

MINUTES
Barth Syndrome Foundation, Inc.
Board of Directors Meeting
July 31, 2024

Members in Attendance:

Kate McCurdy	Board Member, Chair
Jamie Baffa	Board Member, Vice-Chair
Megan Branagh	Board Member
Brandi Dague	Board Member, Secretary
BJ Develle	Board Member
Miriam Greenberg, PhD	Board Member
Mark Greene	Board Member, Treasurer
Emily Milligan	Board Member <i>ex officio</i> , Executive Director
Nina Russell, MD	Board Member
Jonathan Stokes	Board Member

Members in Not Attendance:

Michelle Florez	Board Member
Peter van Loo	Board Member

The meeting, held in person at the Barth Syndrome International Biennial Conference in Bonita Springs, Florida, was called to order by Kate McCurdy on Wednesday, July 31st at 5:33 p.m. ET.

- 1) Welcome
 - a. The meeting began with a welcome from Kate McCurdy, the Chairperson.
- 2) Introductions
 - a. Kate McCurdy requested that each person provide a personal introduction given this group of Board members had never met in person altogether.
- 3) FDA Advisory Committee (AdComm) Preparation
 - a. For avoidance of doubt surrounding BSF's motivations and to best position the review of elamipretide objectively, the Board voted to not pursue and refuse to accept corporate grants or other financial support from the Sponsor through the date of the FDA's final decision about elamipretide's approval for Barth syndrome.
 - b. Furthermore, the Board voted to support up to \$150,000 for media, public relations and strategic communications support focused on advocacy, training of open public hearing speakers, and travel for AdComm participants to Washington D.C.
 - c. The Board charged Emily Milligan with identifying a new media/PR firm to maintain the intent of a degree separation from the Sponsor's contracted parties.

4) The meeting was adjourned by Kate McCurdy at 9:35 p.m. ET.

Respectfully submitted,

Brandi Dague

Secretary