



The 2025 TSSUS Conference

Schedule at a Glance

(as of April 11)

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

Thursday, July 17 (pre-conference)

9:00 am- 4:00 pm

- Board Meeting for TSSUS Board of Directors

10:00 am- 5:00 pm

- Healthy Heart Project Echocardiogram Screenings and Research

1:00 pm – 8:00 pm

- Attendee Check-In and On-site Registration

7:30 pm – 8:00 pm

- First-timer orientation. Learn about the TSSUS conference process so you can make the most of your experience.

8:00- 8:30 pm

- Casual time to visit and meet with others

Friday, July 18

7:00 am – 11:00 am

- Attendee Check-In and On-Site Registration

7:45 am- 8:45 am

- Breakfast for all conference attendees

9:00 am – 5:00 pm

- Healthy Heart Project Echocardiogram Screenings and Research.

9:15 am – 9:45 am

- State-Region Meet-and-Greet. Meet other attendees who live the closest to you.

10:00 - 10:45 am

- Meet People Your Age. Meet other attendees with whom you may have the most in common. You'll have 30 seconds to introduce yourself, and the other person will introduce themselves. Then, when the bell rings, one person moves chairs, and the process starts over. One-minute introductions encourage you to share your name, the main reason for attending the conference, or your favorite hobby. Feel free to watch if you don't want to participate.

Parents of adults, grandparents, and other family members are welcome to attend the group of their choice.

- 18-29 year-olds
- 30-39-year-olds
- 40-49-year-olds
- 50-59-year-olds
- 60+ year-olds
- Partners, adult parents, grandparents, and friends

Parents and school-age kids (sign in and meet the group leaders and those in your group)

- All 4-year-olds and those without TS aged
- 5-7-year-olds with TS
- 8-10-year-olds with TS
- 11-13-year-olds with TS
- 14-18-year-olds with TS
- Those without TS ages 11-17 (parents/family welcome but not expected)

11:00 - 11:45 am

- Defy gravity! Turner syndrome is like the Wizard of Oz; it initially seems all-encompassing and elusive, and it is an adventure. You can rise through your strengths and become stronger than you ever thought possible. What tools and people will you gather at the conference to prepare you for the next phase of your adventure? Cindy Scurlock, TSSUS CEO/President, and Jeanna Lee, TSSUS Board Chair

11:45-12:15

- Parents sign kids out of the youth group.

12:15 pm - 1:15 pm

- Lunch for all conference attendees

1:15 pm - 1:45 pm

- Parents sign kids back into the youth group.

1:45 – 2:30 pm

- The Basics of Turner Syndrome—Whether you're new to TS or seeking a refresher, this introductory session will cover the fundamentals of TS and guide you in managing TS care. Because TS is complicated, all questions are welcome. Dr. Iris Gutmark-Little will present
- Understanding the TS Brain; Understanding Nonverbal Learning Disabilities (NLD) Part 1—This introductory session will review how processing information that is not spoken or heard (nonverbal) affects specific skills essential to learning and social communication. NLD can contribute to challenges with anxiety, depression, relationships, and organizational skills, to name a few. Dr. Dean Mooney will present
- Cultivating Friendships. Forming and maintaining adult friendships can be a challenge. Acquire essential skills to navigate the interpersonal complexities of friendships effectively. We will discuss initiating conversations with potential friends, and standard "rules" for interacting with them. Mara Gittess and Holly Slonina will guide you through role-plays addressing key principles, including active listening, respecting boundaries, body language, and other essential concepts.

2:45-3:30 pm

- Heart Strong: Cardiovascular Care- Learn about TS heart risks, screenings, abnormalities, care guidelines, and prevention strategies. Presented by Dr. Siddharth Prakash
- Understanding the TS Brain; Understanding Nonverbal Learning Disabilities (NLD) (continued) Presented by Dr. Dean Mooney
- Best Advice Peer Discussion for 18-29-year-olds. The discussion may cover topics such as relationships, health, fertility, and self-esteem. Facilitated by Bria Kelly and Jeanna Lee

3:45-4:45 pm

- Endocrine Care for Children and Adolescents. The endocrine system regulates hormones and is vital in TS care. Learn about the issues related to TS; growth and growth hormone therapy options, estrogen and estrogen replacement therapy, thyroid, diabetes, and more. Dr. Iris Gutmark-Little

- Understanding the TS Brain; Understanding Nonverbal Learning Disabilities (NLD) Part 2-Identification and assessment of NLD and social/emotional characteristics. Presented by Dr. Dean Mooney
- Job and Career Planning for Success. Finding a job that values your unique skills and talents, keeps you engaged, and supports your needs can be challenging when you have neurological or social differences. Discuss why facing your limitations is healthy and tips for identifying what strengths you have. Presenter TBD

4:45 – 5:00 pm

- Parents sign kids out of the youth group.
- Dinner on your own.
- Download the Portland, Oregon, “Near Me Now” app to locate nearby restaurants.

7:30 pm– 10:30 pm

- Consultations with Dr. Dean Mooney (appointments may be made online)

7:30 pm– 9:00 pm

- Butterfly Society & Major Donor V.I.P. Reception Hosted by TSSUS (invitation only) – Join us in celebrating TSSUS monthly giving and major donors at a cocktail reception with desserts. Hosted by Becky Brown, Director of Development and Communications

8:30 – 11:00 pm

- Karaoke! You’re going to be popular! Conference attendees under 18 will kick off karaoke, and at 9:30, we will transition to adult singers. Everyone is welcome at all times.

Saturday, July 19th

7:45 – 8:45 am

- Breakfast for all conference attendees

8:45 am- 9:15 am

- Parents sign kids into the youth program.

9:00 am – 12:00 pm

- Healthy Heart Project Echocardiogram Screenings and Research

9:15 – 10:00 am

- Medical Advances in TS Research. Discover current TS research projects and how they may affect you. Learn how you can positively impact the future of TS by participating in the TS Research Registry and Clinical Trials. Presented by Dr. Siddharth Prakash and Cindy Scurlock

10:15-11:00 am

- Endocrine Care for Women with TS. Ensure you manage or monitor your needs related to estrogen replacement, thyroid function, blood pressure, bone health, diabetes, weight, vitamin D levels, cholesterol, and other relevant health concerns. Presented by Dr. Iris Gutmark-Little
- Nonverbal Learning Disabilities Part 1: Learning and Behavioral Interventions for Family, School, Work, and the Community. Presented by Dr. Dean Mooney
- Best Advice Discussion Panel for Parents of Kids aged 4-10. Every girl with TS is different, but much of the same information applies to education, friendship, and parenting. Panel attendees: Mysti Harrison, Holly Slonina, and TBD.

11:15-12:00

- Hear All About It TS is associated with a higher risk of hearing loss and middle ear disease. Review the TS care guideline recommendations for diagnosing and treating hearing loss and explore the latest advancements in hearing technology. Presented by Lyndsay Duffus

- Nonverbal Learning Disabilities Part 1 (continued): Learning and Behavioral Interventions for Family, School, Work, and the Community Presented by Dr. Dean Mooney
- Best Advice Discussion Panel for Parents of Kids aged 11-18. Every girl with TS is different, but much of the same information applies to education, friendship, and parenting. Panel attendees: Mysti Harrison, Holly Slonina, and TBD

12:00 - 12:15 pm

- Parents sign kids out of the youth program for lunch.

12:15 pm to 1:15 pm

- Lunch for all conference attendees

1:15 pm- 1:45 pm

- Parents sign kids back into the youth program.

1:45 – 2:30 pm

- Reproduction and Fertility. A Review of the TS clinical guidelines for planning for pregnancy and reproductive assisted technologies. Presented by Dr. Liz Rubin and Dr. Paula Amato
- Understanding the TS Brain; Understanding Nonverbal Learning Disabilities (NLD) Part 2; Resources to support success. Presented by Dr. Dean Mooney
- Aging and TS Peer Discussion. Facilitated by Barbara Flink, for those 55 years old and above

2:45 – 3:30 pm

- Defying Your Anxiety -Anxiety is a common emotion, especially for women with TS. This workshop will dive into how to recognize anxiety and what anxiety is. It will teach you multiple Cognitive Behavioral Therapy (CBT) exercises that have been proven to reduce symptoms of anxiety. Presented by Mara Gittess and Holly Slonina in the Lloyd Center Ballroom
- Understanding the TS Brain; Understanding Nonverbal Learning Disabilities (NLD) Part 2 (continued); Resources to support success. Presented by Dr. Dean Mooney
- 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 Billy Scurlock
- Significant Others of those with TS Discussion and Support – Discuss the challenges and benefits of having a partner with TS. Facilitated by Paul Kenward and Mitch Melman
- Chill time and Jewelry making

3:45 – 4:30 pm

- Driving and Navigation Skills. Driving is a complex task that requires executive function skills, including working memory, inhibition, attention, decision-making, and other cognitive abilities. Learn practical ways to improve driving skills and how visual perception problems affect driving ability. Presented by Jeff Plastrik
- To Be Determined
- Gravity-Defying Stories. We all have a story inside us, and sharing a short, compelling one is empowering. Interactively discuss common story themes related to TS or life in general, learn how to draft your story, and start writing! Presented by Jeanna Lee

4:45 – 5:05 pm

- Conference Closing, Insights, and Next Steps. Please share your input about the conference so we can continually improve and learn how to stay connected with others in the future.

5:05 – 5:30 pm

- Parents sign kids out of the youth program

6:00 – 7:00 pm

- Dinner for conference attendees

8:00- 11:00 pm

- Pink and Green Wickedly Good Dance Party
- Mix and mingle by the pool for the quieter crowd
- See you for the hike tomorrow or see you next year!