BDSRA Foundation Board Meeting
July 9, 2026
8:30 am to 5:30 pm
Westin Chicago Lombard

Attendees:
Gretchen Fieschko
Kate Haller
John Ireland
Suzette James
Wayne Kiefer
Barb McDonough
John Patterson
Dave Pearce
Mathias Schmidt
Fred Surrey
Ned Timmerman
Barb Wuebbels

Absent:
Ed Harriman
Chris Lowden

Meeting was called to order at 8:43 pm by Barb McDonough

- **Honoring Recent Batten Angels**
  Fred Surrey led a moment of silence to honor all the Batten Angels.

Acceptance of the minutes from June 15, 2026 meeting: Kate motioned for the acceptance of the minutes. Barb M, seconded. All voted to accept the minutes.

By-Law Committee Update: John Patterson
Article VII Meetings Section 1 Board Meetings

- Suggested addition in *italics*: The Board of Directors shall meet *at least* quarterly on the designated date and time and by the specified means or at a specific place as set by the Board. Meeting notice may be given by phone, telegram, mail, electronic device, e-mail, or personal communication at least two (2) weeks prior to the meeting. A Special Meeting may be called with 24-hour prior notice that states the time, date, place, communication method, and cause for such meeting.
- Suggested addition in *italics*: *"Minutes of all Board Meetings will be posted on the BDSRA website within thirty (30) days of Board approval and will include any financial reports which were approved at the meeting."*
- **"ARTICLE VIII – COMMITTEES Section 1. Standing Committees"**

- Suggested changes in *italics*: “The following committees shall be established:
    - *Support Committee*
    - *Research Committee*
    - *Advocacy Committee*
    - Executive Committee
    - Finance *and Audit* Committee
    - *Development and* Fundraising Committee
    - *Human Resources Committee*
- The Standing Committee Chairpersons and members shall be appointed by the Board Chair.
- The Board Chair may appoint other committees as needed.”
- The Chairs of each committee, both Standing and Ad Hoc, were actioned to draft the purpose of that committee to be added to the By-Laws. Due by end of August.
- Additionally, the By-Laws will be amended to say that “in the event that there is no Executive Director, the Board will drive all decisions.”
- The legal name of our organization is Batten Disease Support and Research Association. Barb M will be statutory to refile this name with the Ohio Secretary of State.

Finance and Audit Committee Update: Presented by Wayne

Wayne presented updated year-to-date numbers for income and expenses, donations and bank balances. Also distributed three documents: Income Statement, Statement of Funds, and Balance Sheet. Thanks to John P for putting these documents together.

Research Update: presented by Mathias

Suzette moved (John I seconded) that Ineka’s and Heather’s hours related to Conference be paid out of restricted conference funds if such funds are available. This was approved by the Board.

Mathias moved (Kate seconded) that we enter a six-month contract with Ineka Whiteman. This was approved by the Board.

Town Hall in September: A critical message for the Town Hall audience regards the financial situation and explaining the categories of donations Restricted and Unrestricted, underscoring the need for Unrestricted donations to support ongoing operations of the organization.

Board Composition and Terms:

Barb M as chair requested Board members to cite their plans for continuing on the Board. Four board members will be retiring from the Board. As of August 1, 2026, John Ireland and Barb Wuebbels will discontinue. At year-end, Fred Surrey’s and Kate Haller's terms will expire. We thank all of these board members for their many years of dedicated service to the Board and the Community. Once the vacancies are announced, Board applications will be posted along with the skill sets desired in the third quarter of this year.

Support Committee: Chair Barb W

Barb W presented some ideas for family support that could become a part of the Support Committee. Since she will be leaving the Board, we need a new Committee Chair to take these on.

Closed Facebook Page:

John Ireland is currently the moderator of the BDSRA Closed Facebook page and will no longer be able to serve that function. Ned Timmerman offered to take that over so John will transition the role to Ned.

Advocacy Committee:
Ned presented some programs for advocacy focus: Family Communications, Family Advocacy, Family Support, Community Awareness (PR), Family Navigation for newly diagnosed families. Also suggested that the BDSRA should be updated and include the National ARC (Attachment, Regulation, Competency) so that families can navigate to their individual state resources. It was noted that due to restricted resources to update the website, we will bundle updates for a later date.

The Board moved to an Executive Session.

The meeting was adjourned at 5:38 pm.