



Conference Schedule (as of April 22)

Please note, the days, times and locations of sessions may be adjusted prior to the conference.

Thursday, July 18

9:00 am- 4:00 pm

- Board Meeting for TSSUS Board of Directors

3:00 pm – 8:00 pm

- Attendee Check-In and On-site/Late Registration in the Foyer and Registration Desk #2, near Grand Ballroom D

7:30 pm – 8:30 pm

- Age-Specific Mixer. Come as you are to meet and mingle with people your age or your child's age. Ballroom locations to be announced.

8:30- 10:00 pm

- Casual time to visit and meet with others. Executive ballrooms and pool area.

Friday, July 19

7:00 am – 11:00 am

- Attendee Check-In and On-site/Late Registration in the Foyer and Registration Desk #2, near Grand Ballroom D.

7:45 am - 8:45 am

- Breakfast buffet for all conference attendees in Ballroom C,D&E.

9:15 am – 9:45 am

- Welcome and Conference Basics. Hakuna matata-be worry free! We will start by relaxing and focusing on what's most important - you! We will review the details of the conference, so you know what to expect each day, and discuss the most recent TS research and why it's important. Speakers: Cindy Scurlock and Jeanna Lee in Ballroom H&I.

9:45 - 11:45 am

- What You Need to Know About TS It's not necessary to know everything about TS, so what do you need to know? TS specialists will spend 10-30 minutes covering a specialty and highlighting what you must consider. Based on your current and near future needs, you'll know what sessions are most important for you to attend this year. Specialties include audiology, cardiology, dental, dermatology, endocrinology, fertility, gastroenterology (stomach), genetics, learning, neurology, psychology, and tips on general care. Ballroom H & I.

12:15 pm - 1:15 pm

- Lunch buffet for all conference attendees in Ballroom C, D&E

1:45 pm – 5:15 pm

- Understanding the TS Brain; Understanding Nonverbal Learning Disabilities (NLD) – This introductory session will review how processing information that is not spoken or heard (nonverbal) affects certain skills essential to learning and social communication. NLD can contribute to challenges with anxiety, depression, relationships, and organizational skills, to name a few. You are guaranteed to have some “ah-ha” moments. Presented by Dr. Mooney in Executive Ballroom H.

1:45 – 2:45 pm

- Turner Syndrome – The Basics – This introductory session will start with the basics about TS and TS care and will move at a slow pace. No question is too simple because TS is complicated.

1:45 – 4:00 pm

- Challenges or a Disability? – Determine if you may qualify as a person with a disability and learn about what it could mean for you. Many people with disabilities work successfully but need accommodations.

1:45 – 4:00 pm

- Family Planning – Join your peers in a discussion about the pros and cons of expanding your family through in-vitro fertilization, adoption, and fostering to adopt. Presented by Holly Slonina and Joanne Foodim in Salon 11/12.

3:00 -4:00 pm

- Genetics: Beyond the Basics – Genetics are wild! Did you inherit red hair, a hitch hiker thumb, or a windows peak? Why is guilt or shame related to a TS diagnosis when no one is to blame? Your genetics make you unique. Presented by Melissa Crenshaw in Ballroom I.

3:15-4:15pm

- Aging and TS – Identify the strengths and challenges of your group (by age) as related to TS. Advise TSSUS on the group’s collective needs. Facilitated by Barb Flink in Salon 18.

4:15 – 5:15 pm

- Karyotypes Explained – If you have a unique karyotype, you are not alone. Learn more about the terms mosaic, deletion, isochromosome, Y material, and more. Also learn why those with the same karyotype can have vastly different health concerns. Presented by Melissa Crenshaw in Ballroom I.

4:15 – 5:15 pm

- Health Insurance and TS – Why do different insurance companies treat individuals with TS differently? Can you force a company to cover medically necessary treatment? Where do you start and who may help? Presented by Kathleen Kane in Salon 11/12.

4:15 – 5:15 pm

- People of Racially and/or Culturally Diverse Backgrounds Discussion and Support – Facilitated by Jeanna Lee and Elizabeth Kwon in Salon 18.

5:15 – 5:45 pm

- Youth Program Sign Out – Please pick up your children in Salon 19 (upstairs, top of elevator).

6:30 -8:30 pm

- Butterfly Society & Major Donor V.I.P. Reception (invitation only) – Those who participate in the TSSUS monthly giving program and those who are major donors are invited! We want to celebrate you with a cocktail reception with light appetizers. This event requires an invitation which you will find in your registration packet. This is an adults-only event hosted by TSSUS in Salon 1.

Saturday, July 20th

7:00 – 10:00 am

- Attendee Check-In and On-Site / Late Registration at the Butterfly Store.

7:45 – 8:45 am

- Breakfast Buffet – for all conference attendees in Ballroom C, D & E.

9:15 – 10:30 am

- Job Accommodations and TS – Learn about accommodations that may assist you in improving productivity and on-the-job success. Even if you don't have a disability like anxiety or difficulty with instructions and timed tasks. Presented by Kathleen Kane in Salon 11/12.

9:15 – 10:30am

- Dad's Discussion Group – Share, learn, and laugh about the joys and challenges of parenting a child with TS. Identify the strengths and challenges you face related to TS. Advise TSSUS on your group's collective needs. Facilitated by TBD in Salon 18.

9:15 – 11:30 am

- Nonverbal Learning Disabilities: Learning and Behavioral Interventions for Family, School, Work, and the Community - Learning and Behavioral Interventions for Family, School, Work, and the Community. Presented by Dr. Dean Mooney in Executive Ballroom H.

9:15 – 11:45 am

- TS and the Heart – Learn about heart conditions such as systemic high blood pressure, coronary heart disease, and stroke. Additionally, current heart research will be summarized. Presented by Dr. Siddharth Prakash in Ballroom I.

10:30-11:45am

- 18–29-Year-Old Discussion and Support – Identify the strengths and challenges of your age group as related to TS. Advise on the group's collective needs. Facilitators: Bria Kelly and Jeanna Lee in Salon 18.

12:15 to 1:15 pm

- Lunch Buffet in Ballroom C,D, & E

1:45 – 2:45 pm

- Endocrinology – Discussions about growth hormone and estrogen replacement therapy (ERT). Presented by Michelle Rivera and Iris Gutmark-Little in Ballroom I.

1:30 2:30 pm

- Continuation of Nonverbal Learning Disabilities: Learning and Behavioral Interventions for Family, School, Work, and the Community – Continuation from the earlier session. Presented by Dr. Dean Mooney in Executive Ballroom H.

1:45 – 2:45 am

- Significant Others of those with TS Discussion and Support – Identify the strengths and challenges of your group as related to TS. Advise TSSUS on the groups collective needs. Facilitated by Paul Kenward and Mitch Melman in Salon 18.

1:45 – 4:00 pm

- How to Be Your Best Butterfly – Have you ever felt stuck, lonely, left out, or tired of hearing “no”? Develop the skills aimed at improving your self-acceptance, self-compassion, and self-love. Facilitated by Mara Gittess and Holly Slonina in Salon 11/12.

3:00 – 4:00 pm

- Finding a Good TS Doctor – Finding a good TS doctor or working with your current one can be easier if you are prepared. Learn about realistic expectations, the process of transitioning from pediatrics to adult care, changing doctors, finding knowledgeable ones, gently educating doctors, and insurance considerations. Presented by Iris Gutmark-Little and Joanne Foodim in Salon 11/12.

3:00 – 4:00 pm

- TS Research Update – Learn about the latest TS research studies, how TSSUS supports research, and how you can make a difference. Presented by Dr. Siddharth Prakash and Cindy Scurlock in Ballroom H.

4:30 – 5:00 pm

- Youth Program Sign Out – Please pick up your children in Salon 19 (upstairs, top of elevator).

Dinner on your own.

7:30 – 11:00 pm

- Glow DJ Dance Party in Ballroom H/I.