BDSRA Foundation Board Meeting
May 18, 2026
4 pm – 6:45 pm PST

Attendees:
Gretchen Fieschko
Kate Haller
John Ireland
Suzette James
Wayne Kiefer
Chris Lowden
Barb McDonough
Mathias Schmidt
Fred Surrey
Barb Wuebbels

Absentees:
Ed Harriman
John Patterson
Dave Pearce
Ned Timmerman

Meeting was called to order at 4:03 pm by Barb McDonough

- **Honoring Recent Batten Angels**
  Kate Haller read the name of the children who have passed recently, followed by a moment of silence: David Turner and Paul Jere (PJ) Snider

Acceptance of the minutes from April 19, 2026 meeting: Kate motioned for the acceptance of the minutes. John I. seconded. All voted to accept the minutes.

Finance Committee Update: Presented by Wayne
Taxes: BDSRA received a letter from the City of Columbus, OH, stating that BDSRA owed over $ 10,000 in back taxes for 2025. This is in addition to other state taxes in arrears from 2025. Wayne has contacted Rob Mackey who referred him to Intuit. Intuit is responsible for submitting state payroll taxes. It may take 30 days to hear back.
Audits: Recommendations included: BDSRA should raise the threshold for depreciation of capital assets from $500 to $5,000. BDSRA starts a new depreciation schedule as of now. Wayne motioned to accept the recommendation. Fred seconded, all voted to approve. Audit also recommended that two people count cash instead of one person. Since we rarely receive cash donations at the office, the recommendation will carry to the conference. Most donations to office are checks or by credit card. Checks are scanned and deposited so there is a "paper" trail. Board agreed that we have the requisite controls in place in the office. Kate asked about the deficiency noted in the 2023 audit letter regarding deposits and disbursements related to BDSRA

serving as fiscal agent under an agreement with another organization. The process has been revised to identify these as restricted accounts payable.
Suzette motioned to approve the audits. Fred seconded. All voted to carry motion.
Labyrinth: Kate noted that now that the audits are completed, it is critical that the Database Manager file the audits with Labyrinth as soon as possible so that fundraising in previously blocked states can be reinstated.

Organizational Update: Presented by Suzette and Barb
The restructuring of FTE headcount resulted in about $10,000 a month reduction in operating expenses. The FTE Marketing role has been eliminated, the FTE Office Manager role has been reduced to a low number of hours monthly. The FTE DataBase manager role will become a contractor role under a different title. Contract SOW will have measurable time bound milestones tied to payments. BDSRA board will continue to build out a Operations role which will include accountability for reconciliation of the audits. Also, Labyrinth follow up is currently the responsibility of the Database manager and will continue to be until further notice. Regarding the future operations of BDSRA, the board agrees that Operations and Development are two key areas necessary to support BDSRA. Donor management and database management could eventually fall under the Development position.

Committee Updates:
Science Committee: Mathias held the first science committee meeting under his leadership. Members: Dave, John P., Suzette and Chris. On behalf of the new committee, Mathias proposed an adjusted mission statement: *Our long-term vision is a world without Batten disease. Our mission is to support and advocate for Batten families, fund and facilitate research, treatments and a cure*. The committee would also like to reapproach research priorities to include a more balanced portfolio from bench research to clinical research.

Conference Committee: Suzette and Barb updated the board on conference activities and current funders ($190,000 pledged to date). Large donors include BioMarin, ForeBatten, Hailey's Heros, Our Promise to Nicholas. Volunteers will help staff registration and other areas to reduce costs from sending all BDSRA staff and Site Solutions staff. Regarding the physical and online memorial to be available at the conference, Chris Lowden volunteered to assist Noah Siedman and learn from him of the building and maintenance (the inner and outer workings) of the memorial at the conference.

NOTE: ***The Board was reminded that the July 9 board meeting will be held at 8:30 am in Lombard at the Westin and people should plan to fly in on Wednesday night for dinner and stay through the entire conference.***

Fundraising Committee: Suzette updated the board that the **Board-driven fundraising appeal** as email has been sent out and the US Post letter to donors in our database who have ever given $250 and above will be sent soon. **Grants:** we continue to look for new grant opportunities. **Fam Funds:** Chris Hawkins is managing these and trying to enlist more families. **Board Fam Fund:**

Thank you to the Board members who have contributed either to Conference, to Board Fam Funds for operations and any other areas. Reminder to consider donating to Board Fam Funds if you have not already and that these donations are publicly noted on the Fam Funds page with the balance as of this meeting, ~$14,000.

Wayne moved to adjourn the meeting, Suzette seconded. **The meeting was adjourned at 6:35 pm.**

Upcoming meetings:

Next Board of Directors meeting will be June 15. In Person meeting 7/9 Conference, other monthly dates will be refined around previously stated dates. (8/16, 9/20, 10/18, 11/22, 12/20)