

**SPECIAL THANKS TO OUR
CLIMBING TO A CURE
SPONSORS**

PLATINUM

BIOMARIN



GOLD

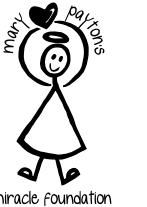


ForeBatten FOUNDATION

REGENXBIO

SILVER

Amicus Therapeutics



BRONZE

Anonymous
Gayle Holton Design
Metro NY/NJ Chapter BDSRA
Polaryx Therapeutics, Inc.
Sanford Children's Research Center
Spark Therapeutics

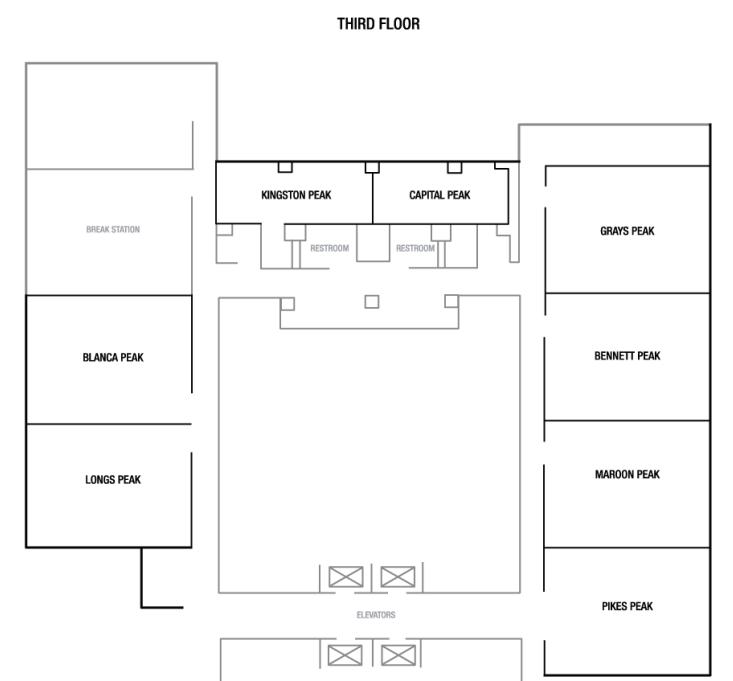
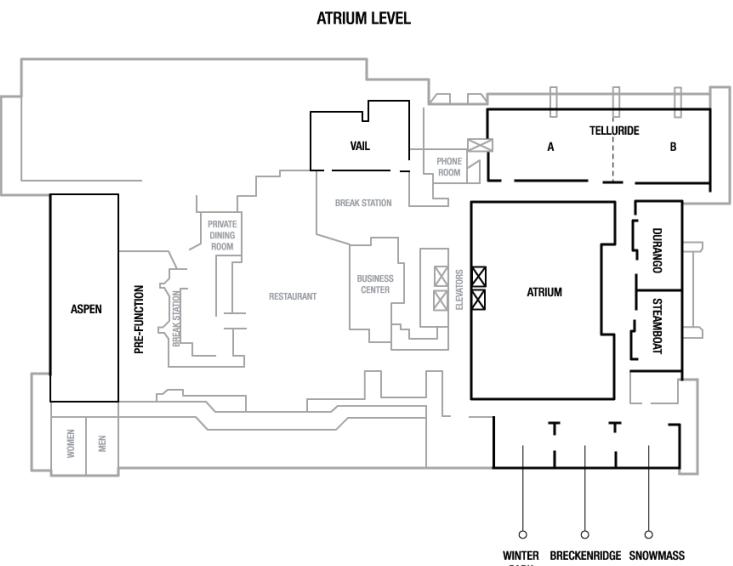
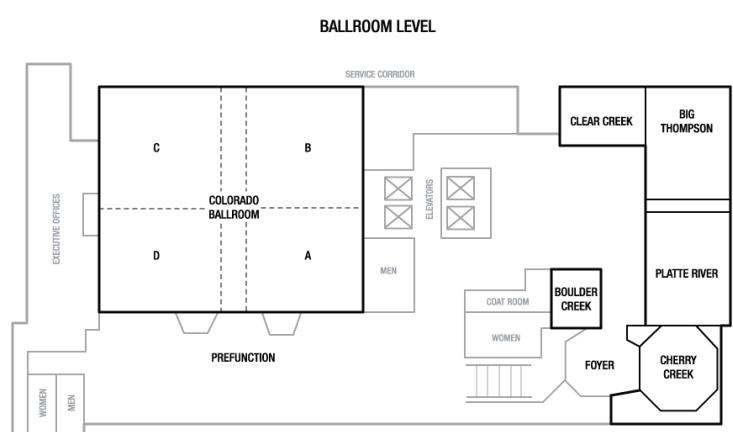
TEAL

Drew's Hope Research Foundation
Ethan's Reason
Web, Carol and John Ireland
Joel, Christine, Jaron & Kody Maynard
Zekelman Industries

PATRON

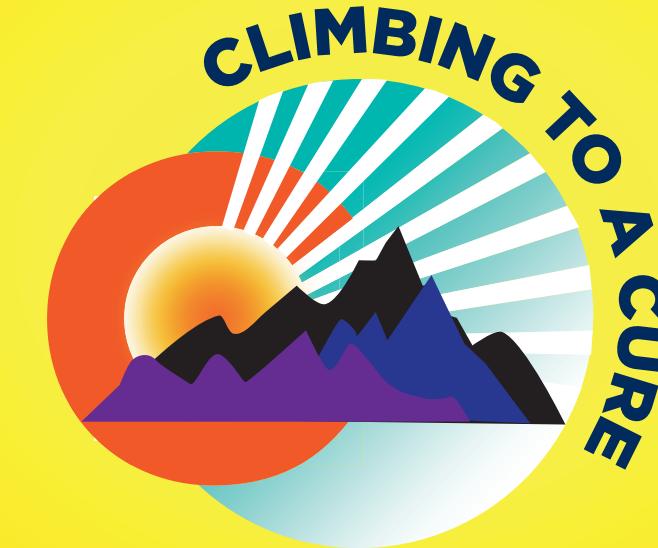
Brian and Evan Callan
Garrett the Grand
Little Batten Warriors
Ohio Chapter BDSRA

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



**BDSRA Conference
Denver, Colorado
July 18-21, 2019**

CONNECT with BDSRA



/bdsra



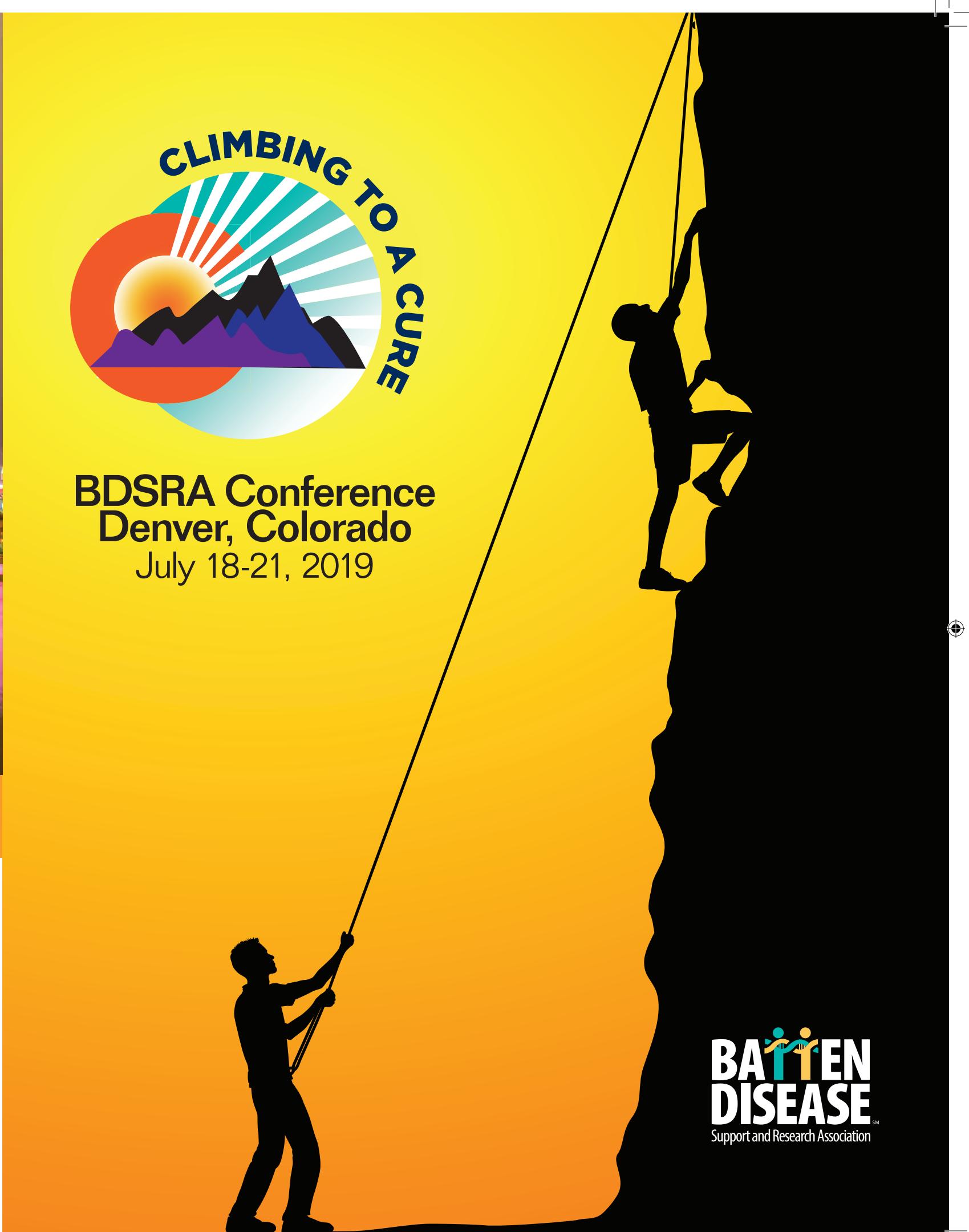
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**BATTEN
DISEASE**
Support and Research Association

www.bdsra.org



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** Coordinated by Randy Royalty

8:00am-4:30pm: **Board Meeting** Vail

Noon-8:00pm: **Conference Registration and Scientific/Medical Studies Registration** Platte River

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. (Light appetizers and a cash bar will be available) Hotel Bar Area

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. Big Thompson

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. (Lifeguards will be provided) Pool

7:30-9:30pm: **Welcome Reception**: All conference attendees welcome! (Light snacks and a cash bar will be available) Colorado Ballroom A & B

9:00pm-Midnight: **Texas Hold'Em Poker Tournament**: All conference attendees are invited to participate in a Texas Hold'Em Poker Tournament Clear Creek

9:30-11:00pm: **Adult SIBS** meet up (21+) Meet in Hotel Lobby

Friday, July 19

7:45-8:45am: **Breakfast on your own**

8:30am-6:00pm: **Conference Registration and Scientific/Medical Studies Registration** Platte River

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. Big Thompson

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. Telluride B

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. Snowmass, Breckenridge, Winter Park, Durango, Steamboat

9:00am-10:00am: **Announcements and Opening Session** Colorado Ballroom A & B

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 Tøssebro, 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. **Cherry Creek 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. Big Thompson

Breakouts by Type of Batten Disease: These sessions are for parents to meet one another and talk about the unique challenges they face.

3:45-4:45pm:

CLN1 Moms Clear Creek

CLN1 Dads Big Thompson

CLN2 Moms Vail

CLN2 Dads Colorado Ballroom B

CLN3 Moms Aspen

CLN3 Dads Colorado Ballroom A

CLN5-8 Moms Telluride A

CLN5-8 Dads Cherry Creek

Undiagnosed Moms Boulder Creek

Undiagnosed Dads Platte River

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. Longs Peak

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. Blanca Peak

11:00am-1:00pm:

Lunch (meal ticket required)

Colorado Ballroom C & D

1:00-5:00pm:

Life Goes On

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.

Meet in Hotel Lobby

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. Snowmass, Breckenridge, Winter Park, Durango, Steamboat

1:15-2:15pm

CONCURRENT SESSIONS

Physical Therapy for Batten Patients

Danielle Peiffer, 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.

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. (Lunch provided) (SIBS Shirts Required)

8:30am-Noon:

Farewells

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 (Coffee, tea, and water will be provided)

Colorado Ballroom A & B

9:45am-Noon:

Batten Research Overview

Researchers share latest basic research findings (Coffee, tea, and water will be provided)

Colorado Ballroom A & B

10:00am-10:00pm:

The Batten Disease Memorial

is on display throughout the weekend for reflection and remembrance. Telluride B

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. Big Thompson

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. Big Thompson

1:00-1:00pm:

Lunch (meal ticket required)

Colorado Ballroom C & D

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. (Coffee, tea, and water will be provided)

Aspen

1:00-3:00pm:

Pet Therapy

for affected children

Snowmass, Breckenridge, Winter Park, Durango, Steamboat

1:00-5:00pm:

Childcare

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Snowmass, Breckenridge, Winter Park, Durango, Steamboat

1:00-5:00pm:

Music Therapy

for affected children

Clear Creek

1:00-3:45pm:

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.

Vail

12:00-1:00pm:

Lunch Buffet (meal ticket required)

Colorado C & D

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: Pikes Peak

Ages 10-13: Grays Peak

Ages 14-17: Maroon Peak

18 & older: Bennett Peak

5:00-6:00pm:

Preparation for the Kid's Parade

SIBS and their loved ones

affected by Batten disease get decked out in themed accessories for

this special event.

Platte River Foyer

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.

Ballrooms A-D

6:30-8:00pm:

Banquet and Program (meal ticket required)

Ballrooms A-D

8:00-11pm:

Dance Party

The ultimate dance party and the SIBS Dollar Dance

Ballrooms A-D

11:30am:

Farewells