

Friday, July 10, 2026 – Agenda

Complimentary breakfast provided for all attendees – Drury Hotel 2 nd floor				
9:00 am to 12:30 pm	SSSA Board Meeting: Board Members Only			
1:00 pm to 5:00 pm	Conference Registration: Pickup materials, name badges, drop off Silent Auction items, and childcare registration.			
1:00 pm to 5:00 pm	Gait Clinic: Dr. Steve Dugan will answer questions about gait, supportive devices, orthotics, and management of comorbidities that may affect gait patterns.			
1:00 pm to 5:00 pm	Doctor #1 Appointment Dr. Jill Fahrner	Doctor #2 Appointment Dr. Jacqueline Harris	Doctor #3 Appointment Dr. Alison Foster	Doctor #4 Appointment Lauren West
5:00 pm to 6:00 pm	Networking Reception Meet other families attending the conference prior to dinner. Cash bar will be open until 9:00 pm			
6:00 pm to 10:00 pm	Welcome Dinner and Silent Auction A buffet dinner will be served, followed by more opportunities to reunite with old friends and meet new attendees. Dinner will be followed by a DJ and dancing, photo booth, along with the Silent Auction. Bidding ends at 9:00 pm.			
10:00 pm	End of Evening Event			

Saturday, July 11, 2026 – Other Activities

Complimentary breakfast provided for all attendees – Drury Hotel 2 nd floor				
8:00 am to 8:30 am	Childcare Drop-Off			
9:00 am to 12:00 pm	Childcare: Ages 0 to 3	Childcare: Ages 4 to 6	Childcare: Ages 7 to 11	Childcare: Ages 12+
8:30 am to 11:00 am	Adult Sotos Track (onsite)			
12:00 pm to 1:00 pm	Children Lunch: Lunch to be provided for the children.			
11:00 am to 3:00 pm	Adult Sotos Track (offsite) Shuttle to Disney Springs for lunch, shopping, and sightseeing.			
5:00 pm	Childcare Pick-Up			
5:00 pm	Families on their own for the evening			

Saturday, July 11, 2026 – Conference Agenda

Complimentary breakfast provided for all attendees – Drury Hotel 2 nd floor				
8:30 am to 9:30 am	Keynote Presentation <i>When Connection Leads the Way: Expectations Through a TBRI® Lens</i> Joy and Stephen Zedler, The Pearl Project Explores how Trust-Based Relational Intervention® (TBRI®) helps families hold healthy expectations while leading with connection. Guided by the TBRI® principles of Empowering, Connecting, and Correcting, two speakers will share practical, trauma-informed strategies for creating structure that supports regulation, setting expectations that foster growth, and responding in ways that strengthen trust rather than strain it. Designed for families raising children with special needs, offering hope, clarity, and tools for navigating daily challenges with compassion and confidence.			
9:50 am to 10:50 am	B1: We Have a Diagnosis. Now What? Dr. Brad Schaefer, University of Arkansas Dr. Schaefer achieved board certification in Pediatrics, Human Genetics, and Pediatric Endocrinology. He is a founding fellow of the American College of Medical Genetics, and a fellow of the American Academy of Pediatrics.	B2: Neurodevelopmental Manifestations of Sotos Syndrome Dr. Jacqueline Harris, Director of the Epigenetics Clinic at Kennedy Krieger Institute Dr. Harris is interested in genetic and epigenetic causes of neurodevelopmental disorders - particularly intellectual disability .		
11:00 am to 12:00 pm	B3: Sotos Syndrome: A Genetic Condition with Epigenetic Consequences Dr. Jill Fahrner, Epigenetics and Chromatin Clinic, Johns Hopkins University School of Medicine Dr. Fahrner is an assistant professor in the Departments of Genetic Medicine and Pediatrics at the Johns Hopkins University School of Medicine.	B4: Adult Features of Sotos Syndrome Dr. Alison Foster, Geneticist, Birmingham Children's Hospital, UK This presentation focuses on the adult features and manifestations of Sotos Syndrome. Dr. Foster received her undergraduate degree in Human Genetics from University College London in 2003.		

1:00 pm to 1:50 pm	<p>B5: Speech, Language, and Communications in Sotos Syndrome Lauren West, MS CCC-SLP This session will focus on navigating the complexities of communication for individuals with Sotos. Lauren is a speech-language pathologist for the Elkhorn Public School District near Omaha, Nebraska.</p>	<p>B6: Roadmaps and Caremaps: A Journey of Connections, Networks, and Transitions from Diagnosis to Adulthood Linda Starnes, FL Dept of Health Children's Medical Services We all have different journeys, yet many common needs for helpful connections, as families with a loved one with Sotos Syndrome. Learn tips, resources, and recommendations from a seasoned parent on traveling the journey to adulthood.</p>
2:00 pm to 2:50 pm	<p>B7: From Vision to Clinic: Building the First Multidisciplinary Sotos Syndrome Clinic Jayme Betts, Dr. Mandy Nagy & Dr. Leah Wibecan, Mass General/Harvard Medical School Attendees will gain insight into the clinic's phased launch strategy, early patient engagement, and the operational framework for long-term sustainability.</p>	<p>B8: From Parent-to-Parent: A Panel Discussion Parent Panel Panelists will respond to the same set of common, real-life questions, offering honest perspectives on how they navigated shared challenges at various points in their journey. Topics may include managing repetitive questioning, late toilet training, bullying, anxiety, major milestones such as learning to drive, and getting a job.</p>
3:00 pm to 3:50 pm	<p>B9: Caring for the Caregiver Dr. Melody Parsons Research suggests that primary caregivers—particularly those supporting individuals with significant developmental, medical, or behavioral needs—often experience chronic stress and trauma responses. Participants will explore practical tools to build self-awareness, resilience, and healthier coping practices within the realities of long-term caregiving.</p>	<p>B10: The Brain in Learning 101 Tara Bonner, The Arrowsmith Project Understand the role of cognitive function in learning, independence, and daily life, and explore how targeted cognitive approaches may offer meaningful opportunities for individuals with Sotos Syndrome. The session also features first-hand insights from a Sotos Syndrome family who completed the program, sharing real-life experiences and the impact it had on their child and family.</p>
4:00 pm to 5:00 pm	<p>B11: Using Technology to Advance Your Advocacy Dr. Melody Parsons This session offers practical strategies for navigating the complex systems of medical care, educational planning, and public benefits for individuals with Sotos syndrome. Participants will learn about low-cost, easy-to-use, and accessible technologies that can support effective advocacy. Also included are the benefits and limitations of using AI as a tool to strengthen advocacy efforts.</p>	<p>B12: Finding Your Voice: Sharing Your Child's Diagnosis with Confidence Melissa Godesky For many parents, one of the hardest parts of the journey after a diagnosis is learning how to talk about it. Who do you tell? What do you say? How much should you share? And how do you do it in a way that empowers both you and your child? This session will focus on building confidence, finding language that feels authentic, and creating a supportive space for parents to learn from one another.</p>
5:00 pm	Conference Programming Concludes for the Day – Families on their own for the evening	

Sunday, July 12, 2026 – Agenda

Complimentary breakfast provided for all attendees – Drury Hotel 2 nd floor				
8:00 am to 9:00 am	Childcare Drop-Off			
9:00 am to 12:00 pm	Childcare: Ages 0 to 3	Childcare: Ages 4 to 6	Childcare: Ages 7 to 11	Childcare: Ages 12+
9:00 am to 10:00 am	Doctors Questions and Answers Discussion Panel: Doctors from the SSSA Medical Advisory Board will answer questions submitted in advance, followed by questions from the audience.			
10:00 am to 11:00 am	SSSA Board General Meeting Updates The Sotos Syndrome Support Association is your association devoted to serving your needs. Everyone is urged to attend the Association General meeting on Sunday morning for input into the direction and projects of the SSSA.			
11:00 am to 12:00 pm	Adult Sotos Questions and Answers Discussion Panel Adults with Sotos will talk about life from their perspectives and answer audience questions. Hear about what they are doing now, including jobs, school, driving, love and the future. Parents will fill in details about their childhood, including interventions and therapies, school, sports, and more.			
12:00 pm	Childcare Pick-Up			
12:00 pm	End of Conference Programming – Lunch on the own			
1:00 pm to 5:00 pm	Doctor #1 Appointment Dr. Jill Fahrner	Doctor #2 Appointment Dr. Jacqueline Harris	Doctor #3 Appointment Dr. Alison Foster	Doctor #4 Appointment Lauren West
5:00 pm	End of the doctor's appointments and conclusion of the conference.			