

**MINUTES**  
**Barth Syndrome Foundation, Inc.**  
**Board of Directors Meeting**  
**August 27, 2025**

**Members in Attendance:**

Kate McCurdy	Board Member, Chair
Jamie Baffa	Board Member, Vice-Chair
Megan Branagh	Board Member
Brandi Dague	Board Member, Secretary
Michelle Florez	Board Member
Steven Graessle	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
Peter van Loo	Board Member
Stacey Woodward	Board Member

**Invited Guests**

Melissa Huang, PhD	Staff, BSF
Laura Duvelius	Staff, BSF
Lindsay Marjoram, PhD	Staff, BSF
Emily Madalinski	Staff, BSF
Steve McCurdy	Volunteer

**Members in Not Attendance:**

BJ Develle	Board Member
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**Affiliate Leaders Attending as Observers**

Michaela Damin	Barth Syndrome UK
Florence Mannes	Association Barth Syndrome de France
Susan Hone	Barth Syndrome Canada
Christiane Hope	Barth Syndrome Canada

The meeting, held via Zoom, was called to order by Kate McCurdy on Wednesday, August 27<sup>th</sup> at 12:00 p.m. ET.

## **1. Welcome**

Kate McCurdy welcomed all attendees and said that drafting of minutes from the July BOD meeting would be delayed, given the recent workload.

## **2. Financials**

Mark Greene presented a draft of the current financials:

1. While there has been higher spending on Advocacy in 2025, much of the year-to-year changes in that and other expense lines reflect differences in staff time spent on various activities thereby resulting in a reallocation of salaries and related expenses across such lines rather than large changes in actual spending
2. BSF's investment portfolio value is reflecting the benefit of the recent strength in the stock market; increased ~\$179k in unrealized gains through July
3. In terms of the forecast, we had anticipated an earlier PDUFA date re: elamipretide and are no longer expecting to be able to apply for or hopefully receive a large educational grant from Stealth that we budgeted for 2025.
4. Donations are projected above budget in the new forecast due to major donors and Happy Heart fall fundraiser.
5. The budget did not anticipate Emily Madalinski's maternity leave; the current forecast includes monies for consultant help to cover her responsibilities
6. The above aside, elamipretide's ultimate approval or denial may likely have a material impact on both donations and expenditures to occur in the balance of this year.

## **3. BSF Fundraising Strategy**

Kate welcomed Laura Duvelius to discuss her ideas about BSF's fundraising strategy, her first presentation to the BoD after 90 days on the job. Key points included:

1. Fundraising is merely the transactional part of a culture of philanthropy
2. Critical for donors to know that BSF is more than just elamipretide; we are broad and do a lot, and offer many programs and exceptional services as we pursue our mission
3. Fund development is all about relationships (creating, growing, nurturing, matching)
4. Donor communications must show human side to inspire people
5. We need tools to better do donor research/prospecting
6. Discussed plans re: Giving Tuesday, corporate fundraising for conference, foundations, Happy Heart Week (HHW) event and our Annual Appeal
7. BSF current strengths:
  - a. Long relationships with donors
  - b. Strong volunteer fundraisers
  - c. Engaged community
  - d. History of financial growth and stability
8. BSF current challenges:
  - a. Too few volunteer fundraisers carry the bulk of our fundraising
  - b. Limited donor communications / limited direct BSF relationship with

donors

- c. Data weaknesses (easy to let data hygiene slide, attrition from people unsubscribing, etc.)
  - d. Need to improve giving among non-legacy families
  - e. Uncertainty of FDA outcome re: elamipretide
  - f. Limited prospects in other funding sources
9. 2026 Development goals laid out very broadly

#### **4. Advocacy Update**

Kate offered an overview of the highlights of what has transpired recently re: elamipretide

1. 8/18/25 Stealth announced it had resubmitted its NDA to the FDA (usually 30-day turnaround)
2. 8/20/25 Stealth received letter from FDA that the NDA submission was complete and had been accepted for review with a PDUFA date of 2/26/26 because it had to be a class II submission HOWEVER they committed that they were planning to respond by 9/26/25
3. Stealth told us that they could survive financially that long, if that timetable held
4. BSF's Wednesday evening advocacy Zoom calls have focused on galvanizing people, organizing plans and standardizing messages
5. We have expanded alliances with UMDF, MitoAction and some others, including some families with other mitochondrial diseases
6. A few families went to DC in August to advocate, as they didn't want to regret that they had not done everything they could, given the urgency they feel
7. Patient outreach resulted in an important meeting with FDA leadership to convey patient experience data. BSF also leveraged the opportunity to offer continued thought partnership to advance regulatory policies adequate and appropriate for ultra-rare diseases communities, including Barth syndrome.
8. Emily has been invited to speak at the Rare Disease Caucus Briefing hosted by EveryLife Foundation on 9/11/25
9. There is lots going on!

#### **5. Executive Session**

Meeting was adjourned at 2:02pm ET.

Emily Milligan Executive  
Director