BDSRA foundation
Batten Disease Support + Research + Advocacy
Batten Disease Advocates for a Cure

BDSRA Board Meeting
July 10, 2025
8:00 am - 5:00 pm

Members Present

✓Darlene Royalty	✓Amy Fenton Parker	✓Wayne Kiefer
✓Barb Wuebbels	✓Barb McDonough	✓Fern Leal-Pardinas
✓Fred Surrey	✓ Kate Haller	✓John Patterson
✓Gretchen Fieschko	✓ David Pearce	
✓John Ireland	✓Suzette James	

Call to Order

The meeting was called to order by Darlene Royalty at 8:02 AM.

Reading of Names of Recent Batten Angels

Gretchen Fieschko read the names of our recent Batten Angels who have passed since February 1st, and we had a moment of silence to honor their memory.

Minutes

Kate Haller motioned to approve the minutes for board meeting of April 27th, 2025, which Gretchen seconded. Minutes have passed and will be posted on the BDRSA website.

President Report

- President's report presented by Amy
- Reviewed participation and success of the IBAD fundraising events.
  - Ex. Organized Virtual Runs with T-Shirt and participating teams
- Gave update on Support and Programs available to Batten community
- Gave update on Research and reviewed exciting news about research grant awards
- Gave update on Advocacy events
  - Letters to Congress and personal meetings with Congress Representatives
- Gave update on status of Memorial functionality/issues

- Memorial is up and running on the BDSRA website
- Software updates needed in order to maintain screen panels

- Discussed the power of social media and provided recommendations to the board:
  - Participate in Social Media posts and sharing of posts
  - Update and share LinkedIn Profiles
  - Suggested need to track funding received as a result of Social Media events and sharing

- Reviewed upcoming events at conference, such as Media coverage, Saturday night banquet, and Lincoln Children's Zoo event (sponsored by Sandhills Global)

- Discussed the need to create a Public Relations (PR) Policy and Press Kit

- Shared BDSRA Survey plans:
  - 3 Post Conference Surveys would go out after the conference regarding Conference over all, Childcare, and the Life Goes On program.
  - Annual satisfaction survey will go out again at end of year.

- Discussed sponsorships and sponsorship thank you letters
  - Do you know others?
  - Perhaps article on Saturday night dinners at Banquet which is one of many programs offered.

- Reviewed Goals and Objectives of Board and Organization.
  - Requests to Board include
    - Notes of appreciation and encouragement to staff are always appreciated
    - Engagement in activities and events whenever possible to show support

- **We affirmed the issuance of the following grants:**

Applicants	Funding Information	
Center	**Funding Requested in 2024**	**Amount Awarded**
Colorado Children's Hospital	$ 50,000.00	$ 47,591.00
Children's Hospital of Orange County	$ 50,000.00	$ 39,271.00
Kennedy Krieger Institute	$ 49,988.00	$ 39,078.00
Michigan Medicine	None requested	--
Nationwide Children's Hospital	$ 39,900.00	$ 23,411.00
NYU Lagone Health	$ 24,998.00	$ 22,608.00
Rush University Medical Center	$ 26,973.00	$ 25,089.00
University of North Carolina at Chapel Hill	$ 18,000.00	$ 14,000.00
University of Rochester	$ 50,000.00	$ 37,266.00
		$ 248,314.00

- A representative from every Center of Excellence was present at the Lincoln Conference.

- **We affirmed the issuance of the following grants:**

Batten Disease Global Research Initiative Grant Recipients 2025

Project	Institution	Primary Investigator	Grant Amount	Paid on	Ref #
Defining the anatomical basis of dysphagia or the inability to swallow in Batten Disease	Washington University in St. Louis, School of Medicine	Jonathan Cooper	$50,000.00	7/24/2025	ACH
Exploring the efficacy of bis(monoacylglycero)phosphate (BMP) synthesis pathway intermediates in treating CLN8 Batten disease in (BMP) synthesis pathway intermediates in treating CLN8 Batten disease in preclinical models	School of Clinical Medicine, University of Cambridge	Kasparas Petkevicius	$50,000.00	6/30/2025	Wire
Integrative -Omics Profiling and Biofluid Biosignature Development in Large Animal Models of CLN1, -2, -3, -5, and -6.	Sanford Research	Jill Wiemer	$55,000.00	7/30/2025	Check Processed
Repurposing drugs for Batten disease	UCL Great Ormond Street Institute of Child Health	Sara Mole	$65,000.00	7/30/2025	Wire
TPP1 Dried Bloodspot assay feasibility t	UCL Great Ormond Street Institute of Child Health	Wendy Heywood	$49,528.00	7/30/2025	Wire
			$269,528.00		

Note: The 6th grant was canceled due to employment contract between Researcher and University.

Financial Committee

- The Financial committee reviewed 4 options to replace Merrill Lynch
    - Vanguard, Chase, Thrivent, and Fidelity
    - Received overview comparison of fees and services offered.
    - Tabled further discussion pending more information

- Report/updates were presented by Fred
    - Fred reviewed the y-t-d Budget vs Actual
    - Confirmed that if donations are requested to go to a specific fund, that every effort is made to make sure that they go to the requested fund.

- As part of the 990 Audit, a time study is done each year to track the hours spent that are allocated for a specific category (Ex. Research, Advocacy, Conference, et.) It was suggested that we track and included Zoom usage to allocate costs appropriately.

- Wayne motioned that beginning 7/1/25, to allocate the compensation for the **Head of Research and Medical Affairs** and the compensation for the **Director of Family Support** to appropriate restricted funds.
    - Darlene seconded the motion.
    - Motioned passed

- There were many questions and discussions to clarify income reports

- Discussed the possibility of changing accounting practice from Accrual approach to Cash Basis approach – discussion tabled as change cannot be made mid-year.

- Fred Surrey announced that he is stepping down as treasurer immediately due to the time constraints needed to provide to this position.

- John Patterson motioned the following:

    - *Whereas* it is necessary to provide timely and accurate financial information to the BDSRA board and other interested parties,
    - *And whereas* it is necessary to provide financial information, which is segregated by funds,
    - *Be it resolved* that all members of the Finance Committee will be given read-only access to all financial data belonging to BDSRA including, but not limited to, the QuickBooks database, the Charity Engine database, statements to all accounts at banks, investment houses and other financial institutions within the limits of the current number of licenses and existing contracts.
    - *Be it further resolved,* all members of the Finance Committee will have access to all documents related to the finances of BDSRA including, but not limited to, the chart of accounts, any policies and procedures which currently exist, historical bank and investment statements and any other documents which are pertinent to the finances of BDSRA.
    - *Be it further resolved* that all members of the Finance Committee will have unrestricted access to all members of the BDSRA staff and all accounting services currently employed by BDSRA including, but not limited to, Robert Mackey and Don Wells in consultation with the Chief Executive Officer.
    - *Be it further resolved* that the Finance Committee will review and modify if necessary or establish policies and procedures which will lead to monthly financial reports which may be easily segregated by fund. Templates for the proposed reports will also be prepared. Such policies, procedures and templates will be presented for reviewed and approved by the BDSRA Board within three months of the approval of this resolution.
    - *Be it further resolved* that within three months of the approval of the policies, procedures and templates by the Board the Finance Committee will begin issuing such financial reports within ten days of the end of each month.
    - The above Motion was passed by the following board members in attendance (Darlene Royalty, Barb Wuebbels. Gretchen Fieschko. John Ireland, Barb McDonough, David Pearce, Suzette James, Wayne Kiefer, Fern Leal-Pardinas and John Patterson). The following 2 board members abstained from voting: Fred Surey and Kate Haler.

- **Additional notes:**

    - Conferences and donations are currently down for ALL non-profit organizations.
    - Discussed media promotion ideas; ex. PSAs on TikTok, Instagram and Facebook

Fundraising

- Suzette presented Fundraising Committee update.
    - Announced/promoted Noah's Hope fundraiser scheduled for Nov 9, 2025
    - Discussed other fundraising ideas/options (Script, online Auction Items, Raise Right)

- Wayne reviewed Fam Funds report.
    - Fam Funds are currently ahead of targeted budget.

Conference

- Amy provided update 2025 Family Conference Sponsorships, registrations, programs, and other conference details.

- Darlene announced 2026 Family Conference set to take place in Lombard, IL from July 9-12, 2026 at the Westin Lombard Marriott

Communication Improvement Initiatives

- The Board will schedule "Ask the Board" meetings on a quarterly basis
    - Meetings will be scheduled for both East and West Coasts in order to accommodate more participants. More information to come.
    - Representatives from the Board will be present at all meetings.
    - All are welcome to attend

- Email contact information will be provided for all board members so they can be contacted directly.

- Fern presented "The 8 Foundational Pillars of the BDSRA Board of Directors" to be embraced by all board members. Foundations include (more details to come):
    - Transparency
    - Trust
    - Communication
    - Family-Centered Service
    - Stewardship
    - Collaboration
    - Inclusion
    - Accountability

Elections of New Officers

- Dave Pearce nominated the following considerations for the open positions:
  - Chair: Barb McDonough
  - Vice Chair: Suzette James
  - Treasurer: Wayne Kiefer
  - Secretary: Gretchen Fieschko
    - Dave Pearce motioned to accept nominations
    - John Ireland seconded
    - Motion passed

- Positions of the Chair, Vice-Chair, and secretary will be effective 1-1-2026

- Treasurer will be effective immediately due to Fred stepping down

- Position-elects will "shadow" the current position representatives for the remainder of the year, and attend future Executive Board meetings in preparation of transition.

Closing Comments made by Darlene

- Darlene made motion to adjourn. Wayne seconded the motion.
  - ADJOURNED 5:07 CT

<u>Next Meeting Dates</u>

- October 26, 2025 – 1 PM Eastern Time
- January 30-31, 2026
- April 2026 TBD
- July 9, 2026 – 9 AM Central Time