BDSRA foundation

Batten Disease Advocates for a Cure

show me the PATH TO A CURE

July 12 - 14 • St. Louis, Missouri

Two roads diverged in a wood, and I –
I took the one less traveled by,
And that has made all the difference.

- *Robert Frost*

Dear Families,

We often talk about the "Batten Journey," but we rarely talk about the path we walk and where it all began. Whether your 2024 path included Advocacy during Rare Disease Week in February or raising awareness during International Batten Disease Awareness Day, we are so glad that your 2024 path has led you to St. Louis this week.

Thank you for your feedback on last year's conference. We took it all to heart, and, as a result, this year's conference is dynamic. One-third of families here are new to the conference, so be sure to welcome them. Grandparents and Support People, we're glad you are here! The Life Goes On group and SIBs have special activities and outings, so look for them on the agenda and in the app. FREE CHILDCARE is available for Little Explorers 5 and under, and Explorer Day Camp is open to affected loved ones of all ages.

Whether you are actively caring, living with grief, or supporting a loved one, everything is open to you. If you are unsure of what to choose, talk to other attendees or ask our team. Friday and Saturday Breakouts by CLN Types and Bereavement for Moms, Dads, and Grandparents, have volunteer moderators who received training in June. Please look for your designated area to meet via signage or ask for help. Take advantage of all the sessions the conference has to offer and look for select sessions you missed on the conference website in the weeks to come.

We rearranged the agenda, decided to forgo a keynote speaker, and planned to dive right into Batten disease research. There is so much to share! Additionally, every family attending can participate in research studies while you are here, and there are other studies you can do from the comfort of your home. Please check in for appointments at the Research Study Registration table. We are grateful for the collaboration of all the Batten Researchers and Clinicians in making this possible and their willingness to share all the information gathered here. Research is the path that will lead us to a cure, and your participation is important.

We believe this year's conference offers something for every member of our Batten community. Planning for financial needs, NeuroJourney, and State Policy are just a few. Remember that Ask-A-Doc and Ask-A-SIB are not only for parents but for everyone who experiences life with an affected loved one. Think about how your relationship correlates with those you accompany on the Batten journey and what might be of most value to you.

The truth is that all of us took the path less traveled to get to this conference. It's the path so few know about but one we share on the Batten journey. We are committed to walking with you every step of the way, and we hope that makes all the difference.

Amy Fenton Parker
President & CEO

BDSRA foundation

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

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2024 FAMILY CONFERENCE PROGRAM

Thursday, July 11		
Time	**Event**	**Meeting Room**
8:30 am-5:00 pm	Board Meeting	Lindbergh
4:00 pm-7:00 pm	Families Check-in / Information Desk	Concourse Foyer
6:00 pm-7:00 pm	New Families & Buddies Orientation & Reception	Gatwick
6:00 pm-7:00 pm	Grandparents & Extended Family Reception	Orly B
6:00 pm-7:00 pm	Donors' Reception	The Library (beside hotel lobby)
6:30 pm-9:00 pm	SIBs Swimming, Dinner & Games	Outdoor Pool
7:00 pm-9:00 pm	Welcome Reception - *Everyone Is Welcome!*	Concourse A/B
9:00 pm-11:30 pm	Poker!	Lindbergh
9:00 pm-Until	SIBs Outing (21+)	Offsite

Friday, July 12		
Time	**Event**	**Meeting Room**
6:00 am-7:15 am	Yoga *Provided by: Lori Brown, BDSRA Canada*	Lambert D
7:30 am-8:00 am	Prayer	Orly B
7:30 am-5:00 pm	Families Check-in / Information Desk	Concourse Foyer
7:30 am-5:00 pm	Explorers' Day Camp	Lambert
7:30 am-9:00 am	*Breakfast	Concourse A/B
8:30 am-5:00 pm	Exhibits Open	Concourse Foyer
8:30 am-9:00 pm	Memorial Room Open	Renaissance (12th floor)
9:00 am-9:15 am	Welcome & Housekeeping Information Speaker: Amy Fenton Parker, BDSRA	Concourse C/D
9:15 am-12:30 pm	The Science – Research Session Speakers: Dr. Jon Cooper, Washington University in St. Louis Dr. David Pearce, Sanford Research Dr. Tom Wishart, University of Edinburgh Dr. Ineka Whiteman, BDSRA	Concourse C/D
9:15 am-10:30 am	SIBs Fun & Games!	Lindbergh
10:30 am-10:45 am	Break	Concourse Foyer
10:45 am-12:30 pm	SIBs Breakout Sessions	Ladue, Lindbergh & Truman
10:45 am-12:00 pm	SIBs Branches of Hope: Reaching for the Light Speaker: Linsey Hammon, Lighthouse of Hope	Orly B
12:30 pm-2:00 pm	*Lunch	Concourse A/B
2:00 pm-3:15 pm	Breakout Sessions: 1. # Case Management 101 Speaker: Dr. Joe Vigil, Department of Veterans Affairs 2. Palliative Care: Debunking the Stigmas Speakers: Dr. Heather Brown, Kennedy Krieger Institute Dr. Kourtney Santucci, Children's Hospital Colorado 3. Finding Guidance Speaker: Maria Hopfgarten, Courageous Parents Network	Concourse C/D Gatwick Heathrow
2:00 pm-3:15 pm	Life Goes On: Acknowledging the Unseen Speaker: Linsey Hammon, MS, Lighthouse of Hope	Orly B
2:00 pm-3:30 pm	Pet Therapy *Provided by: Dogs on Duty*	Lambert (Explorers' Camp)
2:00 pm-4:45 pm	SIBs Breakout Sessions	Ladue, Lindbergh & Truman
3:15 pm-3:30 pm	Break	Concourse Foyer

Meeting rooms are on the first floor, unless otherwise indicated

*Pre-registration Required # - Recommended for First-time Attendees

2024 FAMILY CONFERENCE PROGRAM

CONTINUED

	Friday, July 12, *continued*	
3:30 pm-4:45 pm	Support Groups By CLN Type (for families with living children) Grandparents/Family Supporters & Bereaved	To Be Announced
4:45 pm-5:15 pm	SIBs Group Picture	Concourse Foyer
5:30 pm-9:00 pm	*SIBs Outing: City Museum Bus departs from exit near Orly Room	Offsite
5:30 pm-10:00 pm	*Life Goes On Outing: Dinner & Comedy Club Bus departs from exit near Orly Room	Offsite
8:00 pm-10:00 pm	Trivia Night!	Concourse A/B

Saturday, July 13		
Time	**Event**	**Meeting Room**
6:00 am-7:15 am	Yoga *Provided by: Lori Brown, BDSRA Canada*	Lambert D
7:30 am-8:00 am	Prayer	Orly B
7:30 am-4:00 pm	Families Check-in / Information Desk	Concourse Foyer
7:30 am-5:00 pm	Explorers' Day Camp	Lambert
7:30 am-9:00 am	*Breakfast *Board members will be available for questions*	Concourse A/B
8:30 am-4:00 pm	Exhibits Open	Concourse Foyer
8:00 am-6:00 pm	Memorial Room Open	Renaissance (12th floor)
8:30 am-8:40 am	Welcome & Housekeeping Information Speaker: Amy Fenton Parker, BDSRA	Concourse C/D
8:30 am-10:00 am	SIBs Breakout Sessions	Ladue, Lindbergh & Truman
8:40 am-10:00 am	Ask-A-Doc Speakers: Dr. Nicholas Abreau, NYU Langone Health Dr. Scott Demarest, Children's Hospital Colorado Dr. Yael Shiloh-Malawsky, UNC School of Medicine Dr. Jennifer Vermilion, University of Rochester Medical Center Dr. Ray Wang, Children's Hospital of Orange County	Concourse C/D
8:45 am-12:45 pm	*Life Goes On: Create & Sip	Orly B
10:15 am-2:45 pm	*SIBs Outing: Science Center Bus departs from exit near the Orly Room	Offsite
10:15 am-11:30 am	Breakout Sessions 1. Behavior, Cognition & Learning Speakers: Dr. Charles Albright, Nationwide Children's Hospital Bekah Bowman, Author, *Can't Steal My Joy* Dr. Andrea Miele, Children's Hospital Colorado Dr. Kourtney Santucci, Children's Hospital Colorado Dr. Jessica Scherr, Nationwide Children's Hospital 2. How to Develop A Life Plan For Your Child With Disabilities Speaker: Kacy Seitz, ChFC,® CLTC,® ChSNC,® Northwestern Mutual 3. Advocacy Speaker: Emily Stauffer, EveryLife Foundation	Concourse C/D Gatwick Heathrow
11:30 am-11:45 am	Break	Concourse Foyer
11:45 am-12:45 pm	Support Groups By CLN Type (for families with living children) Grandparents/Family Supporters & Bereaved	To Be Announced
12:00 pm-4:30 pm	Centers Of Excellence	Lindbergh
12:00 pm-1:45 pm	*Lunch	Concourse A/B

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*Pre-registration Required # - Recommended for First-time Attendees

2024 FAMILY CONFERENCE PROGRAM

CONTINUED

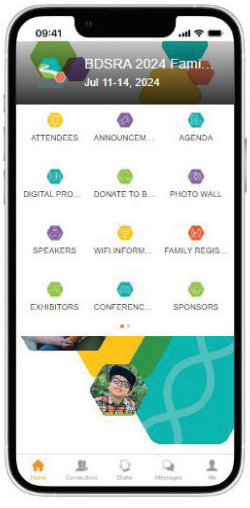
	Saturday, July 13, *continued*	
1:45 pm-3:00 pm	Breakout Sessions 1. Managing Caregiver Stress/Burnout Speaker: Dr. Joe Vigil, Department of Veterans Affairs 2. Ask Me Anything Moderator: Dr. Jon Cooper, Washington University in St. Louis 3. ABLE Accounts vs. Special Needs Trusts: An In-Depth Discussion Speaker: Kacy Seitz, ChFC,® CLTC,® ChSNC,® Northwestern Mutual	Concourse C/D Heathrow Gatwick
2:00 pm-3:30 pm	Music Therapy: An Engaging Experience Speakers: Amanda Wick, MMT, MT-BC Crystal Weaver, MHA, LPC, CRC, MT-BC	Lambert (Explorers' Camp)
3:00 pm-3:15 pm	Break	Concourse Foyer
3:00 pm-4:30 pm	SIBs: Swimming Ages 6-12	Outdoor Pool
3:15 pm-4:30 pm	Breakout Sessions 1. Ask-A-SIB 2. Anticipatory Grief Speaker: Dr. Joe Vigil, Department of Veterans Affairs 3. Brainstorming for Future Programing Moderators: John Patterson, BDSRA Board Member Brian Bertsch, Batten Grandparent	Orly B Heathrow Gatwick
5:15 pm-6:00 pm	Kids Prepare For Parade	Gatwick
6:00 pm-11:00 pm	*Dinner Dance	Concourse A/B/C/D

Sunday, July 14		
Time	**Event**	**Meeting Room**
8:00 am-10:00 am	*Breakfast	Concourse A
9:00 am-10:30 am	Celebration Of Life	Renaissance (12th floor)

Download Our BDSRA Annual Family Conference Mobile App

FULL AGENDA, SPONSORS, ATTENDEE CONNECTIONS, CONFERENCE INFO AND MORE ALL AT YOUR FINGERTIPS!

AGENDA UPDATES AND ADDITIONAL INFORMATION ABOUT THE SESSIONS ARE AVAILABLE IN THE CONFERENCE APP.



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2024 FAMILY CONFERENCE PROGRAM

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Thursday, July 11		
Time	**Event**	**Meeting Room**
6:30 pm-9:00 pm	Swimming, Dinner & Games	Outdoor Pool
9:00 pm-Until	Outing (21+)	Offsite

Friday, July 12		
Time	**Event**	**Meeting Room**
9:15 am-10:30 am	Fun & Games!	Lindbergh
10:45 am-12:30 pm	Breakout Sessions	Ladue, Lindbergh & Truman
10:45 am-12:00 pm	Branches of Hope: Reaching for the Light	Orly B
2:00 pm-4:45 pm	Breakout Sessions	Ladue, Lindbergh & Truman
4:45 pm-5:15 pm	Group Picture	Concourse Foyer
5:30 pm-9:00 pm	*Outing: City Museum Bus departs from exit near the Orly Room	Offsite

Saturday, July 13		
Time	**Event**	**Meeting Room**
8:30 am-10:00 am	Breakout Sessions	Ladue, Lindbergh & Truman
10:15 am-2:45 pm	*Outing: Science Center Bus departs from exit near the Orly Room	Offsite
3:00 pm-4:30 pm	Swimming Ages 6-12	Outdoor Pool

Life Goes On

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Friday, July 12		
Time	**Event**	**Meeting Room**
2:00 pm-3:15 pm	Acknowledging the Unseen Speaker: Linsey Hammon, Lighthouse of Hope	Orly B
5:30 pm-10:00 pm	*Outing: Dinner & Comedy Club Bus departs from exit near the Orly Room	Offsite

Saturday, July 13		
Time	**Event**	**Meeting Room**
8:45 am-12:45 pm	*Create & Sip	Orly B

Sunday, July 14		
Time	**Event**	**Meeting Room**
9:00 am-10:30 am	Celebration Of Life	Renaissance (12th floor)

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BDSRA Staff

Amy Fenton Parker,
President & CEO

As the chief steward, Amy creates a caring environment that the keeps the patient and family at the center of care in everything BDSRA does to support, advocate, and facilitate research for treatments and a cure. The President & CEO works with the Board of Directors and staff to create and achieve mission-driven goals, further develop and implement the strategic plan and objectives, and cultivate partnerships for greater community impact and the financial health of BDSRA. Please contact Amy with stewardship, fundraising and legacy questions, industry collaboration, or assistance learning more about BDSRA.

Patrick Kotnik,
Marketing & PR Coordinator

As Marketing & PR Coordinator, Patrick works closely with staff to develop and execute BDSRA's marketing needs. He is an expert multitasker who is tech-savvy with advanced understanding of social media marketing (organic and paid), website maintenance, graphic design, copywriting/editing, and messaging for internal and external stakeholders. This includes content on BDSRA's social media platforms, The Illuminator newsletter, website modifications, Linktree, virtual event registration, and printed materials. For questions or inquires pertaining to BDSRA's social media, website, or marketing campaigns – please contact Patrick.

Noah Siedman,
Database Manager

As database manager, Noah is responsible for collecting, tracking, and maintaining incoming grants, donations, and registration information. He works closely with the Office Manager to ensure that donations are properly stewarded throughout the gift acceptance process. Noah builds accessible, sustainable systems to inform decisions regarding development, marketing, and advocacy so that BDSRA can present a data-driven picture of its status and prepare for future growth. A rare sibling and advocate, Noah brings an important perspective to BDSRA with his commitment to building inclusive rare communities. For questions regarding the gift acceptance process, grants and tributes, please contact Noah.

Ineka Whiteman, Ph.D.,
Head of Research & Medical Affairs

As BDSRA's Head of Research & Medical Affairs, Dr. Whiteman oversees the Foundation's research investment and grant process for all Batten disease CLN types, to ensure the organization fosters and supports the best possible research into Batten disease in the United States and internationally. Dr. Whiteman also explores and identifies opportunities for new research avenues and partnerships, works with industry partners on research pipelines and clinical program opportunities, and builds authentic, collaborative relationships with key groups, including our families, researchers, clinicians, advocates, and industry partners. She maintains current knowledge of the scientific and clinical research landscape and leads the Foundation's scientific education initiatives. Please contact Dr. Whiteman for any questions related to Batten disease research and clinical trials.

Linda Barkhurst,
Office Manager

As BDSRA Foundation's Office Manager, Linda leverages her extensive knowledge and administrative experience in the healthcare industry to organize the day-to-day needs and objectives of BDSRA. These include donation management, business inquiries, grant fulfillment, and supporting the team with multiple other general needs.

BDSRA Board of Directors

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PARTICIPATE IN RESEARCH STUDIES

Every family has the opportunity to participate in research studies at this year's conference. For more information or to make an appointment, visit the Research Study Registration table.

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