BDSRA Foundation Board Meeting
June 15, 2026
4 pm – 7:00 pm PST

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

Meeting was called to order at 4:03 pm by Barb McDonough

- **Honoring Recent Batten Angels**
  Suzette James read the name of the children who have passed recently, followed by a moment of silence: Julius "Juju" Leggs McClary and Layla Hollin Graham

Acceptance of the minutes from May 18, 2026 meeting: Mathias motioned for the acceptance of the minutes. Barb M, seconded. All voted to accept the minutes.

Operations Update: Suzette James
Charity Engine, the BDSRA customer relationship management system (CRM): The database of donors continues to require significant corrections due to errors in addresses and coding. A plan for updating it will be discussed. A Board sub-group will be formed (John I. and Chris L) to develop processes and a plan to correct errors.

Staff model: will continue to move to contract/part-time/consultant vs full time employee staff. A job description for an *Operations manager* who does reconciliations as well as other administrative tasks will be created by Wayne and presented to Board at the July meeting. *Database manager*: role will be assigned metrics and deliverables focused on donor database management. A *Development manager* is an essential role for the near future with roles and responsibilities to be drafted for Board review.

Labyrinth: With the audits completed, Kate requested again to work with the database manager to get the updates to Labyrinth to enable fundraising again in some key states.

Finance and Audit Committee Update: Presented by Wayne

Wayne distributed the Statement of Activity by class and thanked John P for all his diligence and hard work on continuing the effort of correct fund accounting. The audits for 2023 and 2024 are complete. The 2025 audit will be completed later this year and then we will be caught up. Wayne presented the significant savings so far this year from restructuring and reducing operational expenses. He reinforced that BDSRA is behind budget in donations for operational expenses. Mathias stated that BDSRA should continue to have universal time sheets completed by each employee/contractor in order to understand and assign expenses toward Family Support and Conference.

Science Committee Update: Mathias presented

Previewed the keynote speaker for conference: Sharon King who will discuss gene therapy. Mathias also reviewed the focus/research objectives of the recipients of the BDGRI grants and noted that it would have been useful for the researcher to include how their basic research would translate to or inform future clinical research. Also stated, that future grants need to include more translational research.

Science committee was tasked to propose a path going forward with the consultancy agreement for Ineka Whiteman, topic to be discussed at July meeting during Executive Session.

Conference committee: Suzette and Barb

NOTE: Meet the Board will be during LUNCH ON FRIDAY from 12-1:30. All board members should plan to attend.

Suzette reported that we have more registrants than last year, ~ 220 people, we have distributed the stipends, the room block has been completely filled and is closed. The donations for conference are likely to be over last year and are 90% received. There will be a Fam Fund table to encourage new families this year.

Fundraising Committee: Suzette

Suzette updated the board that the **Board-driven fundraising appeal** via US Post letter to

donors in our database who have ever given $250 and above went out week of June 10. **Grants:** we continue to look for new grant opportunities. **Board Fam Fund:** *Thank you to the Board members who have contributed either to Conference, to Board Fam Funds for operations and any other areas. Reminder to consider donating to Board Fam Funds if you have not already and that these donations are publicly noted on the Fam Funds page with the balance as of this meeting, ~$16,000.*

Policy and Procedure Committee: John P.
John informed the board that Article of Incorporation (Ohio Secretary of State – old address) states that our registered name is: "Batten Disease Support and Research Association" but the Bylaws state that our name is "Batten Disease Support, Research and Advocacy Foundation". John hereby recommends that the Bylaws need to be updated to reflect the Articles of Incorporation and additionally our Tradename (as registered with Ohio Secretary of State) is "BDSRA Foundation."
ACTION: Website should be updated to state our full registered name as well as our DBA name and abbreviated name.

NB: John P also updated Mathias that our mission statement in the by-laws differs from the one presented by Mathias: The current By-laws contain the following:

"**Section 2. Mission and Vision"**

Our long-term vision is a world without Batten disease. Our mission is to support Batten families at whatever stage they are in their journey, fund and facilitate research, and advocate for treatments and a cure."

The suggested adjusted mission statement presented by Mathias:

"Adjusted" Mission statement

Our long-term vision is a world without Batten disease. Our mission is to support and advocate for Batten families, fund and facilitate research, treatments and a cure."

The phrase missing in the adjusted mission statement is "at whatever stage they are in their journey"

ACTION: The board needs to vote at the July meeting on whether to add the omitted phrase back in to the adjusted mission statement and then update the by-laws and website.

John P. also reviewed the standing and ad hoc committee names as stated in the by laws and requested the board continue to refer to the committees by the name in the by laws. Additionally, John requested that full list of chairs and members for each committee be outlined.

ACTION: complete full list of chairs and members by July board meeting.

BDSRA Standing Committees		
Proposed Name	**Previous name**	**Chair**
Support	New: Community Outreach & Engagement	Barb Wuebbels
Research	New: Science & Research	Mathias Schmidt
Advocacy	Advocacy	Ned Timmerman
Executive	Executive	Barb McDonough
Finance and Audit	Finance	Wayne Kiefer
Development & Fundraising	Fundraising	Suzette James
Human Resources	New: Human Capital	Barb McDonough

BDSRA Ad Hoc Committees		
Proposed Name	**Comment**	**Chair**
Conference	Includes Memorial and SIBS	Barb McDonough/Suzette James
Marketing & PR		Gretchen Fieschko
Strategic Planning		Gretchen Fieschko
Policy & Procedures		John Patterson

ACTION: Committee chairs requested to complete members list as well as review by-laws and develop plans to share with full board in upcoming meeting.

Advocacy Committee: Ned Timmerman

Ned presented an Advocacy Committee one year reactivation plan with these key components: Organize existing advocacy efforts, strengthen awareness and engagement, support families more effectively and build a stronger voice for the Batten community. The three areas of focus would be family navigation, legislative engagement and community awareness. The near-term priorities are to establish the committee, organize what already exists and create visible momentum.

PR/Social Media/website: Gretchen

Gretchen updated the board regarding a PR opportunity brought to us by Amanda Beedle to have a BDSRA spokesperson on Chicago Channel 32 Fox news in July. Mathias will be live via zoom with newscaster Natalie Bombke on July 10.

Wayne moved to adjourn the meeting, Suzette seconded. **The meeting was adjourned at 6:47 pm.**

NOTE: ***The Board was reminded that the July 9 board meeting will be held at 8:30 am in Lombard at the Westin and people should plan to fly in on Wednesday night for dinner and stay through the entire conference.***

Upcoming meetings:

Further monthly dates will be refined around previously stated dates. (8/16, 9/20, 10/18, 11/22, 12/20)