



**BDSRA Board Meeting  
February 3, 2024**

**Members Present**

✓ Darlene Royalty  
✓ Barb Wuebbels  
✓ Fred Surrey  
✓ Donna Fogle  
✓ John Ireland

✓ Amy Fenton Parker  
✓ Tony Ferrandino  
✓ Barb McDonough  
✓ Kate Haller  
✓ David Pearce

✓ Suzette James  
✓ Wayne Kiefer  
✓ Fern Leal-Pardinas  
✓ John Patterson  
X Kyleen Douglas

Opened meeting with Team Building activity.

Reading of the Batten Angels names lost between July and December, 2023

**Dec 2023 Meeting Minutes** approved (2/3/2024) Approved: **Yes**

Motion to accept: **Dave Pearce**; Seconded by: **Suzette James** and **Fern Leal-Pardinas** All accepted.

Meeting called to order by Darlene Royalty

**Financial Report** - (presented by: **Fred Surrey**)

Board Comments:

- Amy is doing a good job at keeping expenses down.
- Funding is down as expected.
- Transactions in Restricted Account have been clearly defined. The account has been carefully audited and balances.
- Processes have been implemented to clearly track all Finance Transactions going forward.
- 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.

**Merrill Lynch Report** - (Presented by: **Tony Ferrandino**)

- Discussed investment strategies used for planning purposes for grant spending.



Motion to accept Financial Report: **Barb McDonough**; Seconded by: **John Patterson**

**Centers of Excellence - Discussed and shared update on progress** - (Presented by: **Dave Pearce**)

- Discussed importance of the role that Centers of Excellence will play in current projects, by supporting all families, medical professionals, and clinical trials.
- This is an incredible opportunity to bring the collaborative nature of research and support to share information and best practices.
- The clinical projects will be managed in each regional Center of Excellence.
- Centers of Excellence will network 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.

**Strategic Research Outcome Planning** - (Presented by: **Suzette James**)

- Discussed where research funds go and how we plan for the funds to invest in research.
- Discussed the importance of looking at research opportunities for all forms of Batten Disease.
- Talked about the importance of being more proactive and “assertive” when working with the FDA. BDSRA should meet with the FDA and work with them. They will in turn work with us.
- Discussed our research progress (success and failures) demonstrated in the past will help move research forward.
- The Science Committee is currently under development and will be developing areas of focus.

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

- Reviewed experience at “World” event (World Lysosomal Storage Disease conference)
- Shared how the placement of the Scientific Officer was clearly a community lead effort.
- Discussed potential new members to BDSRA.
- Discussed grant proposal to support Mark Sands’ current research regarding news release of project: Discussion tabled until April Board Meeting.
- Annual Family Conference Planning is well under way.



### **Committee Reports**

- Reviewed current committee members
- Emphasized that we really need help from the Committee for Conference due to the change in the PHARMA Industries' lack of funding.
- Kate Haller collected the signed Confidentiality agreements and Conflict of Interest forms from each board member.

### **Next board meetings are:**

- April 28th at 2 Eastern
- July 11 all day starting at 9am Central
- Dec 8 at 2 Eastern