



2026 SATB2-Associated Syndrome Family & Medical Conference Oklahoma City, OK

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This Is Our Story. Every Voice. Every Chapter.
The conference is where learning, connection, and
discovery come together to move our community
forward.

July 22 – 24, 2026

sat
b2 gene
foundation

2026 SATB2-Associated Syndrome Family & Medical Conference Oklahoma City, OK

Dear Friends,

Welcome to the 2026 SATB2-Associated Syndrome Family and Medical Conference.

This year's theme, "**This Is Our Story. Every Voice. Every Chapter,**" reflects the heart of our community. Every family, every individual, every researcher, clinician, volunteer, advocate, donor, and partner has helped shape our story. Together, we have built a community rooted in hope, resilience, and the belief that **Every Voice Belongs Here.**

This conference is especially meaningful as we begin a new chapter for our Foundation with the recent hiring of our first Executive Director. It is an exciting milestone that builds upon the extraordinary dedication and vision of the families, volunteers, Board members, researchers, clinicians, and supporters who have brought us to where we are today. We are grateful for the strong foundation we have created together and excited for what we will accomplish together.

Over the next few days, we invite you to learn, connect, ask questions, share your experiences, and build new relationships. Whether you are attending your first conference or have been part of this community for years, your voice matters, your perspective is valued, and your presence makes us stronger.

Thank you for being here and for being part of our story. Together, we will continue writing the next chapter—with hope, purpose, and the shared belief that every voice truly belongs here.

With gratitude,

Allison Kaczinski, President and Founder

Susan Comparato, Executive Director



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Event Schedule

Wednesday, July 22nd

5:30 PM – 7:30 PM: **Conference Registration and Welcome Reception**
Light hors d'oeuvres served. Dinner on your own.

Thursday, July 23rd

6:00 AM - 9:00 AM: **Breakfast on your own.** For guests staying at Embassy Suites, breakfast at the hotel restaurant is included with your stay.

Childcare (Young DE)

8:30 AM: Childcare Check-In Begins

9:00 AM – 3:00 PM: All children registered for childcare must have been fed breakfast prior to being checked in. Families will be responsible for checking their child out for lunch break. **No meals or snacks are provided within the childcare room.**

9:00 AM:

Room	Topic
Young ABC	Every Voice. Every Chapter. The Story Begins. Allison Kaczinski, President & Founder Susan Comparato, Executive Director David Bright, Research Committee Chair
Young ABC	3D Image Study Presentation Alex Buchner Beaudet, University of Calgary, Canada



SCAN ME



Roundtable Descriptions

10:00 AM:

Room	Topic
Young ABC	Mapping the Future: Building a Path to a Robust and Exciting Life Todd and Stephanie Watkins
Everest	Augmentative and Alternative Communication (AAC) and Assistive Technology (AT) Program Introduction Averie Lucas, M.S. CCC-SLP, Oklahoma ABLE Tech Allyson Robinson, M.A. CCC-SLP, Oklahoma State University
Gaylord	Roundtable Discussions: IEPs: Middle School; Extended Family; and Building Your Village

11:00 AM:

Room	Topic
Young ABC	Parent to Parent: The Road Ahead – A Moderated SATB2 Parent Panel and Q&A Session Moderator: Amanda Cross; Panelists: Lela Patton, Bill Regan, and Jennifer Schulte
Everest	Genetics 101 and the SATB2 Patient Registry Katie Bosanko, M.S., LCGC, Arkansas Children's Hospital
Gaylord	Roundtable Discussions: AAC in Real Life; Dental Issues: Dentists, Braces & More; and Transitions: Middle School to High School

12:00 – 12:50 PM:

Room	Topic
Outside Young ABC	Lunch Break



1:00 PM - 3:00 PM:

Room	Topic
Everest	Sib Shop (in-person attendees only, open to siblings age 6+) Facilitators: Samantha Basave, Sooner SUCCESS and Lora Roberts, Oklahoma Family Network

1:00 PM:

Room	Topic
Young ABC	SATB2 Genetics and Research Updates Yuri Zárate, MD, MBA, University of Kentucky

2:00 PM:

Room	Topic
Young ABC	AAV-Based Gene Therapy for SATB2 - A Research Update Leszek Lisowski, PhD, MBA, and Simone Borsani, PhD student Children's Medical Research Institute

3:15 PM:

Room	Topic
Young ABC	Group Photo - Wear your favorite SATB2 shirts!

7:00 PM - 9:00 PM:

Room	Topic
Young ABC	Family Social Come connect with other SATB2 families! Light desserts, fun activities, and music! <i>Please have dinner on your own prior to attending.</i>



Friday, July 24th

6:00 AM - 9:00 AM: **Breakfast on your own.** For guests staying at Embassy Suites, breakfast at the hotel restaurant is included with your stay.

Childcare (Young DE)

8:30 AM: Childcare Check-In Begins

9:00 AM – 3:00 PM: All children registered for childcare must have been fed breakfast prior to being checked in. Families will be responsible for checking their child out for lunch break. **No meals or snacks are provided within the childcare room.**

9:00 AM:

Room	Topic
Young ABC	SATB2-Associated Syndrome Clinical Updates and Common Questions Yuri Zárate, MD, MBA, University of Kentucky

10:00 AM:

Room	Topic
Young ABC	Helping Without Harming: Supporting Mental Health in SATB2 Natashia Bottoms, MD, University of Arkansas for Medical Sciences
Gaylord	Roundtable Discussions: Group Homes & Beyond; Meaningful Adult Life: Work, Day Programs & More; & Meet the New Executive Director



11:00 AM:

Room	Topic
Young ABC	Navigating Durable Medical Equipment Melissa Tally, Abram's Nation
Everest	Crafting Your Story: Becoming an Ambassador for SATB2 Allison Kaczinski and Susan Comparato, SATB2 Gene Foundation
Gaylord	Roundtable Discussion: Parents of Adults with SAS Todd Watkins, SAS Parent

12:00 – 12:50 PM:

Room	Topic
Outside Young ABC	Lunch Break

1:00 - 2:20 PM:

Room	Topic
Multiple Locations	Parent Roundtable Discussions - Multiple Roundtable Topic Options See pages 8 and 9 for schedule breakdown

2:30 PM:

Room	Topic
Young ABC	Every Voice. Every Chapter. The Story Continues. Allison Kaczinski and Susan Comparato, SATB2 Gene Foundation



Friday, July 24th Roundtable Breakdown

Please scan QR code on Page 4 for descriptions

1:00 PM:

Room	Topic
Young ABC	New to Diagnosis: What We Wished We'd Known - Clinical Discussion Katie Bosanko and Rachel Ward
Young ABC	Guardianship and Future Planning: Lived Experiences and Lessons Learned Lela Patton
Young ABC	Dad's Group Evan Eastman
Young ABC	Puberty: Girls Cathy Woodward
Young ABC	Toilet Training and Hygiene Aisling Caffrey
Young ABC	Handling Your Child's Crisis in Real Time: Real Life Strategies Todd Watkins
Young ABC	Housing Support Models and Independence: What's Realistic Stephanie Watkins
Everest	Supporting the non-SAS Sibling Jenna Garwood
Everest	Daily Living Skills and Independence Brad Anderson
Everest	Effective Advocacy: What's Worked for You? Sandra Neil
Everest	Community Services: Tips to Finding Options and Support in Your Area Chip Erickson



1:45 PM:

Room	Topic
Young ABC	New to Diagnosis: What We Wished We'd Known – Family Support Discussion Rachel Ward
Young ABC	Supporting the non-SAS Sibling Jennifer Schulte
Young ABC	Dad's Group Bill Regan
Young ABC	Puberty: Boys Todd Watkins
Young ABC	Puberty: Girls Cathy Woodward
Young ABC	Toilet Training and Hygiene Aisling Caffrey
Young ABC	Handling Your Child's Crisis in Real Time: Real Life Strategies Carrie Watkins
Young ABC	Housing Support Models and Independence: What's Realistic Stephanie Watkins
Everest	Guardianship and Future Planning: Lived Experiences and Lessons Learned Sandra Neil
Everest	Meaningful Adult Life: Work, Day Programs, and More Nancy Daddino
Everest	IEPs 101 Mary Mecham
Everest	Sleep Challenges and Regulation Jenna Garwood



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Kaczinski



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Adam Pietropaolo

Help Shape Our Future

Every voice and every action makes a difference.

- **Survey:** Before you leave, please take a few minutes to scan the QR code and complete our End-of-Conference Survey. Your feedback is invaluable in helping us improve future conferences and ensure we continue meeting the needs of our SATB2 community.
- **Volunteer:** We invite you to explore volunteer opportunities. Whether you can contribute a few hours, provide ongoing guidance, or help with a specific project, your skills can have a direct and lasting impact on our community.
- **Donate:** Please consider donating to the SATB2 Gene Foundation to ensure that life-changing programs and groundbreaking research can occur. Every gift, no matter the size, helps us advance our mission.

Thank you for helping us continue to write the next chapter of our story.



END-OF-CONFERENCE SURVEY



VOLUNTEER OPPORTUNITIES



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Writing the Next Chapter Together

Thank you for being part of this year's SATB2 Family and Medical Conference. We hope you leave with new knowledge, meaningful connections, and renewed hope for the future. Thank you for helping bring this year's theme to life: **This Is Our Story. Every Voice. Every Chapter.** We look forward to continuing the next chapter together, because **Every Voice Belongs Here.**

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