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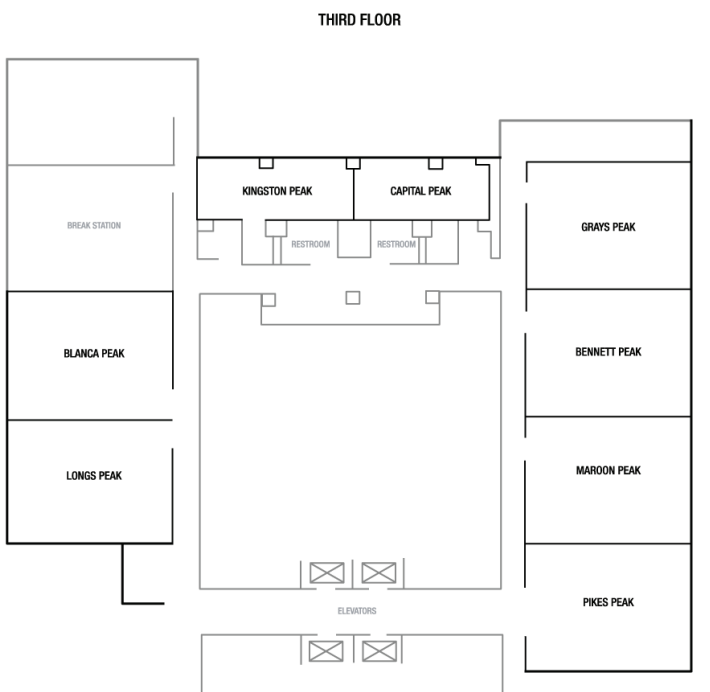
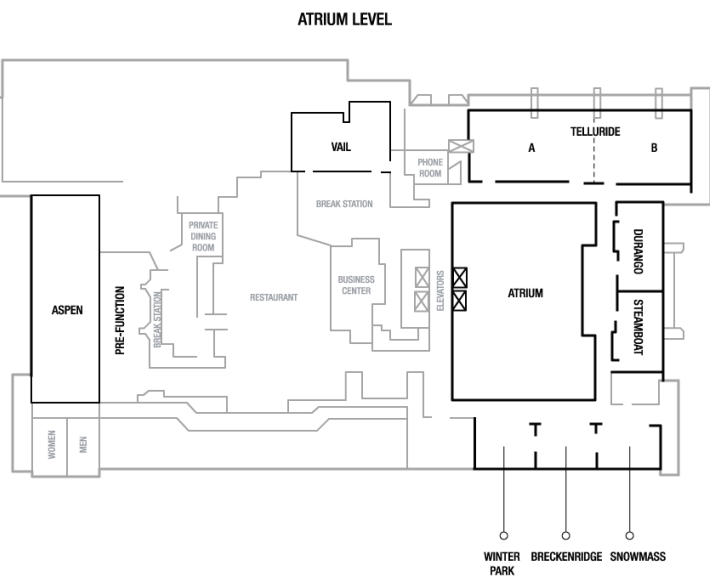
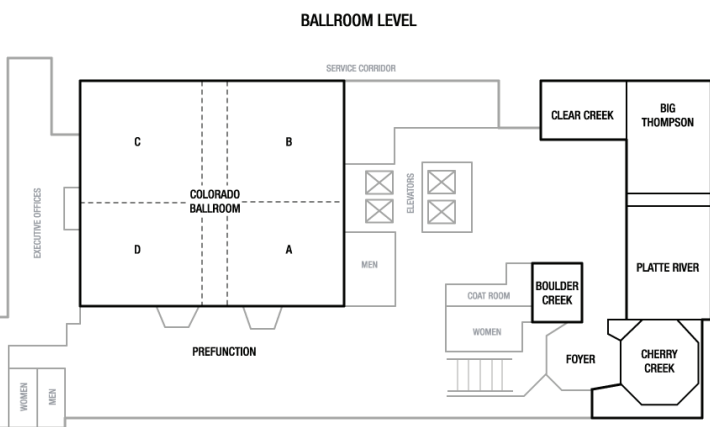
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HOTEL LAYOUT AT-A-GLANCE



2020 BDSRA Family Conference
BDSRA invites you to join us
in Cleveland, Ohio
July 9-12, 2020

InterContinental Hotel Cleveland
9801 Carnegie Avenue | Cleveland OH 44106

CONNECT with BDSRA

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CLIMBING TO A CURE

BDSRA Conference
Denver, Colorado
July 18-21, 2019

BATTEN DISEASE
Support and Research Association

2019 FAMILY CONFERENCE PROGRAM



I am so delighted to be joining all of you for my first BDSRA Family Conference. As you may have heard, I have worked in nonprofit operations for 20 years in some capacity, including time leading a rare disease support organization. I hope to bring that experience with me to work on the behalf of the families of the BDSRA. Over the next few days, I invite you to stop me and introduce yourself and share your story. You may see me in the halls with my boys; Tremayne, my husband and our sons Alex (5) and Andrew (5 months); they are as excited as I am to get to know you.

- Tauna Batiste, Executive Director

Thursday, July 18

8:00am-4:00pm:	Golf Outing <i>Coordinated by Randy Royalty</i>
8:00am-4:30pm:	Board Meeting <i>Vail</i>
Noon-8:00pm:	Conference Registration and Scientific/Medical Studies Registration <i>Platte River</i>
6:30-7:30pm:	Grandparent/Extended Family Happy Hour: Grandparents, aunts, uncles, and all other adult extended family members come together to connect and have a good time. <i>(Light appetizers and a cash bar will be available)</i> <i>Hotel Bar Area</i>
6:00-7:30pm:	New Family Meet and Greet: Families new to the conference meet with BDSRA Family Liaison, Tracy Kirby , and their buddy families to talk about what to expect over the next three days and get to know one another. Joe Vigil, PhD , a bereaved parent, private practitioner, and rehabilitation psychologist, will also join this session for families new to our conference and Batten disease. <i>Big Thompson</i>
7:30-9:30pm:	SIBS Pizza and Pool Party: All SIBS 6 years and up are invited to a Pool Party! Come meet new SIBS, connect with old friends, and have fun. <i>(Lifeguards will be provided)</i> <i>Pool</i>
7:30-9:30pm:	Welcome Reception: All conference attendees welcome! <i>(Light snacks and a cash bar will be available)</i> <i>Colorado Ballroom A & B</i>
9:00pm-Midnight:	Texas Hold’Em Poker Tournament: All conference attendees are invited to participate in a Texas Hold’Em Poker Tournament <i>Clear Creek</i>
9:30-11:00pm:	Adult SIBS meet up (21+) <i>Meet in Hotel Lobby</i>

Friday, July 19

7:45-8:45am:	Breakfast on your own
8:30am-6:00pm:	Conference Registration and Scientific/Medical Studies Registration <i>Platte River</i>
8:00am -8:45am:	First Time/Newly Diagnosed Session: Joe Vigil, PhD , a bereaved parent, private practitioner, and rehabilitation psychologist, answers your questions about conference and Batten disease. <i>Big Thompson</i>
8:15am -8:45am:	Presentation of the New Batten Disease Memorial: Please join us for the dedication of the new Batten Disease Memorial commemorating those lost to Batten disease. <i>Telluride B</i>
8:30am-Noon:	Childcare: Staffed by nurses and highly trained volunteers, our childcare is for those affected by Batten disease of all ages and SIBS 2-5 years old. <i>Snowmass, Breckenridge, Winter Park, Durango, Steamboat</i>
9:00am- 10:00am:	Announcements and Opening Session <i>Colorado Ballroom A & B</i>

Welcome: New **BDSRA Executive Director, Tauna Batiste**

Keynote Speaker Dr. Derek Weaver: **Dr. Weaver** will share his experience as both a Batten SIB and a physician that sees Batten patients.

10:00am-10:00pm: **The Batten Disease Memorial** is on display throughout the weekend for reflection and remembrance. *Telluride B*

10:15-11:45am: **Breakouts by Type of Batten Disease:** These sessions are for parents to meet one another and talk about the unique challenges they face.

CLN1	Moms	<i>Clear Creek</i>
CLN1	Dads	<i>Big Thompson</i>
CLN2	Moms	<i>Vail</i>
CLN2	Dads	<i>Colorado Ballroom B</i>
CLN3	Moms	<i>Aspen</i>
CLN3	Dads	<i>Colorado Ballroom A</i>
CLN5-8	Moms	<i>Telluride A</i>
CLN5-8	Dads	<i>Cherry Creek</i>
Undiagnosed	Moms	<i>Boulder Creek</i>
Undiagnosed	Dads	<i>Platte River</i>

10:15-11:45am:	Grief and Family Session: Bereaved family members can meet with Joe Vigil, PhD , a bereaved parent, private practitioner, and rehabilitation psychologist to talk about the complexities of grief and share their experiences. <i>Longs Peak</i>
10:15-11:45am:	Grandparents and Extended Family Peer Support: Grandparents, aunts, uncles and others closely involved with Batten families share their experiences with each other. <i>Blanca Peak</i>
Noon-1:00pm:	Lunch <i>(meal ticket required)</i> <i>Colorado Ballroom C & D</i>
1:00-5:00pm:	Life Goes On Outing: A special time for parents (only) who have lost a child to Batten disease to do something fun together. This year will be a Denver City Overview Tour with stop at Cherry Creek. A knowledgeable guide will whisk you around to see top urban attractions, including the State Capital, Union Station, lower Downtown, Denver Civic Park and the Denver Art Museum. <i>Meet in Hotel Lobby</i>
1:00-5:00pm:	Childcare: Staffed by nurses and highly trained volunteers, our childcare is for those affected by Batten disease of all ages and SIBS 2-5 years old. <i>Snowmass, Breckenridge, Winter Park, Durango, Steamboat</i>
1:15-2:15pm	CONCURRENT SESSIONS

Physical Therapy for Batten Patients

Danielle Peifer, PT, DPT from **Nationwide Children’s Hospital** will talk with families about the importance of physical therapy for Batten patients covering such topics as transfers, body mechanics, and equipment. There will be plenty of time for questions and demonstrations. *Clear Creek*

Music Therapy 101: Chiltern Music Therapy therapist, **Rebecca Atkinson**, will discuss the impact music therapy can have and work with parents and extended family members to teach them techniques to use at home. *Cherry Creek*

Partnering with BDSRA to Create a Lasting Legacy For Your Child: Parent panelists **Heather Dainiak**, **Tony and Katie Ferrandino**, and **Bob Jensen** will share their personal stories of their desire to make a difference and have an impactful legacy in their children’s memory. Panelists will share how the larger community can also participate in remembering their child by supporting BDSRA’s mission. The session will also feature a Q&A moderated by **BDSRA Executive Director, Tauna Batiste** and fundraising professional **Amy Funk** of **Ter Molen Watkins & Brandt, LLC** to answer questions about how you can create a community around your child’s legacy. *Big Thompson*

2:30-3:30pm	CONCURRENT SESSIONS
	Lifetime Education in Batten Disease: The JNCL Childhood Dementia and Education textbook is here! Join contributors Bengt Elmerskog , Anne-Grethe Tassebro Heather Adams, PhD , Rebecca Atkinson , Linn Sophie Rian , and Ida Holmen . Together they will share highlights from the book and the overall JNCL and Education Project, and will answer your questions about lifetime education for our loved ones with all forms of Batten. <i>Cherry Creek</i>
	Realm of Caring Presents: Cannabinoid Therapy Support, Education & Research for Batten Disease. Courney Collins , Education Director at the Realm of Caring, will answer your questions regarding the use of cannabinoids for Batten children and discuss their current research efforts. <i>Big Thompson</i>
3:45-4:45pm:	Breakouts by Type of Batten Disease: These sessions are for parents to meet one another and talk about the unique challenges they face.
	CLN1 Moms <i>Clear Creek</i>
	CLN1 Dads <i>Big Thompson</i>
	CLN2 Moms <i>Vail</i>
	CLN2 Dads <i>Colorado Ballroom B</i>
	CLN3 Moms <i>Aspen</i>
	CLN3 Dads <i>Colorado Ballroom A</i>
	CLN5-8 Moms <i>Telluride A</i>
	CLN5-8 Dads <i>Cherry Creek</i>
	Undiagnosed Moms <i>Boulder Creek</i>
	Undiagnosed Dads <i>Platte River</i>
3:45-4:45pm:	Grandparent and Extended Family Ask-A-Researcher: Join us for an hour of Q&A with Dr. Jon Cooper , from Washington University School of Medicine . Dr. Cooper will answer your questions about Batten disease, its progression, and the latest research. <i>Blanca Peak</i>
4:45-9:15pm:	Load Buses for SIBS Outing to Boondocks Come join the fun! The SIBS group will enjoy a night of fun with dinner and 3 hours to play. Activities include: bowling, laser tag, arcade games, miniature golf, bumper boats, Go-Karts, Rookie Track, and a ropes course! All games and activities are included, no cash is needed. <i>(Dinner provided)</i> (SIBS Shirts Required) <i>Meet in Hotel Lobby at 4:45pm</i>
6:00-7:15pm:	Dinner Buffet <i>(meal ticket required)</i> <i>Colorado Ballroom C & D</i>
9:15pm:	SIBS return from Boondocks Any child under the age of 13 will have to be picked up by a guardian <i>Meet in Hotel Lobby</i>
8:00-10:00pm:	Trivia game: A fun evening of team-based trivia <i>Aspen</i>

Saturday, July 20

7:45-8:45am:	Breakfast on your own
8:00am-6:00pm:	Conference Registration and Scientific/Medical Studies Registration <i>Platte River</i>
8:15am- 8:45am:	Genetics and Batten 101: Hemanth Ramesh Nelvagal, PhD and Keigo Takahashi from Washington University School of Medicine will conduct a brief lecture on genetics basics. <i>(Coffee, tea, and water will be provided)</i> <i>Colorado Ballroom A & B</i>
8:30am-1:00pm:	Load Buses for SIBS Outing to The Denver Museum of Nature & Science: The Denver Museum of Nature & Science is the Rocky Mountain region’s leading resource for informal science education. A variety of exhibitions, programs, and activities help Museum visitors experience the natural wonders of Colorado, Earth, and the universe. The SIBS group will get the opportunity to experience the museums exhibits which include: Prehistoric Journey, Expedition Health, Gems and Minerals, Space Odyssey, Wildlife Exhibits, Egyptian Mummies, Our Senses and Leonardo da Vinci: 500 Years of Genius. <i>(Lunch provided)</i> (SIBS Shirts Required) <i>Meet in Hotel Lobby at 8:30</i>
8:30am-Noon:	Childcare: Staffed by nurses and highly trained volunteers, our childcare is for those affected by Batten disease of all ages and SIBS 2-5 years old. <i>Snowmass, Breckenridge, Winter Park, Durango, Steamboat</i>

9:00-9:45am:	Clinical Trial and Translational Research Update: BDSRA Board Member Dr. David Pearce from Sanford School of Medicine will provide an overview of current and upcoming trials <i>(Coffee, tea, and water will be provided)</i> <i>Colorado Ballroom A & B</i>
9:45am-Noon	Batten Research Overview – Researchers share latest basic research findings <i>(Coffee, tea, and water will be provided)</i> <i>Colorado Ballroom A & B</i>
10:00am-10:00pm:	The Batten Disease Memorial is on display throughout the weekend for reflection and remembrance. <i>Telluride B</i>
10:00am-10:45am:	Advocacy Overview: Steve Silvestri from the Everylife Foundation will give an overview of Advocacy and help participants craft their personal story. <i>Big Thompson</i>
11:00am- Noon:	Call to Action: Interested in making a legislative difference now? Join us to learn about Newborn Screening and the action steps we can take as a community to ensure Batten is included in the future. <i>Big Thompson</i>
Noon-1:00pm:	Lunch (meal ticket required) <i>Colorado Ballroom C & D</i>
1:00-2:00pm:	Research Open House & Poster Session – View posters outlining the work of Batten researchers and industry partners from all over the world. Researchers will be on hand to answer questions. <i>(Coffee, tea, and water will be provided)</i> <i>Aspen</i>
1:00-3:00pm:	Pet Therapy for affected children <i>Snowmass, Breckenridge, Winter Park, Durango, Steamboat</i>
1:00-5:00pm:	Childcare: Staffed by nurses and highly trained volunteers, our childcare is for those affected by Batten disease of all ages and SIBS 2-5 years old. <i>Snowmass, Breckenridge, Winter Park, Durango, Steamboat</i>
3:00-5:00pm:	Music Therapy for affected children <i>Clear Creek</i>
2:30-3:45pm:	SIB/Parent Panel Parents are encouraged to come and ask questions they may have about their SIBS. It is important to note that during the SIB/Parent panel, other than the SIBS on the panel, SIBS are not allowed in the room. Parents can freely ask questions about their SIB. As a response, the SIBS on the panel do NOT discuss anything spoken about in confidence by the other SIBS. They will make generalized statement that many other SIBS have made or give their own personal example as a response. The SIB/Parent panel will also NOT discuss anything spoken about in the panel to other SIBS. <i>Vail</i>

4:00-5:00pm:	BDSRA Board of Directors Updates & Meet the New Executive Director: The BDSRA Board and Committees will give updates from their meeting. Additionally this year, there will be time to meet the new Executive Director, Tauna Batiste . At two months in the role, she will share what she sees as opportunities for BDSRA so far. <i>Vail</i>
5:00-6:00pm:	Preparation for the Kid’s Parade – Our Batten kids get decked out in themed accessories for this special event <i>Platte River Foyer</i>
6:00-6:30pm:	Kid’s Parade – Affected children are announced and escorted by the siblings as they make their way into the dining room
6:30-8:00pm:	Banquet and Program <i>(meal ticket required)</i> <i>Colorado Ballroom A-D</i>
8:00-11pm:	Dance Party: The ultimate dance party and the SIBS Dollar Dance <i>Colorado Ballroom A-D</i>

Sunday, July 21

8:00-11:00am:	Conference Registration Open <i>Platte River</i>
8:00-11:30am:	Childcare: Staffed by nurses and highly trained volunteers, our childcare is for those affected by Batten disease of all ages and SIBS 2-5 years old. <i>Snowmass, Breckenridge, Winter Park, Durango, Steamboat</i>
9:00-10:00am:	Breakfast <i>(meal ticket required)</i> <i>Colorado Ballroom A & B</i>
10:00-11:00am:	Celebration of Life: This reflective ceremony honors the memories of loved ones lost to Batten disease <i>Telluride A & B</i>
10:00-11:00am:	First Time/Newly Diagnosed Families Decompression Session: This session, led by Joe Vigil, Ph.D. , encourages conference attendees to discuss their experiences during the weekend and thoughts about the future <i>Big Thompson</i>
11:30am:	Farewells

SIBS AGENDA

Thursday, July 18

Noon-8:00pm:	Conference Registration and Scientific/Medical Studies Registration <i>Platte River</i>
7:30-9:15pm:	SIBS Pizza and Pool Party: All SIBS 6 years old and older are invited to a Pool Party! Come meet new SIBS, connect with old friends, and have a great time. <i>(Lifeguards will be provided)</i> <i>Pool</i>
9:30-11:00pm:	Adult SIBS Outing (21+) <i>Meet in Hotel Lobby</i>

Friday, July 19

7:45-8:30am:	Breakfast on your own
9:00-9:45 am	Friday Morning Kickoff All SIBS gather at the Opening Session before being dismissed to their Icebreaker Session. <i>Colorado Ballroom A & B</i>
10:00-10:45am:	SIBS Icebreaker Session A great session for all SIBS to wake up and start the day with fun filled games and a few introductions <i>Colorado Ballroom C & D</i>
10:45-11:00am:	Break
11:00am-12:00pm:	SIBS Research Session Meet with scientists for Q&A along with learning the latest in testing, trials and research that are currently taking place and what is in store for the future. Age appropriate discussions and activities.
	Ages 6-9: <i>Pikes Peak</i>
	Ages 10-13: <i>Grays Peak</i>
	Ages 14-17: <i>Maroon Peak</i>
	18 & older: <i>Bennett Peak</i>
12:00-1:00pm:	Lunch Buffet <i>(meal ticket required)</i> <i>Colorado C & D</i>
1:00-3:00pm:	SIBS Group Break-Out Sessions This is an opportunity to meet and get to know other SIBS their own age in individualized age discussions and activities
	Ages 6-9: <i>Pikes Peak</i>
	Ages 10-13: <i>Grays Peak</i>
	Ages 14-17: <i>Maroon Peak</i>
	18 & older: <i>Bennett Peak</i>
2:00-3:00pm:	Bereavement Session for SIBS An opportunity for those who have lost a sibling to spend time with other bereaved SIBS and view the Batten Disease Memorial <i>Telluride B</i>
3:00-3:15pm:	Break
3:15-4:45pm:	SIBS Group Break-Out Sessions This is an opportunity to meet and get to know other SIBS their own age in individualized age discussions and activities
	Ages 6-9: <i>Pikes Peak</i>
	Ages 10-13: <i>Grays Peak</i>
	Ages 14-17: <i>Maroon Peak</i>
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1:00pm:	SIBS return from The Denver Museum of Nature & Science
	Any child under the age of 13 will have to be picked up by a guardian <i>Meet in Hotel Lobby</i>
1:00pm-3:00pm:	SIBS Break-Out Session Closing session for the weekend
	Ages 13 & older: <i>Big Thompson</i>
	Swimming Ages 6-12: <i>(Lifeguards will be provided)</i> <i>Meet at Pool</i>
3:00-5:00pm:	SIB/Parent Panel Parents are encouraged to come and ask questions they may have about their SIBS. It is important to note that during the SIB/Parent panel, other than the SIBS on the panel, SIBS are not allowed in the room. Parents can freely ask questions about their SIB. As a response, the SIBS on the panel do NOT discuss anything spoken about in confidence by the other SIBS. They will make generalized statement that many other SIBS have made or give their own personal example as a response. The SIB/Parent panel will also NOT discuss anything spoken about in the panel to other SIBS. <i>Vail</i>
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6:00-6:30pm:	Kid’s Parade Our loved ones affected by Batten disease are announced and escorted by their siblings as they make their way into the ballroom. <i>Ballrooms A- D</i>
6:30-8:00pm:	Banquet and Program <i>(meal ticket required)</i> <i>Ballrooms A- D</i>
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Sunday, July 21

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11:30am:	Farewells

