



BDSRA Board Meeting

April 27, 2025

2 PM - 6:00 pm EDT

Members Present

- | | | |
|---------------------|-----------------------|----------------------|
| ✓ Darlene Royalty | ✓ Amy Fenton Parker | ✓ Wayne Kiefer |
| ✓ Barb Wuebbels | ✓ Barb McDonough | ✓ Fern Leal-Pardinas |
| ✓ Fred Surrey | ✓ Kate Haller | ✓ John Patterson |
| ✓ Gretchen Fieschko | David Pearce - Absent | |
| ✓ John Ireland | ✓ Suzette James | |

Call to Order

The meeting was called to order by Darlene Royalty at 2:00 PM.

Reading of Names of Recent Batten Angels

Barb McDonough read the names of our recent Batten Angels who have passed since February 1st, and we had a moment of silence to honor their memory.

Minutes

Fred Surrey motioned to approve the minutes for board meeting of February 1st, 2025, which Darlene seconded. Minutes have passed and will be posted on the BDRSA website.

Financial Committee

- Fred reviewed the Profit/Loss Statement for 12/31/2024
- Fred reviewed change to structure of budget and adjustments, and final budget as of 12/31/2024
- Fred also reviewed 2025 budget details, entries, concerns, and how to view current accruals.
 - Changes made clearly show income from Fam Funds.
 - Fam Funds are currently coming in from 2 different platforms (Charity Engine & Run Signup). Therefore, it will be trickier to track Fam Funds income for walks/runs. This is too *messy* for the Finance Team to manage.
 - Amy/Beth will strive to use ONE Platform, going forward, for consistency.
 - Processes have been created to manage income from Fam Funds and ensure there is a paper trail for ALL Fundraising Events.



- A *good* Charity Engine Rep will be consulted ASAP to review the platform, so we understand all capabilities and features that Charity Engine has to offer, so we fully utilize the system to support our needs.
- Reviewed the details of the Balance Sheet (Statement of Financial Position).
- Reviewed details on Special Restricted Activity.
- Discusses deference between “General Support” vs Operating expenses.
- Fred also would like to see a quarterly report to be prepared for the Board to review each quarter to see *exactly* where we stand for the remainder of the year.
- John would like to see a Monthly Income Report at the beginning of each month to review fluctuations throughout the year, to help manage and prepare for Financial Unpredictability in order to make changes if needed. This report will be created by the fifth business day of each month for the Financial Committee to review on a monthly basis. Report will include income for both Restricted and Unrestricted Funds.
- A suggestion was made to send a letter to all BDSRA Families to outline funding needs and to ask what programs they would say should be cut.
 - Needs of the Batten Community changes over time – Which are MOST important to you? Where should we put our resources?
 - 2021 Survey will be reviewed and possibly resent due to changing times and new families.
- John Patterson made a motion to provide monthly Income Report each month by the 5th day Business Day of each month to the Finance Committee, and to the entire Board by July 5th, and each quarter thereafter, to review the Financial Health of the Organization and to make decisions if necessary. Wayne seconded the motion. Motion carried.
- Fred made a motion to accept and approve the budget that the Finance Committee sent to Board members on Thursday, 4/26/25. Dalene seconded the motion. Motion carried to approve budget.
- Budget will be reviewed Quarterly (starting in July) and Reforecast will be completed and adjustments will be made if necessary.
- Emergency Board Meetings will be called by Finance Committee or Executive Board if necessary.
- Motion was made by Wayne to make whatever strategic decisions are necessary. John P seconded the motion. Motion passed.



Fundraising

- Suzette presented Fundraising Committee update.
 - Described Living Legend to highlight repeated donors.
 - Presented update on Board Appeal Letter

Investment Companies

- John Ireland and Wayne are working on reviewing investment companies and obtaining a new investment company to best fit our needs.

President Report

- Amy gave update on status of her 2025 SMART Goals.
- Encouraged Board Member participation in the IBAD fundraising events.
 - Ex. Organize Virtual Run with T-Shirt or join an existing team
- Gave update on Support and Programs available to Batten community
- Gave update on Research and shared exciting news about research grant awards
- Gave update on Advocacy events
- Discussed changes at FDA regarding the termination of Newborn Screening Panel
 - Very concerning – Future is uncertain
- Provided update regarding Social Media experiences – Reviewed which is most impactful
- Provided update on Development
- Reviewed preparation for International Batten Disease Awareness Day (IBAD)
 - 300 Votes were received regarding T-shirt Design
 - Virtual Run/Walk Fundraising teams are currently being formed to support the day
- Reviewed requests to Board
 - Notes of appreciation and encouragement to staff are always appreciated
 - Please engage in activities and events whenever possible to show support



Conference

- Amy provided update on current status of 2025 Family Conference regarding Sponsorship, registrations and stipends available.
- Darlene provided update on planning progress and the assistance by the Conference Support Committee – The Nebraska families are fully engaged and VERY supportive with Conference needs

Executive Update

- Darlene reported on the 3 committees that she currently serves on:
 - Conference Support Committee
 - Working closely with the Lincoln Team who are supporting local resources and forming local committees to meet various needs of the conference
 - Executive Committee
 - Meets monthly with Amy regarding current status and activities of her and her staff
 - Policies, Procedures, and Processes Committee
 - Newly formed committee to review current policies and processes and update and create as necessary
- Discussed Elections and offices that are or will be available and needed on the Board
 - Reviewed nomination & volunteer process to fill offices
 - New officers take position during January Board Meeting
 - Discussed process of replacing Board member positions and Executive positions (Chair, Vice Chair, Treasurer and Secretary)
- Barb M made motion to consider re-establishing an “ADHOC Nominating Committee” to seek out new members that have the skills and knowledge that the board is currently in need of.
 - Kate seconded motion. Motion carried.
 - Barb W will chair committee with Barb M & Gretchen as committee members
- Discussed the need for an additional BDSRA Credit Card for the Restricted Funds account to provide a better/simplified tracking process for the Financial Committee

Marketing

- Gretchen provided summary of her marketing background and ideas of the skills and knowledge she can share and help she can offer regarding Strategic Plan

Center of Excellence

- Barb Weubbels provided update on the Centers of Excellence status
 - Some things are unknown at this time due to the recent NIH cuts.
 - 42% of the NIH support was cut, which will have impact on CEOs



- COEs continue to meet and collaborate
- Barb W and Amy gave update on Grant Approval Process and projects that they are working on

By-Laws Update

- Kate gave an update on recommended changes to the By-Laws
 - Updated Article 9 & 11
 - Wayne made motion to accept the changes that Kate made. Gretchen seconded motion. Motion passed
 - Amy will make final updates and distribute to board members
 - Recommended change made to Article 4, Section 1 regarding amount of Board members – Odd number is recommended. This is pending consideration until next meeting.

Closing Comments made by Darlene

- Darlene made motion to adjourn. Barb W seconded the motion.
 - ADJOURNED 6:09 EDT

Next Meeting Dates

- July 10, 2025 – 8:30 AM Central time (at Family Conference)
- October 19, 2025 – 1 PM Eastern time
- January 2026 - TBD