

MINUTES
Barth Syndrome Foundation, Inc.
Board of Directors Meeting
June 22, 2026

Members in Attendance:

Jamie Baffa	Board Member, Vice-Chair (joined in progress)
Megan Branagh	Board Member, Secretary
Michelle Florez	Board Member (joined in progress)
Steven Graessle	Board Member
Mark Greene	Board Member, Treasurer
Kate McCurdy	Board Member, Chair
Emily Milligan	Board Member ex officio, Chief Executive Officer
Nina Russell, MD	Board Member
Jonathan Stokes	Board Member (joined in progress)
Peter van Loo	Board Member
Stacey Woodward	Board Member

Former Members in Attendance:

BJ Develle, LCSW	Former Board Member
Susan McCormack	Former Board Chair
Steve McCurdy	Former Board Chair

Invited Guests:

Michael Bowen	Conference Steering Committee
Shelley Bowen	Staff, BSF
Natalie Cohn	Controller, BSF
Melissa Huang	Staff, BSF
Jessica Lee	Staff, BSF
Emily Madalinski	Staff, BSF
Lindsay Marjoram	Staff, BSF

Affiliate Leaders Attending as Observers:

Elena Bilcu	Barth Italia
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Ralph Easterbrook

Barth Syndrome UK

Florence Mannes

Association Barth Syndrome de France

The meeting was called to order by Chair Kate McCurdy on Monday, June 22, 2026, at 12:00 PM ET via videoconference. A quorum was confirmed.

I. WELCOME AND ANNOUNCEMENTS

Chair Kate McCurdy welcomed all participants and recognized Megan Branagh on attending her first meeting officially serving as Corporate Secretary.

Kate also noted the June 16, 2026, announcement that Stealth BioTherapeutics has changed its name to Mighty Therapeutics. She read from the company's press release, in which CEO Reenie McCarthy credited the patients and families who inspire the company's work, and observed that the new name reflects a clear nod to the Barth syndrome community. References to Mighty Therapeutics in these minutes refer to the company formerly known as Stealth BioTherapeutics.

II. APPROVAL OF MEETING MINUTES

Secretary Megan Branagh invited comments on the draft minutes of the April 29, 2026, meeting. Treasurer Mark Greene proposed an amendment to the section addressing approval of the audit, to clarify that the prior year's results were not restated because the accrued interest adjustment was deemed immaterial on a cumulative basis. The amended sentence reads:

"Two audit adjustments were noted: (1) recognition of \$29,270 in accrued interest income and receivable, identified for the first time this year (compared to \$24,000 in the prior year). No restatement of the prior year was necessary, as the amount was deemed immaterial on a cumulative results basis;" with the remainder of the sentence unchanged.

MOTION to approve the April 29, 2026, minutes as amended was approved unanimously.

III. TREASURER'S REPORT AND FUNDRAISING UPDATE

Mid-Year Forecast

Emily Milligan reviewed significant items that may influence year-end performance relative to the 2026 budget. While a full re-forecast was not undertaken, most anticipated variances are favorable.

- **Mighty Therapeutics grant:** BSF secured a commitment of \$400,000 in unrestricted support, \$100,000 above the \$300,000 budgeted, to support advocacy and related efforts in the United States and Europe. Funds have not yet been received and will be paid in two tranches. Emily thanked Jessica Lee for her role in securing the gift.
- **Affiliate contributions:** Affiliates collectively contributed \$165,000 toward the research grants approved in March, compared to \$150,000 budgeted.
- **Advocacy consultant:** BSF does not currently anticipate needing the budgeted consultant for U.S. reimbursement and access advocacy, given progress working with Anovo and consultants recently retained by Mighty Therapeutics. A recent request to help recruit families to provide

testimony at state-level drug review (P&T) committee meetings is being handled without consultant support but is an area in which BSF may require skilled personnel in the future depending on volume.

- **Program savings:** Savings are expected in SciMed preclinical and research lines, as some strategic plan initiatives advanced without the need for BSF funding, and no on-site visits were required for 2028 conference site selection.
- **Unfavorable items:** The tribute donation forecast was reduced by \$60,000 based on current trends. Unbudgeted expenses include the proposed BarthINSIGHTS records extraction consultant (see Section V) and bioinformatics support from NYU for review of the arrhythmia registry.
- **Arrhythmia project:** \$108,000 in milestone payments remains outstanding and may or may not be achieved in 2026 (see Section IV).

Controller Natalie Cohn presented year-to-date results through May 31, 2026:

- **Revenue:** Approximately \$1.3 million year to date, about \$760k ahead of the prior year, of which less than \$250k relates to the conference, which did not occur in 2025. Emily explained that the year-to-date strength is primarily a timing issue, as two significant gifts arrived earlier than in the prior year, while tribute giving specifically has been running below historical levels.
- **Expenses:** On budget with no unusual items. Year-over-year increases reflect higher costs, modest salary increases, and conference deposits. The unspent balance of the \$481k research budget relates primarily to the arrhythmia milestones and new projects for which funding has not been required to achieve. An unbudgeted journal publication fee of approximately \$3,000 was noted.
- **Balance sheet:** Remains strong. Cash decreased modestly due to the timing of receipts and disbursements. Receivables include the Mighty Therapeutics grant and a Pharmanovia conference sponsorship.
- **Investments:** Despite unfavorable market conditions in May, the portfolio recorded a year-to-date gain of approximately \$135k.
- **Net assets:** \$2.2 million unrestricted and \$3.8 million restricted. The “passage of time” restriction, recorded by the auditors at year-end, reflects 2025 pledges collected in 2026. CZI and Science and Medicine Fund balances decrease as funds are spent and grants are awarded.
- **Off-balance-sheet obligations:** Include the outstanding arrhythmia milestones and remaining balances on conference contracts. All Hyatt deposits due to date have been paid.

Fundraising Update

Jessica Lee presented the following highlights:

- **Overall:** As of May 31, BSF had achieved 52% of its fundraising budget. Grants are in strong shape with the Mighty Therapeutics commitment, and donations from affiliates have already exceeded placeholder budget.
- **Donations:** At 31% of budget, reflecting the lowered tributes forecast; a number of major gifts typically arrive in the second half of the year. An accounting adjustment is pending to correct the categorization of certain donations in the CRM, part of ongoing data clean-up work by Jessica Lee and Emily Madalinski.

- **Conference:** At 74% of budget. Event fundraising and merchandise sales will occur at the conference, and the coming weeks will focus on community sponsorships.
- **NIH R13 grant:** Lindsay Marjoram reported that BSF's NIH R13 application supporting the SciMed portion of the conference received a favorable score and a just-in-time (JIT) information request, a positive though not guaranteed indicator of funding. The primary institute is NHLBI, with potential co-funding from NCATS and NICHD. The budget conservatively assumes \$25,000; BSF received \$40,000 in 2024.
- **Corporate matching gifts:** In April, BSF implemented Double the Donation, a tool on its donation pages that helps donors determine whether their employers match gifts. Since launch, approximately \$3,500 in matches has been secured out of roughly \$12,500 in identified match-eligible donations. Jessica asked board members to encourage their donors to use the tool.

Former Board Chair Susan McCormack asked about plans to capture the remaining eligible matches. Jessica described using the tool's tracking and automated reminders to identify where donors stall, sending year-end reminders, and coordinating personal follow-up with board members and campaign hosts; she invited board members to share the names of donors whose employers offer matching programs.

Form 990

Emily Milligan reported that a draft of the Form 990 is ready for review. The Finance Committee will review the draft and make a recommendation to the board. Natalie Cohn noted that the 990 asks whether the board has reviewed the return, and that BSF's state filings cannot be submitted until the 990 is filed. In an ongoing effort for transparency and timeliness, BSF intends to post the 990 to its website before the conference.

IV. ARRHYTHMIA PROJECT UPDATE

Kate McCurdy reported that the arrhythmia project, which is governed by a milestone-based contract, is over 2 years behind schedule, and that BSF has been concerned about both the status of the registry and the quality of the extremely limited data entered to date. Feedback from two bioinformatics experts engaged by BSF, provided in the pre-reads, flagged data aggregation, data entry, and quality control standards that NYU needs to implement immediately to ensure high quality data outputs.

BSF has held several leadership calls with the NYU team. All parties reaffirmed the importance of the project, as arrhythmias are not well understood in Barth syndrome and remain a major cause of death, and agreed to a "reset" that includes:

- Working as collaborators and partners rather than in a traditional academic grant relationship, recognizing that ineffective communication was at the root of many of the issues.
- Instituting regular meetings among all project participants.
- A short-term goal of producing a manuscript addressing (1) the prevalence of arrhythmias in Barth syndrome, using expanded Holter monitor data, and (2) the relationship of arrhythmias to cardiac function and medical status.

With these understandings in place, BSF arranged for off-cycle, research appointments outside the normal time for on-site research at conference to accommodate the NYU team's travel schedule.

Staff committed to keeping the Board informed as to progress toward resetting the project and achievement of milestones.

V. BARTH INSIGHTS REGISTRY AND REPOSITORY

Melissa Huang introduced BarthINSIGHTS, the next evolution of the Barth Syndrome Registry and Repository (BRR), developed with support from the Chan Zuckerberg Initiative (CZI). Its overarching goal is to ensure that every person with Barth syndrome, wherever they are in the world, is represented, heard, and served by a registry that advances research, informs regulatory pathways for drug development, and demonstrates the unmet needs of the global community.

Staff explained that, through the Matrix platform and the use of a global unique identifier (GUID), the single platform will for the first time consolidate biospecimens, clinical-grade data, and patient-reported outcomes.

Name and Logo

Jessica Lee presented the proposed name, BarthINSIGHTS, developed through a three-day asynchronous online focus group with community members and validated with participants. The branding agency that designed BSF's original logo developed four logo options; staff recommended a sun motif with added color, reflecting hope, community identity, and a nod to the BSF logo. Specifically, the "light bulb" concept emphasizes the sharing of knowledge.

Conversation ensued about how this related to prior discussions about updating BSF's logo font. It was reported that focus groups with older affected individuals found that they feel represented by the current branding, and the decision was made not to change it.

MOTION to approve BarthINSIGHTS as the name and branding for BSF's registry and repository was approved unanimously.

Platform Overview and Phased Rollout

Melissa Huang reported that BSF has migrated all BRR 2.0 data to Matrix, a patient-led platform recommended by peers in the CZI network, and completed beta testing ahead of launch at the 2026 conference. The new platform addresses longstanding participant concerns with self-paced surveys that can be saved, real-time comparisons to the broader community, and symptom tracking. Initial enrollment will focus on U.S.-based, English-speaking participants, with additional languages and U.S. electronic health record integration to follow in late 2026 and 2027. Melissa noted that registry data has already powered two recent publications and will support regulatory-grade post-marketing data, including for FORZINITY™.

Patients as Partners Gift Program

Melissa Huang proposed a Patients as Partners gift program to improve recruitment, retention, and data completeness: a one-time \$80 gift for completing the initial assessment and a \$55 gift for each annual assessment, with the option to donate the gift back to BSF. The amounts were benchmarked against NIH, National Health Council, and peer organization standards and fall at the conservative end of fair market value. Estimated cost is approximately \$4,000 in the first year and just over \$5,000 annually, with a maximum of approximately \$12,000 if all current registrants participate.

It was noted that compensating patients for their time and effort is common practice in meaningful patient engagement and that the amounts are modest and can be adjusted as BSF learns more.

MOTION to approve compensation for BarthINSIGHTS participants of \$80 for completion of the initial assessment and \$55 for completion of each annual assessment was approved unanimously.

Records Extraction Consulting Contract

Melissa Huang presented a proposed scope of work with Dr. Brad Bryan of Source Biologics to build an AI-enabled data extraction pipeline for participants whose records cannot be connected through EHR integration. With participant consent on an opt-in basis, PDF medical records, which can range from 100 to 4,000 pages, would be processed to extract and de-identify relevant clinical data in the same format as Matrix EHR data. Emily Milligan emphasized that privacy and security are paramount. Melissa confirmed that the pipeline will be HIPAA and GDPR compliant, hosted in a secure cloud environment, and limited to BarthINSIGHTS use, and that data will not be used to train AI models.

MOTION to approve the engagement of Source Biologics for the records extraction scope of work at a cost of \$10,500 was approved unanimously.

Following the vote, Melissa noted that per-record processing fees, ranging from approximately \$30 to \$300 per patient record depending on the record, are in addition to the scope-of-work fee; the pre-read estimated up to \$15,000 for a conservative cohort of 50 records. The board discussed whether to approve a cap or a per-record rate and agreed to approve the per-record rate and revisit as experience is gained. Jamie Baffa requested that the consultant provide transparent reporting on AI token usage, as these fees are pass-through compute costs.

MOTION to amend the foregoing approval to include per-record processing fees of \$30 to \$300 per record, passed through based on AI token usage, was approved unanimously.

VI. 2028 CONFERENCE SITE SELECTION

Shelley Bowen reported that selection criteria included meeting space on a single floor, vertical rather than spread-out lodging, limited walking distances, and BSF comprising the majority of hotel guests. A Cvent search of venues in the contiguous United States narrowed approximately 455 venues to 276, and then to a short list including options in Florida, Missouri, and the East Coast and South. Some larger venues were considered but exceeded budget.

Three finalists were evaluated. The Hyatt Regency Coconut Point emerged as the strongest option. The Buena Vista Palace in Orlando was rejected due to its size (approximately 1,000 rooms and 120,000 square feet of meeting space), higher menu costs, and the need to outsource youth activities. The TradeWinds was rejected due to a spread-out layout requiring split lodging during a major renovation and a \$3,000 penalty for using BSF's preferred third-party AV vendor.

Michael Bowen summarized the key terms of the proposed Hyatt contract.

Shelley reported that the conference steering committee recommends returning to the Hyatt for a third consecutive conference. In response to a question from Florence Mannes about the earlier dates, Shelley and Michael explained that BSF's preferred window runs from the third week of June through

the third week of July, excluding the week of July 4, and that the week of July 9 was the less expensive of the Hyatt's available dates.

MOTION to authorize BSF to enter into a contract with the Hyatt Regency Coconut Point for the 2028 conference was approved unanimously.

Kate McCurdy suggested that planning for future conferences consider a new location after three conferences at the same venue. Shelley recommended starting future site searches earlier.

VII. 2026 CONFERENCE

Registration Update

Shelley Bowen reported that registrations are slightly below prior pace but rising, with 15 additional registrations since June 16, and that she will circulate additional information and highlights to the board. Jessica Lee reminded participants that the hotel room block expires June 25, 2026. The Budget Update and Program Highlights agenda items were not presented due to time constraints.

Code of Conduct

BJ Develle presented a proposed Code of Conduct for all conference participants, including families, researchers, clinicians, and advocates, expanding on the prior code developed for staff and volunteers. The code addresses treating others with kindness and respect, honoring differences, and following the rules of the venue. Participants will receive the code in their conference materials and will not be asked to sign it. Lindsay Marjoram noted that a code of conduct is a requirement of the NIH R13 funding for SciMed attendees.

MOTION to approve the Code of Conduct as presented, for inclusion in the materials provided to all conference participants, was approved unanimously.

VIII. ADJOURNMENT

There being no further business, the meeting was adjourned. Kate McCurdy thanked all participants for their input and expressed that she looked forward to seeing everyone at the conference.

Respectfully submitted,

Emily Milligan
Chief Executive Officer