndrome Natural History and Clinical Management Study), already approved by email vote, was ratified again for the minutes here.

3. Vote on Board members

- a. KM proposed James Baffa for consideration as a member of the Board and to serve on the Board Development Committee.
 - i. Discussion followed
 - ii. Nomination approved
- b. BD proposed Nina Russell for consideration a member of the Board and to serve as Board's SciMed Advisor detailing her health and drug development background will fit very well
 - i. Discussion followed
 - ii. Nomination approved.

4. Vote on committee members

- a. Fundraising committee: KM proposed Stacy Woodward, Megan Branagh, Jasmine Champagne and Steve McCurdy.
 - i. Discussion
 - ii. Motion carried.
- b. KM proposed Steve McCurdy to shift from Board development committee to Policies and Agreements committee
 - i. Motion carried

5. Nina and Jamie joined the meeting at 12:25 pm

6. Discussion: Treasurer Update

- a. State of finances are good, especially given Covid pandemic
- b. Reviewed report
 - i. BSF has been purposeful in tightening expenses.
 - ii. Revenue was flat (280,000 in donations compared to 300,000 last year.)
 - iii. YTD BSF is 53% toward budgeted revenue goal (and only five months into the year). Good position.
 - iv. YTD 476,000 expenses compared to 712,000 2019 due to fewer research grants approved.
 - v. Investment account current assets \$4.5 mil. YTD performance in positive, nice recovery after first quarter.
- c. Emily reviewed general contributions and grants report
 - i. Thanked Florence for Barth France's generous grants to BSF this year
 - ii. Government grants; PPP monies currently liability but when forgiven will be reduced
 - iii. Emily opened for discussion-
 - 1. KM pointed out that budget was revised after COVID pandemic and applauded quick action to reduce COVID impact on budget (conference, travel, etc)
 - iv. Report accepted

7. Vote: Nathan Alder Grant Proposal

- a. KM prefaced with budgetary considerations for grant proposals and that this proposal was tabled in Feb 2020
- b. EL reviewed grant proposal

- i. Will expand our understanding of cardiolipin and possibly lead to new treatments
 - 1. Discussion followed
 - ii. Grant awarded as \$50,000 one year grant.
- 8. **Presentation: Family Services Program Focus**
 - a. Shelley presented family services program
 - i. Mission, vision, values driven
 - ii. Reviewed objectives, outcomes, some program details as specific examples
- 9. **Discussion: Family Services**
 - a. KM proposed adding "inclusion" to values.
 - i. Discussion
 - ii. Motion carried.
 - iii. KM proposed developing an inclusion committee. Motion carried.
 - iv. Empowerment of Family Services Committee- KM proposed to develop governing policy for the committee as well as finalize roster.
 - 1. Discussion
 - 2. Motion carried.
- 10. **Announcement/Other business**
 - a. KM- Couple of elements for Board handbook
 - b. KM- Reminder to committees to take minutes and share with Board
 - c. KM- Reminder about SciMed Symposium.
 - d. Strategic planning workshop Oct 3-4
 - e. Reminder next Board meeting

Adjournment

With no further business, the meeting was adjourned at 2:06pm ET. The next Board of Directors' meeting is scheduled for Friday, August 21, 2020 @ 12:00 noon ET.