

BDSRA ANNUAL FAMILY CONFERENCE JULY 14-16, 2023 | DENTON, TEXAS

2023 FAMILY CONFERENCE PROGRAM



GIVE BATTEN THE
BOOT

Thursday, July 13

Time	Event
9:00 am-5:00 pm	Board Meeting
4:00 pm-8:00 pm	Families Check-In / Registration
6:00 pm-7:00 pm	Reception For First-Time Families & Buddies
6:00 pm-7:00 pm	Gathering - Grandparents & Extended Family Members
6:00 pm-7:00 pm	Reception For Sponsors & Donors <i>(By Invitation)</i>
7:00 pm-9:00 pm	SIBs Pool Party & Cookout
7:30 pm-9:30 pm	Welcome Reception / Family Reunion (Everyone Is Welcome To Attend)
9:00 pm-11:00 pm	SIBs Activity (21+)
9:00 pm-11:30 pm	Poker Night

Friday, July 14

Time	Event
7:00 am-5:00 pm	Childcare Available - <i>(Pre-Registration is Required)</i> <i>(Closed 12:00 pm-1:00 pm For Lunch)</i>
7:30 am-5:00 pm	Families Check-In / Registration
8:00 am-8:45 am	First-Time Families / Buddies Gathering
8:30 am-5:00 pm	Exhibits Open
9:00 am-10:00 pm	Memorial Room Open
9:00 am-10:30 am	Welcome & Keynote Address (V)
9:15 am-10:30 am	SIBs General Session
10:30 am-10:45 am	Break
10:45 am-12:00 pm	SIBs - Research Sessions
10:45 am-12:00 pm	CLN Support Groups <i>(Parents With Living Children)</i>
10:45 am-12:00 pm	Grandparents' Support Group
10:45 am-12:00 pm	Life Goes On: Journey Of Healing: Embracing Life After Loss
12:00 pm-1:00 pm	Lunch <i>(Pre-Registration is Required)</i>
1:00 pm-5:00 pm	Life Goes On: Texas Motor Speedway <i>(Pre-Registration is Required)</i>
1:15 pm-2:15 pm	Breakout Session: Rare Disease Advocacy and Policy Change: How to make it happen for YOUR family (V)
1:15 pm-2:15 pm	Breakout Session: Batten 101: What Is Batten Disease? (V)
1:15 pm-2:15 pm	Breakout Session: Behavior, Cognition, And Learning In Batten Disease (V)
1:15 pm-2:15 pm	SIBs - Bereavement & Breakout Sessions
2:15 pm-2:30 pm	Break

2:30 pm-3:30 pm	SIBs - Breakout Sessions
2:30 pm-3:30 pm	Ask-A-Doc (V)
3:30 pm-3:45 pm	Break
3:45 pm-4:45 pm	SIBs - Breakout Sessions
3:45 pm-4:45 pm	CLN Support Groups <i>(Parents With Living Children)</i>
3:45 pm-4:45 pm	Grandparents' Support Group
5:00 pm-6:00 pm	Q&A With the BDSRA Board Of Directors (V)
5:30 pm-9:00 pm	SIBs - Depart For Andy B's
8:00 pm-11:00 pm	Trivia Night

Saturday, July 15

Time	Event
7:00 am-5:00 pm	Childcare Available - <i>(Pre-Registration is Required)</i> <i>(Closed 12:00 pm-1:00 pm For Lunch)</i>
7:30 am-4:00 pm	Families Check-In / Registration
8:30 am-4:00 pm	Exhibits Open
9:00 am-10:00 pm	Memorial Room Open
9:00 am-10:30 am	SIBs - Breakout Sessions
9:00 am-12:00 pm	General Session - Science (V)
9:00 am-12:00 pm	Life Goes On: Diamond Art, Mimosas & Mocktails <i>(Pre-Registration is Required)</i>
10:30 am-2:00 pm	SIBs: The Battlefield <i>(Pre-Registration is Required)</i>
10:30 am-10:45 am	Break
12:00 pm-1:15 pm	Lunch <i>(Pre-Registration is Required)</i>
1:15 pm-2:30 pm	CLN Support Groups <i>(Parents With Living Children)</i>
1:15 pm-2:45 pm	Pet Therapy
1:15 pm-2:30 pm	Life Goes On: Music Therapy
1:15 pm-2:30 pm	Grandparents' Support Group
2:45 pm-3:00 pm	Break
3:00 pm-4:00 pm	Breakout Session: Managing Caregiver Stress & Burnout: The Importance Of Self-Care (V)
3:00 pm-4:30 pm	Music Therapy: Kids
3:00 pm-4:30 pm	Life Goes On: Creating A Living Memorial
3:00 pm-4:30 pm	SIBs - Breakout Sessions
3:15 pm-4:15 pm	Ask-A-SIB (V)
5:15 pm-6:00 pm	Kids Assemble For Parade Preparation
6:00 pm-11:00 pm	Parade And Banquet (V)

Sunday, July 16

Time	Event
8:00 am-10:30 am	Farewell Breakfast - Get Breakfast From The Hotel Buffet And Join Us For A Final Meeting
9:00 am-10:30 am	Celebration Of Life (V)