

BDSRA Foundation Winter Board Meeting
Saturday, January 31 - Sunday, February 1, 2026
River Room, Marriott Chicago O'Hare
8535 West Higgins Road, Chicago, IL 60631

Attendees:

Gretchen Fieschko John Patterson
Kate Haller Dave Pearce
John Ireland Mathias Schmidt
Suzette James Fred Surrey
Wayne Kiefer Ned Timmerman (via zoom due to weather delays)
Chris Lowden Barb Wuebbels
Barb McDonough

Absent:

Edward Harriman

Meeting was called to order at 8:47 am by Barb McDonough

Honoring Recent Batten Angels

John Ireland read the names of the children who have passed since December 19, 2025. We had a moment of silence to honor their memory: Hannah Dolezal, Breanna Neveri, Selena White

Introduction and welcome our new board members: Chris Lowden, Ned Timmerman, Mathias Schmidt

Approval of the minutes from January 18, 2026 meeting.

John Patterson motioned to approve the minutes, John Ireland seconded. Mathias Schmidt abstained due to absence. The board voted to approve the minutes.

Financial report, review of 2025 year-end actual vs budget and overview of proposed 2026 budget:

- **Overview of BDSRA financial condition** for the past 5 years through December estimated year-end showed significant decrease in revenue and exceedingly high increase in expenses.
- **Class Coding system:** John Patterson presented and distributed suggested, improved, simplified Class Codes for more clearly tying Income/Expense items. There was general acceptance of this approach. *John P. suggested inclusion of write-up in minutes.*
- **Statement of Financial Condition and the proposed 2026 budget** presented by Wayne. The budget was *not* formally approved but a motion was made by John Ireland to approve a “provisional” budget until 2/9. John Patterson seconded, a majority of the Board approved the provisional budget for use until a formal budget is approved.
- **2024 and 2025 external audits to be completed by March** after which Labyrinth can file them with California and other states which require them in order to approve fundraising activities on line, e.g. Facebook, Instagram etc. *Kate and Barb W will take the lead in getting the data to Labyrinth*

BDSRA Organizational update, community updates and future communications, and proposed interim operations in 2026: Barb McDonough and Suzette James reported on Interim Leadership Team interactions with BDSRA staff and current priorities. Upon review of the Employee Handbook, Suzette and Barb recommended eliminating “Duvet” days (2 per employee per year) from the Handbook and updates will be reflected in Handbook. Also, importantly, staff will send self-assessments of their performance and outline job roles and responsibilities to Suzette and Barb M by February 9, 2026. Also, time and motion studies by each individual staff member in 15-minute increments will be required for a two-month period.

Town Hall: The Board discussed the upcoming BDSRA Town Hall scheduled for February 15 and how to prepare to address likely questions regarding the Restructuring and plans to continue to manage operations at the BDSRA. The Board created a draft presentation deck with key messaging. As Chair of the Board, Barb M. will present the key slides.

Overview and Updates on NIH Grant, COE and BDGRI: Ineka Whiteman via zoom

1. **Her history with BDSRA:** 2018 started with BDSRA Australia. 2021 started with Beyond Batters Disease Fund. 2023 started with BDSRA

2. **Centers of Excellence (COE’s):** First 9 announced July 2024

-Next general call for COE’s should be no later than Q2 2026

-BDSRA Members of the COE steering Committee: Suzette, Dave.

-The steering committee gives us a chance to provide feedback to the COE’s

Next steps/Actions re COEs:

-COE’s suggested expanding to International; BDSRA would not fund

-BDSRA needs to review the agreements which are located on the shared drive

-In recent years, BDSRA paid for each COE to send one representative to the Family Conference including the cost of travel, accommodation and meals

Dave suggested that given the current situation this requirement should be eliminated and suggested that it would be good to arrange a meeting between: Dave, Suzette, Gretchen,

Jennifer and Erika to discuss the current realities of BDSRA and relationship with COE’s

-The suggestion was made that BDSRA should add a section to our COE page which would allow patient feedback on their experiences with the COE’s

3. **Batten Disease Global Research Initiative (BDGRI):** For the 2026 round, commitments exist for: Australia - \$50k Aus, Canada - \$50K CAN, Others expressing interest in participating: NCL Stiftung, BBDF, Jack’s Thousand Days. Other outreach in progress and results will depend on the top projects chosen. BDGRI is expecting BDSRA to facilitate the funds transfer as it did in 2025.

4. **Batten Disease Clinical Research Consortium (BDCRC/NIH Grant)**

This is a 5-year grant with the possibility of two renewals. The grant is really about \$1M per year. BDSRA is supposed to receive about \$5K per year. Barb Wuebbels made the point that we need to educate our members that the NIH grant does not give BDSRA much financial help

Further Discussions regarding fundraising opportunities

Dave suggested that we should approach the people who used to be active members but have dropped out due to death and lack of interest; being frank – “We need your help”. This can also include members of the now defunct chapters. We might schedule reunion dinners in places where chapters used to exist. Possible single events for legacy families

BDSRA Board Committees

Fundraising: Suzette

Finance and Audit: Wayne

Human Resources: Barb M

Family Conference Committee: Suzette and Barb M

Marketing and PR: Gretchen and Larry McDonough

Advocacy: Ned and Chris expressed interest

Policy & Procedures: John Patterson volunteered to lead

The meeting was adjourned at 12:23 pm Sunday February 1

Note: We will be meeting more often as a full board in 2026 due to the current situation. All meetings are on Sunday at TBD pm. Proposed schedule:

1/30-2/1 in person, 3/22, 4/19 (Easter is 4/5 and Orthodox Easter is 4/12), 5/10 (Mother's Day is 5/17), 6/14, 7/9 in person at Conference, 8/16, 9/20, 10/18, 11/22, 12/20