

MINUTES
Barth Syndrome Foundation, Inc.
Board of Directors Meeting
July 21, 2026

Members in Attendance:

Jamie Baffa	Board Member, Vice-Chair
Megan Branagh	Board Member, Secretary
Michelle Florez	Board Member
Steven Graessle	Board Member
Miriam Greenberg, PhD	Board Member (joined late due to travel complications)
Mark Greene	Board Member, Treasurer (attended by audio)
Emily Milligan	Board Member ex officio, Chief Executive Officer
Jonathan Stokes	Board Member
Stacey Woodward	Board Member

Members Not in Attendance:

Kate McCurdy	Board Member, Chair
Nina Russell, MD	Board Member
Peter van Loo	Board Member

The meeting was called to order by Vice-Chair Jamie Baffa, presiding in the absence of Chair Kate McCurdy, on Tuesday, July 21, 2026, at 5:30 PM ET, in person at the Barth Syndrome International Biennial Conference at the Hyatt Regency Coconut Point in Bonita Springs, Florida. A quorum was confirmed.

I. WELCOME

Vice-Chair Jamie Baffa welcomed board members to the in-person meeting, held during the conference.

II. BOARD AND COMMITTEE MEMBERSHIP

Vice-Chair Jamie Baffa facilitated a discussion on expanding board and committee membership. He noted that BSF's work is growing more complex, with increasing engagement with industry and regulatory agencies, and that several long-serving leaders will be stepping back in the coming years. The board reviewed a grid of current members' terms and experience, which highlighted the board's strengths and some current gaps, as well as the risk that half of the board will reach term limits within three years. The following action item emerged:

- **Board candidates:** Each board member was asked to bring at least one candidate for the board of directors to the next board meeting, preferably someone less connected to BSF today, such as a newer family or a personal connection. Candidates need not be ready to join immediately but should be individuals who would strengthen the board and give serious consideration to joining. The ask also extends to identifying candidates for committee membership.

III. BOARD OPERATIONS AND EFFICIENCIES

The board discussed ways to keep members informed between meetings and to make board meetings more efficient.

- **Board communication “radar”:** A simple tracking document organized into four categories (upcoming decisions, good news, risks and bad news, and upcoming events) will replace lengthy narrative email updates between board meetings. Staff will pilot it, with Jessica Lee’s involvement, before the next meeting cycle.
- **Standing agenda item:** A recurring 10–15 minute “project radar” segment will be added to board agendas for ongoing items, such as the arrhythmia project and Phase IV trial sites, so that they do not require re-briefing each time a vote is needed.
- **Pre-vote briefings:** Short (approximately 30-minute) briefing calls or videos will be piloted ahead of complex votes to give board members context before the full meeting, and assessed after one or two uses.
- **In-person meeting cadence:** The board will decide on and formalize a standard annual in-person meeting in non-conference years, including the possibility of a fall meeting timed with the volunteer workshop. This will require administrative support.

Emily Milligan agreed to evaluate feasibility in context of no administrative support on the team and pilot some suggestions.

- **Administrative support:** While not in the current operational budget, the board encouraged Emily to explore resource options to be able to support the staff with operational and administrative needs. Emily expressed she was already exploring bringing on a consultant in a PTE/FTE capacity and hopes to bring forward a vote for consideration at the next board meeting.

IV. STRATEGIC UPDATES

Emily Milligan provided updates on key strategic efforts. The following action items emerged:

- **Advocacy strategy:** BSF will seek input from rare disease coalition leads to define its advocacy strategy and staffing approach, including a project-based regulatory affairs consultant versus a full-time employee, before committing resources. This was identified as time-sensitive and prioritized for late summer and fall 2026.
- **Rare Disease Week:** In light of the need for a revised Advocacy strategy reflective of post-approval priorities, BSF will decide in Fall 2026 whether to participate in Rare Disease Week 2027 and communicate that decision and its rationale to the community early.
- **Gene therapy resourcing:** BSF will decide whether to evaluate technical landscape and capital strategy for a possible gene therapy investment. Advancing a single program could require up to many millions of dollars, which raises concerns about the extent of BSF’s ability to invest sufficient capital to de-risk a program and advance it to an inflection point of interest to

investors. BSF will also determine the resourcing required beyond current staff bandwidth and bring a recommendation on next steps to the board.

- **Succession planning:** After more than two decades of service to BSF, Shelley Bowen has indicated her desire to retire from staff in the next two to three years. Directors lamented Shelley's intended departure, recognizing her as an irreplaceable contributor whose wisdom, compassion, and tireless devotion to Barth families have shaped BSF's family services, and whose retirement will leave an immense void. At the same time, the board warmly acknowledged her natural and well-earned desire to retire, and was heartened that Shelley intends to remain a committed member of the BSF family as a volunteer. The board will begin a succession planning discussion for her role.
- **Conference family photos:** BSF commits to improved communication to ensure families understand they can choose to include in the Conference slideshow pictures of children who are absent or deceased.
- **European coordinator role:** BSF will continue exploring with affiliates the idea of an international coordinator, ideally someone who is multilingual, to support our international partners and augment their administrative capacity. Hiring the right human resource solution requires endorsement by affiliates and perceived value add to their operations as this resource is intended to benefit all, particularly with their coordination around Phase 4 trial at in-country sites and local government procedures for access to FORZINITY™.

V. ADJOURNMENT

There being no further business, the meeting was adjourned at approximately 8:45 PM ET.

Respectfully submitted,

Emily Milligan
Chief Executive Officer