2024 TSSUS National Turner Syndrome Conference

July 19-20, 2024

This belongs to:
Send us your photos and videos!
We want to see all of your conference experiences –
text your photos to Becky Brown at 832.465.9388.
We’ll post them on social media!

Facebook

Instagram
We are so excited you are joining us in sunny Orlando! Your TS journey has led you to this moment this weekend and with the people at this conference. Think of the conference as a peaceful lazy river and soak in the sights, smells, and chatter. Take a deep breath and enjoy the moment because the people floating near you are your lifeline if you need one. Perhaps you are a happy guide, willing to help people prepare for the rapids that may pop up if life gets stormy. You are here because you want to be prepared. You know that having a plan, the right tools, and people will make your journey easier.

If you need to soak up some sun (with sunscreen, of course), do it! If you want to attend every hour of the conference and then go home and watch the video for every session you missed- do it! Ask questions, make friends, and continue your journey, knowing that TSSUS is strong enough to support you. We are your float (foundation of information), your friend (ready to help), your bucket filler when you are discouraged, and your swim coach (always looking for ways to improve your health).

I'd like to thank EVERYONE who helped make this conference a success- thank you!

We're a serious organization with a serious sense of humor so be a proud flamingo in a flock of pigeons!

I hope to meet each one of you this weekend,

Sincerely.

Cindy Scurlock
President & CEO, M.A., L.P.C.
The Turner Syndrome Society of the United States
Thursday, July 18

9:00 am- 4:00 pm
- Board Meeting for TSSUS Board of Directors

3:30 pm – 8:00 pm
- Attendee Check-In and On-site 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 I – All adults with TS and their family
  Executive Ballroom H – Children with TS in Pre-K, Grades K-2, Grades 3-5 and their family
  Salon 11/12 Children with TS in Middle and High School and their family (2nd floor near the grand staircase)

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 Registration Registration Desk #2.

7:45 am – 8:45 am
- Breakfast Buffet for all conference attendees in Ballroom C, D & E.

8:45 – 9:15 am
- Check children in to the Youth Program in Salon 16 & 17 foyer, 2nd floor.

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, TSSUS CEO/
  President, Jeanna Lee, TSSUS Board Chair, and Becky Brown, TSSUS National Director of Development and
  Communications 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 20-25 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 cardiology, endocrinology, genetics, psychology, and tips on general care.
  Ballroom H & I.
11:45 am – 12:15 pm
- Check children out of the Youth Program for lunch in Salon 16 & 17 foyer, 2nd floor

12:15 pm - 1:15 pm
- Lunch Buffet for all conference attendees in Ballroom C, D & E

1:15 pm – 1:45 pm
- Check children into the Youth Program in Salon 16 & 17 foyer, 2nd floor.

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. Presented by Dr. Iris Little-Gutmark in Executive Ballroom H.

- **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. Dean Mooney in Executive Ballroom I.

- **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. Presented by attorney Kathleen Kane in Salon 11 & 12, 2nd floor.

- **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 Dr. Joanne Foodim in Salon 18, 2nd floor.

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 Dr. Melissa Crenshaw in Ballroom H.

- **Continued Understanding the TS Brain; Understanding Nonverbal Learning Disabilities (NLD)** – Presented by Dr. Dean Mooney in Executive Ballroom I.

- **Continued 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. Presented by attorney Kathleen Kane in Salon 11 & 12, 2nd floor.

- **Aging and TS** – Identify the strengths and challenges of your group 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 Dr. Melissa Crenshaw in Ballroom H.

- **Continued Understanding the TS Brain; Understanding Nonverbal Learning Disabilities (NLD)** – Presented by Dr. Dean Mooney in Executive Ballroom I.

- **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, 2nd floor.

- **People of Racially and/or Culturally Diverse Backgrounds Discussion and Support** – Facilitated by Jeanna Lee and Elizabeth Kwon in Salon 18, 2nd floor.
5:15 – 5:45 pm  
■ Check children out of the Youth Program in Salon 16 & 17 foyer, 2nd floor.

**Dinner on your own.**

6:30 – 8:00 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. Please pick up your invitation at the TSSUS table for this adult-only reception in Salon 1 (take the main hotel elevators to the 2nd floor, or use the grand staircase).

7:30 – 10:30 pm  
■ Consultations with Dr. Dean Mooney by appointment only, in the Room #251, 2nd floor. Easy access from the main hotel elevators.

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**Saturday, July 20th**

7:00 – 10:00 am  
■ **Attendee Check-In and On-Site Registration** at the Butterfly Store in Ballroom D.

7:45 – 8:45 am  
■ **Breakfast Buffet** – for all conference attendees in Ballroom C, D & E.

8:45 am – 9:15 am  
■ Check children into the Youth Program in Salon 16 & 17 foyer, 2nd floor

9:15 – 10:15 am  
■ **TS and the Heart** – Learn about heart conditions related to TS 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 H.

■ **Nonverbal Learning Disabilities: Learning and Behavioral Interventions for Family, School, Work, and the Community** – Presented by Dr. Dean Mooney in Executive Ballroom I.

■ **Job Accommodations and TS** – Learn about accommodations that may help you improve productivity and on-the-job success. Even if you don’t have a disability, you may request accommodations for challenges like anxiety, difficulty with instructions, timed tasks, etc. Presented by Kathleen Kane in Salon 11 & 12, 2nd floor.

■ **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 in Salon 18, 2nd floor.

10:30-11:45 am  
■ **Continued 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 H.

■ **Continued Nonverbal Learning Disabilities: Learning and Behavioral Interventions for Family, School, Work, and the Community** – Presented by Dr. Dean Mooney in Executive Ballroom I.

■ **Continued Job Accommodations and TS** – Presented by Kathleen Kane in Salon 11/12, 2nd floor.

■ **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. Facilitated by Bria Kelly and Jeanna Lee in Salon 18, 2nd floor.
11:45 am – 12:15 pm
- Check children out of the Youth Program for lunch in Salon 16 & 17 foyer, 2nd floor.

12:15 to 1:15 pm
- Lunch Buffet in Ballroom C, D, & E.

1:15 – 1:45 pm
- Check children into the Youth Program in Salon 17 & 18 foyer, 2nd floor.

1:45 – 2:45 pm
- Endocrinology – Discussions about growth hormone and estrogen replacement therapy (ERT). Presented by Dr. Michelle Rivera and Dr. Iris Gutmark-Little in Ballroom H.
- Continued Nonverbal Learning Disabilities: Learning and Behavioral Interventions for Family, School, Work, and the Community – Presented by Dr. Dean Mooney in Executive Ballroom I.
- 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, LPC, MA and Holly Slonina in Salon 11/12, 2nd floor.
- 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, 2nd floor.

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.
- 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 Dr. Iris Gutmark-Little and Dr. Joanne Foodim in Ballroom I.
- Continued How to Be Your Best Butterfly – Facilitated by Mara Gittess, LPC, MA and Holly Slonina in Salon 11/12, 2nd floor.

4:00-4:30 pm
- Closing and Polling Survey: Please stay in the room you are already in and offer your input regarding the conference so that we may continually improve. We really appreciate your input!

4:30 – 5:00 pm
- Check your children out in Salon 16 & 17 Foyer, 2nd floor

Dinner on your own.

7:30 – 8:30 pm
- Karaoke – Ballroom H & I.

7:30 – 10:30 pm
- DJ Dance Party in Ballroom H/I.
- Mix and Mingle on the pool patio.

Please remember. Be courteous to speakers and other attendees by silencing your cell phone during sessions. It’s very distracting when attendees are talking on their phone, texting, or scrolling during a presentation.
Conference Speakers

Melissa Crenshaw, MD
I’m the medical director for the Clinical Genetics Program at Johns Hopkins All Children’s Hospital and also serve as an assistant professor with Johns Hopkins Medicine. My research interests include congenital heart defects, chromosome abnormalities and Turner syndrome. I have additional expertise in the genetics of congenital heart disease and connective tissue disorders and am board certified in pediatrics and clinical genetics. I am also a TSSUS Scientific Advisory Board member.

Joanne Foodim, MD:
I am a woman with Turner syndrome and a retired physician. I had my own practice as a primary care physician in New Haven, Connecticut for over thirty years. In addition, I am a wife, mother and grandmother. It has been my pleasure to be involved with the TS Society for many years, including serving on the professional advisory board. My passion is for educating and supporting women and girls with Turner Syndrome and all those touched by it.

Mara Gittess, LPC, MA:
I’m a psychotherapist in private practice in Houston and have TS myself. I work with children, adolescents, and families for needs related to anxiety, depression, eating disorders, ADHD, bipolar disorder, and various behavioral problems and learning disabilities. I speak English and Spanish.

Iris Gutmark-Little, MD
As a pediatric endocrinologist at the Turner Syndrome Clinic in Cincinnati, Ohio, I’ve been taking care of girls with Turner syndrome for ~15 years. I also treat general endocrine patients as well. In my research, we are trying to learn why patients with Turner syndrome are at risk for cardiovascular disease. I also research long-acting growth hormone. In my free time, I have three wonderful children who keep me busy and happy. I love to exercise, specifically weight-lifting. I also enjoy good food and drink – especially coffee!

Kathleen L. Kane, Esq.
I have represented those denied Social Security Disability Benefits since 1997. After moving to Massachusetts, I expanded my practice at a small firm to include Family Law, Bankruptcy, and other civil litigation cases. I’m a member of the Winthrop Commission On Disabilities, I’m a respected national disability advocate, and supporter of The Marfan Foundation and advocate for the disabled as evidenced by her presentations and workshops on Social Security Disability at the Annual International Marfan Conference, The Ehlers Danlos Society, Ehlers Danlos National Foundation, The Ataxia Foundation, Stickler Involved People, Dysautonomia Support Network, and many more nonprofit organizations nationally.
Dean Mooney, Ph.D., NCSP
I am the founder and director of the Maple Leaf Clinic, a licensed clinical and school psychologist in Vermont, and am a nationally certified school psychologist. I have co-authored several books, including: Nonverbal Learning Disabilities: A Guide to School Success (May 2006), Nonverbal Learning Disabilities: A Guide to School Success – The Teacher’s Manual (Sept. 2007), A Train Ride to Grandma’s (With NO Chocolate Donut) (Sept. 2009), and A Snapshot of Me – A Student with NLD (2016). Maple Leaf Clinic provides neuropsychological, educational, and psychological assessments of children, adolescents, and adults, as well as individual, group, and family therapy, and developmental, educational, and clinical consultations by phone, in-person, or through video chat.

Siddharth Prakash, MD, PhD
I am an associate professor at McGovern Medical School at The University of Texas Health Science Center at Houston. I organized the UT Health Adult TS Clinic and coordinate the UT and TSSUS TS Research Registries. I’m board certified in cardiovascular disease and internal medicine and my clinical interests center on bicuspid aortic valve, thoracic aortic aneurysm, and adult congenital heart disease in patients 17 and older. My research concentrates on the genetic causes of bicuspid aortic valves and related congenital abnormalities involving the left ventricular outflow tract and aorta. I’m a Fellow of the American Heart Association and the American College of Cardiology and the TSSUS Scientific Advisory Board chair.

Michelle Rivera, MD
I am an adult and pediatric endocrinologist at UT Health Houston. I specialize in Turner syndrome care and lead the TS pediatric clinic in Houston and work closely with the TS adult clinic. I received my medical degree from Ponce School of Medicine and am a member of the TSSUS Scientific Advisory Board.

Cindy Scurlock, MA, LPC
I’ve proudly led the Turner Syndrome Society of the United States as President/CEO for 17 years. I’m a licensed professional counselor and an expert in TS support and healthcare. I’ve co-authored numerous journal articles alongside amazing TS healthcare providers and researchers. My daughter, Brooke Kaczynski, has TS and is an enthusiastic first-grade teacher and volunteers in the youth program. My husband, Billy, volunteers as well and depending on the hour, he may say he enjoys it!

Holly Balvin Slonina, LMSW
I am an outpatient therapist for Community Clinical Services. I was diagnosed with TS at the age of 12. I have been in the mental health field since 2014 and have worked in multiple capacities, school, home, and the community. I work with adults, adolescents, and children in relation to anxiety, depression, mood disorders, trauma, and PTSD. I am a licensed foster parent currently going through the process of adoption. In my spare time I love to read, shop, travel and lay on the beach. I live in Maine with my husband, three-year-old son and two cats. This is my first TS conference, and I am very happy and excited to be a part of it!
Natalie Portway, Group Volunteer Coordinator – I am a high school math teacher from sunny southern California. I have two adopted boys, Joe and Nico, and my days are filled with homework, sport and snuggles. In my scarce free time, I enjoy baking and working out, especially running and kick boxing. (Woman with TS and youth team member since 2013)

Andrew Stephens, Leader – I love working with kids because my mother works in a special education classroom, and I’ve been around children with special needs most of my life. My sister, with TS is in her early twenties and my mother, Terra Williams, has volunteered as a TSSUS youth leader for years. When I’m not working, I enjoy spending time with my family and watching sports. (Group leader; brother of someone with TS and youth team member since 2019)

Becca Aye, Co-Leader – I plan to attend college to become a Sonographer. I’m a baby/toddler/young child magnet. I attended my first conference at 7 months old, and this year is my 11th conference; they have always been the highlight of my summers. I have volunteered as a 4-H camp counselor for grades 3-6 for the last two years and am a grade 1 and 4 elementary school classroom helper. (Young woman with TS and youth team member since 2024)

Our youth team leaders LOVE volunteering, and they are crucial to the success of the Conference.

The Youth Program Schedule of Activities by age group will be provided in your registration packet.

34th TSSUS National Turner Syndrome Conference • July 19-20 • Orlando, Florida
**Kindergarten – 2nd Grade**

**Megan Banfield, Leader** - I am an elementary school teacher in the Houston area. One of my besties has TS and I love traveling abroad. (Friend of someone with TS and youth team member since 2023)

**Danielle Cignarella, Leader** – I love being a positive role for the children and showing them, they can do anything they put their minds to. As a teacher, I have worked with children and teens for much of my life and led service clubs such as Autism Speaks and Big Brothers Big Sisters. (Woman with TS and youth team member since 2017)

**Christina Guglielmo, Co-Leader** – I am an adamant crusader for spreading knowledge within the medical community to show that those with TS can do anything and everything. I’m a huge lover of Broadway and am employed with Broadway Across America. I live in sunny Florida. (Woman with TS and youth team member on and off for over a decade).

**Natoli Barbera, Co-Leader** - I’m stoked to be back after several years away! I began my career as a teacher and then spent ten years working on Broadway in NYC. For the last five years, I’ve been living my best life living and working in Orlando, FL. (Woman with TS and youth team member on and off for over a decade).

**3rd-5th Grade**

**Brooke Kaczynski, Leader** - I’m a first-grade teacher in Nacogdoches, TX, and I have volunteered for the Society for many years (my mom is Cindy Scurlock). When I attended the conference as a child, the youth program was a highlight of my year and I have just as much fun being a leader. I enjoy spending time with my friends and family, walking, and my cat, Hunter. (Woman with TS and youth team member since 2018)

**Micaela Durant, Co-Leader** – I’m a Kindergarten teacher in Murfreesboro, TN and got married in June of this year! I have fond memories of singing in the conference talent show and attending the youth program myself, so it seems natural for me to give back by volunteering. (Woman with TS and youth team member since 2024).

**Middle School**

**Megan Banfield, Leader** - I am an elementary school teacher in the Houston area. One of my besties has TS and I love traveling abroad. (Friend of someone with TS and youth team member since 2023)

**Danielle Cignarella, Leader** – I love being a positive role for the children and showing them, they can do anything they put their minds to. As a teacher, I have worked with children and teens for much of my life and led service clubs such as Autism Speaks and Big Brothers Big Sisters. (Woman with TS and youth team member since 2017)

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High School

**Terra Williams** – I’ve been a paraprofessional in the school system, working with students with special needs for many years. I love spending time with my three children and have enjoyed helping my daughter plan a wedding this year. (Parent of someone with TS and youth team member since 2013)

**Chris Portway, Helper/Floater** – As the parent of 2 young boys, I enjoy interacting with the kids at the conference as well as helping make the youth program fun and safe. For the last couple years, I have been helping my wife create the schedule and making sure it runs smoothly. (Husband of someone with TS and youth team member since 2018)

**Elizabeth Pawlik, helper** – I am from Manassas, Virginia (right outside of Washington DC). I graduated with a Bachelor of Science in Biology from Bridgewater College in May 2024. I am working towards becoming a veterinarian and working as a kennel and vet assistant at a veterinary hospital. I have attended every TSSUS conference since 2013 except one. After transitioning out of the youth group, I wanted to continue my involvement in the conferences, so here I am! (Woman with TS and youth team member since 2024)

Non-TS, 11-17 Years

**Terra Williams** – I’ve been a paraprofessional in the school system, working with students with special needs for many years. I love spending time with my three children and have enjoyed helping my daughter plan a wedding this year. (Parent of someone with TS and youth team member since 2013)

**Ryan Cignarella, Co-Leader** – I’m a senior manager at GlaxoSmithKline working on key medicines for patients in research. I openly share the story of our reproductive health journey and we now have a son. The journey has taught us the value of flexibility and free thinking. I welcome every day of this journey as we prepare for a bigger family. (Husband of someone with TS and youth team member since 2023)

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TSSUS Butterfly Store  No trip to the conference is complete without a visit or two to the TSSUS Butterfly Store! You’ll find lots of great souvenirs, butterfly jewelry, bags, fun baseball caps, branded TSSUS merch and the TSSUS Official 2024 Conference Shirt!

Novo Nordisk is a long-term dedicated supporter of the Conference, those with TS, and the TSSUS community. Their team of experts will be on-hand in the Novo Nordisk booth throughout the event to answer your questions about growth hormone therapy. Be sure to thank them for supporting the TS community when you stop by!

University of Iowa Study  Does the X Chromosome Hold the Key? Deciphering Diabetes in Turner Syndrome. Did you know Turner syndrome is associated with an increased risk of developing glucose abnormalities, including diabetes? Dr. Catherina Pinnaro, a pediatric endocrinologist at the University of Iowa, is spearheading a research study to understand why women and girls with Turner syndrome are more likely to develop diabetes than the general population.

Members of the Pinnaro team are here at the TSSUS Conference to answer any questions you may have about the study, logistics, and benefits. Feel free to stop by and speak with them to decide if you might like to participate. If you are not attending the conference but want to learn more about participating in Turner syndrome research, consider joining the TSSUS Turner Syndrome Research Registry (TSRR).

The Turner Syndrome Research Registry is ONSITE!  Dr. Siddharth Prakash, chair of the scientific advisory board, will help you join the TSSUS registry and/or answer your questions about it. Registry participants like you have already contributed to important TS research that supports the community today and for years to come. The process is to 1. Enroll in the registry, 2. Fill out a health survey online, 3. Check your email for requests to participate in studies approved by the TSSUS scientific advisory board.

The TSSUS Healthy Heart Project NEEDS your help  Dr. Michael Silberbach is retiring this year and needs your help to transfer the Healthy Heart Study information to the TSSUS TS Registry. If you or your child had an echocardiogram at the TSSUS conference, please stop by the Healthy Heart table and sign a consent to transfer your records so TS researchers may continue to use your data. You may also stop by the table and wish Dr. Silberbach a happy retirement and welcome the new Oregon TS Clinic director, Kirstie Lechich.

Driving Advice Learning and Behavior Coaching Services  Jeff Plastrik will be available throughout the weekend to advise on driving considerations related to TS. He’s been a driving instructor in the Houston area for years and knows firsthand about driving challenges, as his wife has TS.

Learning and Behavior Coaching Services  Mira Cohen, MSW leads BYBB Coaching Groups for tweens and teens with TS who have neurodevelopmental challenges and associated mental health conditions such as anxiety, depression, OCD, ASD, NVLD, and ADHD. She will be available throughout the weekend to discuss neurodevelopmental challenges and her coaching services.

Book Author Mary Yoakum  Mary is a woman with TS, and her book I’m Just Me is filled with information, personal experiences, advice, and a little humor that speak to both the challenges and gifts that come with TS. If you are a girl or woman with TS and nonverbal learning disorder or the parent of one, this is an honest, warm, compassionate, and helpful look at connecting with others and living your best life. As Mary would put it, “We have challenges, but with patience and love we get there — wherever we want to go.”
The Turner Syndrome Society of the United States is proud to introduce the TSSUS Legacy Society. The Legacy Society is a way for TSSUS to honor those of you who have or will embrace legacy giving by naming TSSUS in your last will and testament and/or naming TSSUS as a beneficiary of your life insurance policy or retirement account. The TSSUS Legacy Society also includes those donors who make Major Gifts to TSSUS.

What Is a Legacy Gift or Planned Gift?
A legacy gift is a gift to TSSUS in your last will and testament. It can be a piece of property, cash, life insurance, retirement fund, or a percentage of your estate. Legacy gifts have begun to play a key role in supporting TSSUS, yet many people don’t know they are an option, how they are paid out, or the tax benefits of these gifts.

* A gift that you’ve planned in your will is considered a planned gift or legacy gift.

What is a Major Gift?
Each nonprofit organization sets their own definition for a “major gift”. For TSSUS, a major gift is any single gift of $1,000 or greater, and a major donor is defined as anyone who has donated a single gift of $1,000 or greater within the last year.

How Do I Leave a Legacy Gift?
Charitable Bequests in Your Will. Legacy gifts (charitable bequests) can be given in two ways. First, you can leave a lump-sum cash amount to TSSUS. These gifts are given separately when you pass away and are not included in your residual estate (everything that’s left after debts/taxes are paid and specific gifts are distributed). You may leave a percentage of your residual (remaining) estate to TSSUS. While a cash charitable gift will remain constant over time, a percentage of your residual estate can grow over time, resulting in a higher potential gift.

Gifts from Beneficiary Designation. (Life Insurance & Retirement Accounts) Many people choose to leave a gift to charity by beneficiary designation. You can name TSSUS as the beneficiary of your life insurance policies or unused retirement assets. These can include individual retirement accounts (IRAs), 401(k)s, 403(b)s, or pensions. A gift to TSSUS through a beneficiary designation may be the most advantageous gift you can make. This allows you to transform your IRA into a legacy of giving. IRA owners are eligible to donate up to $105,000 in tax-free gifts to charity. Because these gifts are often larger than what you might be able to give in your lifetime, they can significantly impact TSSUS. These types of planned gifts are a good option if you have paid-up policies or retirement accounts that you will not use. If you have a large estate, gifting retirement accounts and life insurance policies can help your heirs avoid income and estate taxes.*
What Are the Benefits of Leaving a Legacy Gift?
People often worry that leaving a legacy gift means there will be less to give to their loved ones. The truth is you can make a legacy gift without taking away from the gifts left to your family and friends. Gifts made through bequests or life insurance policies are generally deductible from your estate taxes. This means your estate's taxable value is reduced by the amount of your charitable gifts, potentially resulting in a lower estate tax liability. Legacy giving helps you maximize your philanthropic impact and minimize taxes.

Leave A Lasting Legacy Aside from tax incentives, there are many other reasons to leave a legacy gift. Legacy giving is a way to leave a lasting legacy of generosity and make a cause you care about an important part of your life story. Your gift might also cause others to think about their own philanthropic goals and inspire them to give back as well.

While legacy giving makes it possible to leave much larger gifts than otherwise feasible, it’s important to remember that you don’t have to be wealthy to leave a legacy gift. You can leave as much or as little as you want - there is no gift too small to make an impact on future generations. It only takes a few minutes to leave a gift in your will to TSSUS, but it creates a legacy that lives on forever. In terms of how your legacy gift benefits TSSUS, they are often unexpected. Legacy gifts are dramatically impactful to TSSUS and help us invest in expanding our programs and services more quickly and efficiently.

Leaving a legacy gift is quite simple. When you make your will, you simply include a statement like “I, [name], of [city, state, ZIP], give, devise and bequeath to the Turner Syndrome Society of the United States (EIN 41-1596910) [written amount or percentage of the estate or description of property] for its charitable purposes, including but not limited to general use and purpose.”

Leaving charitable bequests in a will and gifts from beneficiary designation are the most popular way for donors to make planned gifts. Yet, they’re far from the only way. From simple gifts to complex trusts, there are many different types of planned gifts you can discuss with your financial planner.

How Do I Make a Major Gift?
If you would like to become a part of the TSSUS Legacy Society with a major gift, simply donate online

![QR Code]

or by check to the address below.

We Want to Hear from You
Have you left us in your future plans? Please let us know!
We would love to thank and honor you today.
If you would like more information on legacy and major giving, or would like to become a part of the TSSUS Legacy Society, please contact Becky Brown, TSSUS National Director of Development & Communications at: becky@turnersyndrome.org or 800-365-9944.

* Always consult your CPA or financial advisors on tax-related questions.
Are you ready to be a part of something bigger than yourself?
The TSSUS Butterfly Society is an exclusive group of supporters who believe that every person and family touched by Turner syndrome should have access to cutting-edge, up-to-date information, resources, and clinical care guidelines, as well as the opportunity to connect with others in their area through organized social and educational gatherings.

Why Give Monthly?

**IT’S AFFORDABLE.** By giving monthly, you invest what makes sense for you and make an incredible impact over the course of your membership in the Butterfly Society.

**IT’S A COMMUNITY.** Becoming a Butterfly Society member allows you to join a dedicated group of supporters who understand the importance of making a sustaining commitment to advance treatment, research, and support of those with Turner syndrome.

**IT’S SUSTAINED SUPPORT.** Monthly gifts enable us to invest in specific areas of our work, expand our programs, and innovate, because we know we have the ongoing support of the Butterfly Society community.

**IT’S FULFILLING.** You’ll know your investment in the work of TSSUS is driving research, knowledge, and support of the TS community. You’ll understand that without you, this work doesn’t happen. You’ll take pride in knowing that you have invested in the very community you are a part of.

**Butterfly Society Members Receive:**
- An appreciation gift at the annual conference
- Your name listed as a Butterfly Society Member on the TSSUS webpage, and in the TSS Connect Newsletter.
- Ticket to the exclusive Butterfly Society reception at the 2024 Annual Conference and future conferences.
- Complimentary TSSUS Membership for one year (at the $10/month level and above).

TSSUS is celebrating 37 years of serving the TS community. Please consider a monthly gift and join the TSSUS Butterfly Society today.

**Become a Butterfly Society Member today!**
TSSUS Local & Virtual Support Groups

TSSUS support groups could be easily called “friend groups” because it’s important to connect with people that really “get you.” Who else knows how you feel when you must take vacation time for doctors’ appointments, or how proud you are of yourself for not getting lost on vacation? Who can help you overcome your fears about giving a growth hormone injection? Your friends at TSSUS ... that’s who can help you, encourage you, and listen to you!

TSSUS Support Groups are volunteer-led groups that offer TS resources and support to those touched by TS within a specific geographical location.

How can I find a Support Group in my area?  
All TSSUS Support Groups are listed at tssus.org.

Who Can Lead a Support Group?  
Support groups can be led by anyone within the TS community. This includes a person with TS, a family member, or a professional.

How do I start a TSSUS Support Group?  
Contact Deborah Rios at deborah@turnersyndrome.org to discuss the opportunity to organize a group in your community. We also have individual volunteers that host events such as meet and greet or other gatherings. If you would like to host an individual event, please contact Deborah Rios.

TSSUS Virtual Group  
At TSSUS, we have generational Zoom group meetings almost every month. Whether you are a 30-something or a Golden Butterfly, TSSUS offers the opportunity to get together with peers in our age group in a friendly, supportive atmosphere.
Salons, Signature 2 Room and Hospitality Suites

Level 2

Junior Ballroom Below

Grand Ballroom Below

Executive Ballroom Below

To Convention Center
West Concourse

Restrooms

To Parking
Garage

Pre-function

Registration Desk 4

Pool Balcony

Executive Ballroom Below

Signature 2 Meeting Room

Escalators & Stairs

Level 2
Imagine your local neighborhood park filled with old and new friends from the TS community who have come together to raise awareness for TS! TSSUS created the Chasing Butterflies Walk program to do just that. As the national signature fundraising event for TSSUS, the walk program allows you to create friend and family teams, to raise funds. We offer great incentive prizes for fundraising at each level, too!

It only takes 1-2 volunteers to coordinate with TSSUS to hold a Chasing Butterflies Walk in your area. Half of all proceeds raised will be used to support established TSSUS programs in your area like local get-togethers and conference scholarships for local members when your walk raises $1,000 net. If a walk raises $5,000 net or more, the walk coordinator and one (1) co-coordinator will each receive a scholarship to the TSSUS National Conference!

For more information, stop by the TSSUS table and talk to Deborah or Becky, or email deborah@turnersyndrome.org after the event.

TSSUS would like to celebrate and recognize the 2023 Chasing Butterflies Walk’s top fundraisers!

Shannon Rodgers
Spring Hill, Florida
raised $6,675

Talia Bartelini
Purchase, New York
raised $14,435

Lynda Taylor
Newark, Delaware
raised $4,414

Did you know 50% of the funds raised at TSSUS Chasing Butterflies Walks are used to fund scholarships and programs in the states where they were raised? Through their efforts as TSSUS Chasing Butterflies Walk coordinators, these ladies helped fund conference scholarships to this event!
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TSSUS Staff

Cindy Scurlock, MA, LPC, President and CEO
In 1997 my daughter, Brooke, was born with TS, and TSSUS was our lifeline. After countless weeks of searching for information on TS, I knew I had to help make the process easier for the next person. I discovered TS information was important yet connecting with others was priceless. Who else really understands what it feels like to spend all day at doctors’ visits and leave without answers or information you don’t understand? In 2007, I graciously accepted the opportunity to work for TSSUS and closed my counseling practice. I have a master’s degree in community counseling and a bachelor’s degree in psychology and biology. I love spending time outdoors with my husband, Billy (he’s the informal comic relief at TSSUS events), our daughters, Brooke and Ally, and dogs Cookie and Slinky. We also have chickens.

Becky Brown, National Director of Development & Communications
In my role as the National Director of Development and Communications for TSSUS, fundraising efforts and communications strategies, as well as social media presence are my responsibilities. As a child, my parents instilled in me the notion that just one friend could change someone’s life and that, whenever possible, I should be that friend. I think this is what led me to a life-long career in the nonprofit sector, and in service to the people they help. I have worked in a senior leadership role in development and communications for national and regional nonprofits for more than 24 years. Before that, I had a successful career as the national sales manager for nationwide Spanish-language and general market radio groups and the owner/publisher of a regional children’s magazine. I studied nonprofit management and communications at Le Tourneau Christian University in Houston, Texas.

Deborah Rios, National Director of Member Services
I began working over 15 years ago as a part-time employee for TSSUS. In 2008 I attended my first conference and met so many with TS, their families, and their friends. My passion to help others began in my early years as I found myself compassionate and a friend to everyone. I spend much of my workday helping those with TS navigate the many resources TSSUS offers, connecting people to others and TS experts, and often just there to listen when someone needs that individual support. Outside of work, I love spending time with my children, thrift shopping and fishing with my husband, Jimmy, and cuddling with my dogs, Paisley, and Lily. I attended Alvin Community College and was involved in alliances/clubs such as ACC Student Ambassadors and Active Minds where I found my “fit” for helping others.

Bobby Marsh, Director of Finance and Administration
My journey through life has taken me in a completely different direction than when it started. I spent 28 years in the automotive industry as a leader in operations and sales. When my daughter was born, it was evident that her life would not be a normal one and the path that I thought I was on would start to change. She was diagnosed with cerebral palsy and later with a seizure disorder along with other conditions. Her struggles became my passion to ensure her life is full of experiences and to not allow her the chance to live life to the fullest. Through many other non-profits, we found the means to allow her to experience many things. Because of that, I became more involved as a volunteer to help others like my daughter. While doing this, I started looking at other ways I could help non-profits with my experience and started helping with operations and accounting. In 2015, I came to TSSUS as a part time bookkeeper and embraced the mission of the organization. In 2021, I left my automotive career and focused entirely on accounting and working more with non-profits. I have been fortunate to now be working full-time for Turner Syndrome Society in embracing their mission.
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Turner Syndrome Society of the United States

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