

## MINUTES

Barth Syndrome Foundation, Inc.

Board of Directors Meeting

October 29, 2021

### 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
Michelle Florez	Board Member
Brandi Dague	Board Member
B.J. Develle	Board Member
Megan Branagh	Board Member
Andrew Buddemeyer	Board Member
Peter van Loo	Board Member

### Invited Guests

Shelley Bowen	Director of Family Services, BSF
Brett Smith	Operations and Communications, BSF
Erik Lontok	Director of Research, BSF
Michael Bowen	Policies & Agreements Committee

### Members in Not Attendance:

Florence Mannes	Board Member
Nina Russell, MD	Board Member
Maryanne Chrisant, MD	Board Member

### AGENDA

1. *2022 Conference*

The meeting, held via Zoom, was called to order by Kate McCurdy on Friday, October 29 at 12:02 p.m. ET.

1. Kate thanked everyone for their willingness to make time for the conversation and reiterated key expectations of board members, especially the need to put the interests of the community at large above our own and those close to us
2. Forecasted that it will be a difficult discussion and decision to make
3. Emily set expectations around the distinction between our own personal risk tolerance versus the risk tolerance we should bear as an organization

4. Emily reinforced that the goal of today's conversation is to decide whether we would host an in-person conference, a hybrid conference, or a completely virtual conference in 2022
5. Discussion followed
6. Proposal to have an in-person conference with options for families to participate virtually
7. **APPROVED:** Pursue the planning of an in-person conference, with health and safety protocols informed by our medical advisors, while incorporating remote components
8. Board acknowledge that the world could change in a way that would force us to change, but that we will move forward with planning without hesitation until that time comes
9. Kate McCurdy adjourned the meeting at 1:00 p.m. ET with no other business pending

Respectfully submitted,

Jamie Baffa – Secretary