

TSSUS National TS Conference

Frequently Asked Questions

Who should attend the conference?

The conference is for all ages – from 3 years old to senior citizens. All age groups with TS will be represented in attendance. Spouses/significant others, parents, siblings, grandparents, and extended family members attend the conference as fully registered conference attendees. We encourage healthcare providers and TS researchers to attend as well.

When should I arrive/depart?

The Conference begins early Friday morning. You should plan to arrive on Thursday, July 17th. Registration/check-in will be open on Thursday 1pm-6pm and Friday 7am-10:30am. The conference concludes on Saturday night (July 19th) after the DJ Dance Party. There **may** be an optional group outing Sunday for those that choose to stay on through Monday.

Are any group outings planned?

TSSUS may plan an optional self-pay group outing on Sunday, July 20st, TBA. Details to follow.

When is the deadline to receive the discounted group room rate?

Hotel room reservations must be made by June 19, 2025, in order to receive the discounted group rate unless the group room block sells out before the deadline. **Your room reservations may be dropped from the TSSUS block if you are not registered for the Conference.**

Which airport is closest to the hotel?

Portland International Airport (PDX) is 10 miles from the hotel

How much does it cost?

All registration fees can be found on the **Annual Conference** portion of the TSSUS website under the **Events** menu tab.

Paid TSSUS members receive a discount. If you have not yet joined TSSUS as a member, now is a great time to partner with us! If you plan to attend as a family, please select the

“Family Membership” to receive the discounted price for each family member.

You will also need to consider the cost of the hotel, travel, shuttle to/from hotel, and meals for Thursday, and dinner on Friday and Saturday. Breakfast and lunch will be provided on Friday and Saturday and are included in your registration.

What is included in the conference registration fee?

The registration fee covers all conference activities and special events, all education sessions, and five conference meals (breakfast and lunch on Friday and breakfast, lunch, and dinner on Saturday).

What about transportation from the airport to the hotel?

The Portland TriMet tram travels to and from the hotel and airport for \$3. See webpage for full details.

What is a good age for my child to attend the conference?

This is really a personal decision based on your child. Our youth program is divided by age group with age-appropriate activities. Your child must be fully potty trained to be in the Youth Program. Younger children (age 3+) will have childcare and activities planned for them so that parents may enjoy the conference.

Starting at age five, children with TS can interact with others in their age group and build friendships, participate in activities and have special presenters that discuss TS-related topics on their level. The group numbers seem to increase around age nine, as this is when most parents begin to notice an increase in social difficulties and school challenges.

The conference offers children with TS an opportunity to connect with others who are going through the same experiences and who understand them. Siblings and children of those who have TS ages 3-16 are welcome to attend and will have a program of activities as well.

What should I bring with me?

- * A notebook and a favorite pen to take notes
- * A sweater or light jacket, as the meeting rooms can get chilly.
- * Comfy walking shoes
- * A favorite lanyard and pins from previous conferences
- * Medical records that show your karyotype
- * You may also want to bring some extra money to purchase resources, and logo/awareness items from the TSSUS Butterfly Store.

What should I wear during the day and for the Saturday evening DJ Dance Party and/or the Butterfly Society VIP Reception?

Both events are come-as-you-are casual. Feel free to dress up or come as you are from the day.

If you have more questions, please e-mail them to info@turnersyndrome.org.

