



BDSRA Board Meeting
July 11, 2024
8:30-am - 5:00 pm CST, St. Louis, Missouri

Members Present

- | | | |
|-------------------|---------------------|----------------------|
| ✓ Darlene Royalty | ✓ Amy Fenton Parker | ✓ Suzette James |
| ✓ Barb Wuebbels | ✓ Tony Ferrandino | ✓ Wayne Kiefer |
| ✓ Fred Surrey | ✓ Barb McDonough | ✓ Fern Leal-Pardinas |
| ✓ Donna Fogle | ✓ Kate Haller | ✓ John Patterson |
| ✓ John Ireland | ✓ David Pearce | X Kyleen Douglas |

Meeting called to order by Darlene Royalty at 8:30 am

Reading of the Batten Angels July 2023-June 2024 – Donna Fogle

April Meeting Minutes approved (7/11/2024) Approved: Yes

Dave Pearce motioned to approve; **Barb Wuebbels** Seconded: All accepted

Presidents Report (presented by: **Amy Fenton Parker**)

Important Notes/Comments:

- 347 Registrants for 2024 Family Conference, however there were a few cancellations.
 - 340 Attendees
 - 49 got funding to attend through the Calvert Endowment and additional donations
 - 24 Grandparents attended
 - 34 1st time family attendees
 - 47 Professionals
 - 16 family grants were awarded
- Well over 20 themes were submitted for the conference this year – Thank You!
- 100% of the Board is currently contributing to BDSRA.
- Minutes are posted after each board meeting.
- Application process is in place to recruit new board members - 9 applications received in 2022.
- Donna Fogle is resigning from the board at the end of this year after 10 years of service.
- The Annual Family Conference Planning worked very hard to plan a successful 2024 conference.
- Amy is very thankful that the current BDSRA staff is a strong, cohesive, dedicated Team.
- An annual review process is in place for all staff members.
- The Executive Committee members meet monthly.
- The Financial Committee members meet monthly also.



BIG NEWS

BDSRA Canada has adopted our logo, and are partnering with us now.

We are supporting the technical operations of BDSRA Canada. They will in turn pay us to support them.

We are so happy to have the President of BDSRA Canada and the President of BDSRA-UK both at the conference this year!

Additional Virtual programs have been added and are offered regularly.

We are happy to WELCOME Heather Daniak (Part-Time) as the Director of Family Support. Welcome Heather!

Family Support

- BDSRA is doing a great job in offering various virtual family support programs, with increasing attendance.
- The Conference Committee offered virtual and in-person New Family Orientation, which is very beneficial for the first- time attendees.
- BDSRA offers support for Family Fundraising Events, which makes the event process so much easier for the event Hosts and participants as well. A couple of easy fundraiser event ideas:
 - No Show Ball or Birthday Party
 - No Show Golf Outing, Walk/Run, or other event
 - The BDSRA Staff & board are here to assist!

Centers of Excellence

- Centers of Excellence have now been established and located throughout the country to help meet the family needs.
- There are currently 5 Centers of Excellence and 4 Affiliates.
- The Centers of Excellence meet monthly, and collaborate as needed.
- Highlighted the importance of the role that Centers of Excellence will play in current projects, by supporting all families, medical professionals that participate in the current projects.
- The clinical projects are managed in each regional Center of Excellence.
- Centers of Excellence are networking to share knowledge, treatments, medications, and most current successes and results.
- Centers of Excellence will enable BDSRA to receive more impactful results on research investments to benefit the BDSRA Community as a whole.



Global Research Initiative

- **BDSRA** is partnering with BDSRA Foundations to provide research grants.
- Research will gain greatly by this global collaborative effort.
- Donations toward Research must be encouraged to be dedicated to “General Research” to be able to make the greatest impact in research activity which will in turn help ALL forms of Batten Disease.

Marketing is doing a great job with social media.

Family Conference 2025

- Begins the evening of July 10th - 13th, 2025
- The conference will be held at **The Lincoln Marriott Cornhusker Hotel located in downtown Lincoln, Nebraska!**

Industry Partners Updates

Three Industry Partners presented virtual updates to the BDSRA Board:

- REGENXBIO
- Beyond Batten Disease/Theranexus
- Neurogene (CLN 5)

2024 YTD FINANCIALS – presented by Fred Surey (Treasurer)

- BDSRA has realized an improved Profit & Loss statement for YTD 2024, however, fundraising is imperative to provide a sound, operational organization.
- To help support the BDSRA Foundation Kate moved to direct 7% of restricted donation to support operating funds. Dave 2nd the proposal. Motion carried.
- Wayne moved to reclass the interest earned on account funds to the Operations Fund effective 2024 (does not apply to Calvert Endowment Fund for conference attendance). Dave seconded the move. Motion carried.
- Kate moved to finalize an ongoing plan by January 2025. Darlene Seconded the move. Motion carried.
 - The plan must be clear about the costs of having an annual conference and the reduction of contributions from our sponsors (Industrial Partners).



- The plan must also be clear about the good things that are happening at BDSRA for Research and Support.
- The cost of the conference is a third of the annual Budget.
- Tony motioned that Wayne will do research to compare costs between Merrill Lynch & Fidelity to manage and transfer the interest earned. Kate 2nd, motion carried

Commitment of Terms – Replacement of Board Members

- Issue – With board members leaving, we must have a plan for succession.
- Officers of the board must step down from their *current* position after two 3-year terms.
- Do we need term limits for regular board members?
- The plan will be reviewed and discussed in depth at the December 8th, 2024 Board meeting.
- In December 2024, Donna Fogle (and possibly Tony Ferrandino) will be retiring from the BDSRA Board. Trent Lewis already resigned earlier this year, and possibly 1 more may be stepping down.
- Our goal is to have staggered terms to replace board members regularly.
- Currently there will be 2 open positions for 2026.

Note: Date and location of February 2025 board meeting has not been finalized.

Committee Updates

- SIBS Updates presented by John Ireland
- Support – Darlene Royalty: Worked very hard
- Advocacy – Donna Fogle (New chair needed): Barb Wuebbels will take over chair position
- Science & Research – updates presented by Dave Pearce
- Finance & Audit – Fred Surrey: Committee meets monthly
- Development – Suzette James: Growing Fundraising Efforts
- Human Capital Management – Barb McDonough: Committee on call as needed
- State Registrations – Kate Haller: Reviewed State Registrations and plan to resolve issues.

Next board meetings are:

- December 8, 2024 at 2 eastern
- Feb 2025 (TBD) all day starting at 9am central

Minutes by Barb McDonough