

2017 Family Conference Program

Subject to change



Thursday, July 6

- 8am-4pm: Golf Outing
8am-5pm: Board of Directors Meeting
Noon-8pm: Conference Registration and Scientific/Medical Studies Registration
6:30-7:30pm: **Grandparent/Extended Family Happy Hour**
6:30-7:30pm: **New Family Mixer** Batten parents Brock and Ellie Benroth and BDSRA staff welcome families attending their first conference and provide an overview of conference events
7:00-9:00pm: Sibs Game Night Party
7:30-9:30pm: **Welcome Reception** Light snacks and a cash bar will be available
9pm-Midnight: Join in the **Texas Hold'Em Poker Tournament**
9:30pm-11pm: Sibs 21 and older meet up

Friday, July 7

- 7am-6pm: Conference Registration Open
7:45-8:45am: Breakfast on your own
9:00-9:30am: **Opening Celebration in Point State Park**
We would like to celebrate the past 30 years with everyone, including affected children and siblings
9:30-11:00am: Sibs group meets for team building
9:30-11:00am: **Opening Session** 30 Years in Review
10:00am-Noon: Childcare for affected children, and the Teddy Bear Club for children ages 2-5
11:00-12:00: **First Time/Newly Diagnosed Session** Joe Vigil, PhD, a bereaved parent, private practitioner, and rehabilitation psychologist, will facilitate this session for families new to our conference and Batten disease.
10am-10pm: The Batten Disease Memorial is on display throughout the weekend for reflection and remembrance
11:00-Noon: Sibs Group Research Sessions – designated age groups have a chance to meet with the scientists and ask questions
12:00-1:00pm: **Founders Celebration Lunch** Join us in paying tribute to those families, researchers and community members who have been here since the very beginning
1:15-3:00pm: SIBS meet again by age groups for facilitated discussions and activities
1:15-2:30pm: Memorial Open to SIBS only
1-5pm: **Life Goes On Outing** for those parents who have lost a child to Batten disease enjoy a tour of Pirates stadium
1-5pm: Childcare for affected children, and the Teddy Bear Club for children ages 2-5
1:15-2:15pm **Concurrent Sessions:**
Grandparents/Extended Family Session
Stress, Coping and Wellness for Caregivers
Symptom Management
2:30-3:30pm **Concurrent Sessions:**
How to Tell Your Story from Grocery Store to Capitol Hill
Education and School Strategies
3:45-5pm: **Concurrent Sessions:**
Yes, you can do this!: Navigating Special Needs Finance & Insurance
Children, epilepsies and cannabinoids
6:00-7:15pm: Dinner
5:30-10pm: Sibs Outing to Carnegie Natural History Museum
8:00-10:00pm: **Trivia game** A fun evening of team based trivia

Saturday, July 8

- 7:30am-6pm: Conference Registration Open
- 7:45-8:45am: Breakfast on your own
- 8:30am-Noon: Childcare for affected children, and the Teddy Bear Club for children ages 2-5
- 9am-3:00pm: Sibs Outing and Lunch at Science Center
- 8:15- 9:00am: **Genetics 101** In this early morning pre meeting research Jon Cooper, PhD will conduct a brief lecture on genetics. *(Coffee, tea, and water will be provided)*
- 9:00-9:45am: **Batten Research Keynote**
- 10:00-12:00pm: **Batten Research Overview and Clinical Trial Updates** Batten researchers and industry science professionals share latest findings basic research and on trials current and upcoming. Attendees will have ample opportunity for questions. *(Coffee, tea, and water will be provided)*
- 10am-9pm: The Batten Disease Memorial is on display for reflection and remembrance.
- 12:15-1:15pm: **Scientific Discovery Lunch** 30 years of hard work and dedication have brought us to where we are, come celebrate our scientific journey
- 1-5pm: Childcare for affected children, and the Teddy Bear Club for children ages 2-5
- 1:00-2:30pm: **Research Open House & Poster Session** View posters outlining work from Batten researchers from all over the world.
- 2:00-3:00pm: **CLN1 ♦ CLN2 ♦ CLN3 ♦ CLN5-8 ♦ Undiagnosed Moms Session / CLN1 ♦ CLN2 ♦ CLN3 ♦ CLN5-8 ♦ Undiagnosed Dads Session** These peer led discussions are for mothers and fathers of children with various forms of Batten disease to share experiences and challenges, as well as offer and receive support.
- 2:00-3:00pm: **Grief and Family**
- 3:00-5:00pm: **Sib/Parent Panel** Parents and siblings of those with Batten disease have a conversation about cares, concerns and coping
- 3:00-5:00pm: Age-designated Sibs art project and sessions
- 5-6pm: Preparation for the Kid's Parade -- Our Batten kids get decked out in themed accessories for this special event
- 6-6:30pm: **Kid's Parade** Affected children are announced and escorted by their siblings as they make their way into the dining room
- 6:30-8pm: **Banquet and Program**
- 8-11pm: **Dance Party** The ultimate dance party and the SIBS Dollar Dance

Sunday, July 9

- 7:45-8:45am: Breakfast on your own
- 8:00-11am: Conference Registration Open
- 8:30-11:30am: Childcare for affected children, and the Teddy Bear Club for children ages 2-5
- 9:00-9:30am: **Sunday Morning Meditations** Uplifting poems and music
- 9:45-11:15am: **Celebration of Life** This reflective ceremony honors the memories of loved ones lost to Batten disease
- 9:45-11:15am: **First Time/Newly Diagnosed Families Decompression Session** This session encourages conference attendees to discuss their experiences during the weekend and thoughts about the future
- 11:30am: Farewells