



## BDSRA Board Meeting

October 26, 2025

1:00 pm EST

### Members Present

✓ Darlene Royalty  
✓ Barb Wuebbels  
✓ Fred Surrey  
✓ Gretchen Fieschko  
✓ John Ireland  
✓ Amy Fenton Parker

✓ Barb McDonough  
✓ Kate Haller  
✓ David Pearce  
✓ Suzette James  
✓ Wayne Kiefer  
✓ John Patterson

Absent:  
Fern Leal-Pardinas

### Call to Order

The meeting was called to order by Darlene Royalty at 1:05 pm

### Honoring Recent Batten Angels

Darlene read the names of children who have passed since July 10, 2025. We had a moment of silence to honor their memory.

### Minutes

The minutes for July meeting were corrected by adding that all grants were affirmed by the Board. Minutes were approved with revision.

**Town Hall:** Darlene Royalty to host the East Coast Town Hall and John Ireland to host the Pacific Coast on Sunday, November 9, 7PM in both EST and PST.

### **ACTIONS:**

- All board members are requested to attend one or both meetings.
- Amy will send out the Zoom meeting to all board members for both meetings.
- Once a participant signs up for a meeting, they will receive an invitation for all future meetings.
- Participants can sign up at the last minute, or while meeting is in session.

### **President's Report** presented by Amy

**Annual Appeal:** in the US mail to those who use US Mail to donate; email to other donors to follow.

**Impact Report:** will be released week of October 27, 2025.

**IRS Letter:** due to delinquent 2018 990 filing, IRS levied a fine of \$10,000. Amy and Don constructed and mailed letter to IRS to explain extenuating circumstances prevented BDSRA from timely filing. We await a response. Amy also updated IRS on our new office address.

**Office lease:** Amy has requested a new month to month lease at \$1,500 monthly.

**Family Fund** meeting will be held Monday, October 27. (can we add OBJECTIVES of this meeting?)



**BDGRI:** 30 letters of expression have been received by BDSRA and given to BDGRI Committee; requests total \$ 1.5 million. Maximum per grant as stated on website is \$50,000. Next phase will be for the Committee to vote on which requests will be approved to go to next phase for full application. The Committee is comprised of 4 clinicians and 4 researchers representing Australia, US, Canada, UK and Germany.

**COEs:** Three new institutions have been approved into the COEs. Mt. Sinai to be a COE Affiliate; UNC moves to becoming a full COE; and Boys Town has applied to become a COE Affiliate.

**NIH Grant:** has not been publicly announced by BDSRA since Kennedy Krieger is in charge of first public announcement, then BDSRA has a press release ready for public posting. Additionally, of the \$8 million grant over 5 years, \$5,000 will be used to support part of Science Officer (Ineka's) salary annually. Also, part of the grant will be used to support development of a natural history study similar to DEM CHILD, called REDCAP.

**PR suggestion:** it was suggested that BDSRA should build a PR story around how one bequeathed gift supported the development of the COE program, which led to the BDGRI, which led to the NIH grant.

**ACTION:** Amy to share the slides and videos that Ericka created to describe how the NIH grant will be used. It was suggested that after review of Erika's program, a subset can be created for BDSRA families to outline what the NIH grant can and cannot be used for (e.g. the grant funds cannot be used for interventional trials).

**Finance Committee:** Wayne Kiefer

**Updated YTD budget vs actual figures were presented.** A discussion of Fam Funds posting led to suggestions for new method of tracking to clarify where the restricted and unrestricted Fam Funds are posted.

Three new policies drafted by the Finance Committee (excluding Fred Surrey who did not participate).

- 1. Funds Transfer Policy:** This policy was amended to read that Amy will prepare a "Weekly Report of All Transactions from restricted to unrestricted checking accounts and vice versa from Unrestricted to Restricted and disseminate it to the full board. Approved by Board (Attached)
- 2. Stock Gift Policy:** A draft including outlined in steps was presented to the Board for review. Will revisit at next meeting.
- 3. Use of Restricted Funds Policy:** Draft was presented to the Board for review – will review at next meeting.
- 4. Use of Non-Restricted Funds Policy:** In process – awaiting review and final vote.
5. Records Retention policy was reviewed and approved by the Board (attached).

**Policy and Procedure Committee:** Darlene reported that she continues to review the Policies and Procedures. The policy for Record Retention was re-reviewed and amended per Kate's suggestion: All I-9s shall be held for 2-3 years.

**Family Conference planning:** Amy and Darlene reported that Site Solutions offers the most competitive bid and included a 3-year commitment. Gretchen asked to get clarity on some specific questions, she will email Amy and Darlene separately. No decision was finalized and the contract is not signed.

**Fundraising Committee:** Suzette James

**Thank You cards** for special donors: members of this committee are handwriting specially designed thank you cards to list of donors from BDSRA. This is a best practice adopted from other non-profits such as Make a Wish.

**Promos with See's Candy, Krispy Kreme Donuts,** are designated as "passive" fundraising programs where BDSRA merely needs to build awareness and supply a link to membership so that BDSRA receives some proceeds from these companies.



**Fam Funds:** Conducting a lessons learned and educational meeting week of October 27, 2025. No new Fam Funds have been established.

**Grants-Larry:** Waiting to hear from Nationwide in Feb. Looking into Root & Wings

**Large Companies-** Amanda approaching some Chicago based international companies for support: Blistex, NuMotion. Also investigating Round-Up At The Register

**Proposal to cover funding for Science Officer, Admin Support and BDGRI grants** and for 5 years \$600,000. Amy developed and submitted a proposal to a large donor

**Comprehensive Marketing and Fundraising Plan:** Gretchen presented some thoughts and ideas on how to develop a comprehensive 1–3-year plan so that we have a roadmap of what we need to raise, who we need to approach and what collateral needs to be developed. This is a priority to begin in the new year. Fundraising committee members will collaborate with Amy and her team.

**Candidates for Board membership:**

The Board voted in three of the candidates. Those board members who did not have a chance to interview the fourth candidate will meet with him week of October 27 and will report back. The interviewing board members met with the 4<sup>th</sup> candidate and unanimously voted for his inclusion. This outcome was shared with the Board voted to accept all 4 as new board members. Once that was decided, Darlene notified the candidates of the outcome and will announce their addition in the November Luminator.

The meeting was adjourned at 3:25 pm EST.

**Next meeting:** Dec 14, 2025 - Time to be announced