



BDSRA Board Meeting
February 1, 2025
8:30 AM - 5:00 pm CST, Chicago

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 | |
| ✓ John Ireland | ✓ Suzette James | |

The meeting was called to order by Darlene Royalty at 8:36 AM.

Welcomed Gretchen as New Board Member! Gretchen comes with valuable knowledge and experience to share.

Barb McDonough read the names of our recent Batten Angels, and we had a moment of silence to honor their memory.

Dave Pearce motioned to approve the minutes for December 2024 meeting, which John Ireland seconded. Minutes have passed and will be posted on the BDSRA website.

President/CEO Presentation

- Amy presented an overview of the 2024 BDSRA Achievements and a preview of future plans to the Board.
- Discussed how to assimilate important research information out to the Batten community better by sharing of information as it becomes available.
- Research information is now available on www.battenresearch.com
- Recapped the hiring the Director of Family Support – will be very helpful to work with volunteers to increase engagement of the Batten community members.



Fundraising Discussions and Recommendations

- Gretchen made a motion to create a comprehensive plan with critical context to provide to stakeholders regarding research fundraising to better explain the process. (Amy, Gretchen, & Suzette will create this. Jon Patterson seconded – motion passed.
- Need to discuss more about “Plansgiving”.
- Work more intently for Vendor Support who regularly provide services to the Batten families.
- Rebrand Chapter concept for local conference planning and support.
- Create Checklists for processes and follow up items
- Follow up on finalizing audits, which is critical for fundraising efforts – perhaps have conference call with Finance Committee and auditor/Don Wells.
- Discussed reviewing Sub-Committees – Do they meet regularly? And, the need to improve communication between sub-committees and the overall Board of Directors.

Review of the Financials

- Amy reviewed the investment changes recommended by Tony.
- Board discussed researching best investment options, and requesting quotes from various investment companies to change from Merrill Lynch. John Ireland and Wayne formed a committee to research this information.
- Fred will supply updated Merrill Lynch statement for research committee to work with. Tony will be invited to participate on the committee.
- Finance committee will be reviewing the “Investment Policy for any needed updates.

Family Conference Plans

- Darlene gave an update of 2025 conference plans.
- Darlene will be meeting with families of Lincoln area that are excited about hosting the annual family conference in their area.
- A survey will be sent out regarding future conference planning topics.



Centers of Excellence (COEs) Update

Barb Wuebbels gave an update on the progress of the COE project.

Fundraising Committee Update

- Suzette presented a summary of the Fundraising Event Plans and ideas. Ideas include:
 - Small dinners hosted by families
 - Hosting Gala to support the annual conference expenses
 - All other ideas are welcome
- Discussed ways to connect past donors back to support BDSRA

Financial Report

- Fred presented Budget update and Financial Report.
- Discussed having 2 Financial Reports for both Operating and Restricted.
- Discussed making changes to the budget/expense recording and reporting for better understanding.
- Discussed process improvement solutions to develop a simplified, more accurate Income/Expense tracking. (Wayne will update process if necessary).
- Amy will provide numbers that will be pulled out of the budget.
- Actions to be completed by end of March.

Upcoming Events

- Amy has received a grant to attend Rare Disease Week.
- Valentines Day event via Zoom meeting with families who would like to participate.

4:45 pm – Darlene motioned to adjourn - Dave seconded. Meeting adjourned.

Next Meeting Dates

- April 27, 2025 – 1PM Eastern time
- July 10, 2025 – 8:30 AM Central time (at Family Conference)
- October 19, 2025 – 1 PM Eastern time