

tss Connect™

Turner Syndrome Society
of the United States
Fall 2019



2019 TSSUS Activities Map



Healthy Heart Project

Butterfly Society

2019 National Conference Summary

TS Choice Awards



The Turner Syndrome Society of the United States advances knowledge, facilitates research, and provides support for all touched by Turner syndrome.

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TSS Connect • Fall 2019

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The Turner Syndrome Society of the United States is a national 501(c)(3) nonprofit organization dedicated to providing support and health-related information to those with Turner syndrome, their families, and the medical community. TSSUS is the leading authority on the condition.

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As many of you may know, my daughter with Turner syndrome is now 21 years old – yes time flies! Being a part of TSSUS has helped my family in ways too numerous to count, but today I'm thinking about how my involvement with the Turner Syndrome Society has helped us proactively plan for Brooke's routine health needs. I quickly realized that the people I'd met at our local Houston events helped me understand TS in ways I'd never imagined before.

Personally, I was lucky enough to have been involved in a local TS group prior to seeing and meeting hundreds of people at my first TSSUS National Conference, yet the experience was still thrilling and overwhelming.

At this year's conference, I heard from a disturbing number of people that their parent, spouse, or even doctor ignored or minimized the health implications of TS. I remember when Brooke was diagnosed, I desperately attempted to justify everything she had by pointing out which family member was short, who had a high roof mouth, a broad chest, and so on. Finally, although not easily, I accepted her diagnosis and focused on what I needed to do to help her the best I could. I was somewhat in denial of her having Turner syndrome because I didn't understand it fully. I was fearful of what it meant for her health. I didn't know how to explain her condition to others, and I didn't know if somehow our family tree or environmental factors caused her to have TS.

Knowledge is truly power and I encourage everyone with TS to take the time to understand the condition by reading the patient-friendly version of the Clinical Practice Guidelines for the Care of Girls and Women with Turner Syndrome, found on our website (tssus.org) under "Living with TS" and "Guidelines and Checklists." If you're a parent, you owe it to your child to do the same.



If you're a person with TS, you owe it to yourself to be your own expert advocate. It's important to understand all the implications of TS so you will recognize an issue if one arises.

I've heard from more than a handful of people saying their doctors argued with them about having TS; saying it couldn't be possible, they didn't look or act like they had TS. I question what that even means. It's sad that those with TS are at a great disadvantage because they may not look or act differently enough that people recognize or respect their needs enough to understand them.

The rare genetic difference in people with TS is real. The differences among people with TS are real. Some will never live independently, some are medical doctors, and most exist between the two extremes. The support the Turner Syndrome Society of the United States provides is real because we understand everyone is unique and everyone supporting someone with TS has unique needs as well.

Sincerely,

Cindy Scurlock

Cindy Scurlock, President
The Turner Syndrome Society of the United States

The TSSUS Healthy Heart Project

The TSSUS Healthy Heart Project (HHP) has been serving the TS community for the last 16 years. In

Nashville this year the team gathered once again and performed more than 130 echocardiograms. The goal of the HHP is to obtain focused ultrasound images of

the heart (echocardiograms or “echo”) in girls and women with Turner syndrome. The TSSUS HHP is a service to the TS community and also works to understand the multiple cardiovascular problems that can happen in Turner syndrome.

At the 2019 TSSUS National Turner Syndrome Conference, we again found undiscovered problems among the participants and we have already connected them with their caregivers at home. During each session highly motivated participants from the TS community complete a medical survey, get measurements of height, weight and blood pressure, and undergo a focused echo. The images collected from participants are made anonymous and later analyzed. The TSSUS HHP is the world’s largest database of echo measurements of the aorta in girls and women with Turner syndrome. The data collected over the years has led to multiple medical publications that have continued to advance the knowledge of cardiovascular disease in this amazing group of girls and women. Numerous important scientific studies have already been published. These studies have been the basis for some of the most important recently published guidelines for cardiac care.

This project has been possible thanks to the hard work of devoted volunteers that travel from all over the United States. This year the front desk team was led by Dorothy Baume and included Barbara Flink, Linda Kalb, Paul Kenward, Brenda Gruwell, Carolyn Gruel, Caitlin Sullivan, and Anne Nabor. Brittani Ehrhorn, the chair-elect of the TSSUS Board of Directors, led the vital signs team that included Adria Bibbs, Laurie Gibbs, Tamara Brown Dreher, Michaelena Teachmond, and Dr. Evan Los. We are extremely grateful to the Vanderbilt Children’s Hospital and to the “muscle” of the project, the extremely hard working echo sonographers that travel to the meeting and do hundreds of echos in 2 days, a demanding task. These included Corie Havens and Jennifer Sublett from Vanderbilt; Courtney Cassidy from Denver Children’s Hospital, Rita Franz from Children’s Mercy in Kansas City, and Stephanie Schmidt from the U. of Minnesota Masonic Children’s Hospital.



During the 10 sessions over the past 16 years, the project has averaged approximately 112 echos per session. This year in Nashville, with the support of a generous donation from the TSSUS Minnesota Chapter, we had a significant achievement as we broke the 1,000 mark and finished with a total of 1,115 echocardiograms. There were 132 echos done during the 2 days of the Conference. How impressive are the Turner participants? There are 3 participants that have never missed one session, that is, they have participated 10 times over the 16 years! Approximately 70 participants have participated 5 times over the past 10 years. Both are impressive numbers!

TSSUS Healthy Heart Project		
	Year	Total Echos
1	2003	138
2	2004	115
3	2005	113
4	2007	87
5	2009	113
6	2011	87
7	2013	121
8	2015	102
9	2017	107
10	2019	132
	Total	1115

In order to keep the TSSUS Healthy Heart Project moving forward, the plan is to ask the 578 participants in the Project to allow us to place all of this information into the Turner Syndrome Research Registry (the TSRR). If you are a participant, you will hear from one of us soon.

Emilio Quezada, M.D. Turner Syndrome Society Healthy Heart Project Co-Director • Asst. Professor Pediatrics | Division of Pediatric Cardiology UC San Francisco | Benioff Children’s Hospital
E-mail: emilio.quezada@ucsf.edu



2019 TS Conference

The 32nd Annual TSSUS National Turner Syndrome Conference in Murfreesboro, Tennessee was a huge success! Nearly 750 people attended from 44 states and several countries including Australia, Canada, Columbia, England, and Japan!

This year's theme was *Find Your Voice*, and the speakers, entertainment, and exhibitors provided attendees with information, resources, and encouragement to help them do just that.

The weekend kicked off Thursday with optional tours in the afternoon to the Grand Ole Opry, and sight-seeing of celebrity homes. That evening, there were optional activities including cupcake decorating with MadiCakes and Butterflies with Brushes Paint Night with Ashley for early arrivals.

Friday, the first official day of conference, kicked off with a concert by Nashville recording artist and reality TV star, Lawson Bates, from UPtv's hit show "Bringing Up Bates." Lawson thrilled conference attendees with an impromptu meet and greet after the show where he signed autographs, posed for selfies, and visited with fans.

Friday afternoon was filled with a variety of educational sessions for all ages. The 50+ group had speakers on Social Security, selecting the right hearing aids, and exercise tips for women with osteoporosis. TSSUS President Cindy Scurlock conducted an orientation session for young adults ages 18-25 to help them get the weekend started and offered tips for getting the most out of the conference.

Dean Mooney, PhD., a clinical and school psychologist and a favorite conference speaker, spent the afternoon providing fathers the opportunity to openly discuss their challenges, successes, strategies, and fears about raising a child with Turner syndrome in a safe and supportive environment.

After Friday's educational sessions, Becky Brown, National Director of Development and Communications for TSSUS, held a special V.I.P. donor reception for supporters of the monthly giving club, the TSSUS Butterfly Society. Gracious donors participating at the \$30 per month level and above were recognized with a special appreciation gift.

Friday ended with an energetic and inspirational concert by YouTube sensation Cimorelli, a band of six sisters, one of whom is a young woman with TS. Line dancing lessons and Open Mic night allowed attendees to showcase their own talents.

Saturday morning's keynote speaker, Jessica Janniere, challenged everyone to "Look Up and Beyond" negative life experiences and to use their voices. Drawing from traumatic experiences in her own life, Jessica encouraged everyone not to allow their situation to control them. She engaged the entire audience in an uplifting chant of "My voice ... My power!" Everyone in the room recognized their voice matters, and were inspired to use it – not only during the conference but forever. Jessica's inspiring talk really reinforced the *Find Your Voice* theme of this year's event.

The TSSUS staff and Board of Directors followed the keynote with the official Annual Meeting of the TSSUS membership. Board chairwoman, Emily Havrilak, opened the meeting with a "mission minute" and shared her personal story and how TSSUS inspired her. Treasurer, Sarah Sullivan, reported on the financial health of the organization, and Kathleen Maley introduced candidates for the parent-at-large position on the board. TSSUS President/CEO, Cindy Scurlock, gave a moving presentation about the Society's accomplishments over the last year, talked about the importance of the Turner Syndrome Research Registry and it's current and future potential, shared our current strategies and upcoming strategic planning, and encouraged the TSSUS community to let their voice be heard. Brittani Ehrhorn talked about how one program, the TSSUS Healthy Heart Project, impacted her life by identifying a serious cardiac issue.

Last but not least, Becky Brown talked about the importance of diversifying funding due to the declining support from growth hormone companies, and the dramatic positive impact the TSSUS Butterfly Society Monthly Giving Program is having on TSSUS programs, resources and services. She called upon current Butterfly Society members to increase their monthly support amount as the program enters its third year, and invited others to compassionately consider joining as donors. TSSUS continues to advance knowl-





edge, offers personal support, educational programs, and facilitates research for those touched by TS. So many of you answered the call, and we thank you.

The rest of the morning and afternoon offered eighteen educational sessions by expert speakers on wide-ranging topics, along with private consultations.

Saturday night kicked off with the TS Choice Awards and Talent Show after the dinner banquet. TSSUS recognized individuals who have gone above and beyond in service to the TS community and the Turner Syndrome Society. TS Choice Award recipients are listed on pages 12-13.

Sunday included popular sessions on tissue donation for research and a parenting panel of mothers, plus 8 other sessions. After the closing remarks, people packed the hotel lobby to attend two optional tours to Nashville. The conference experience was powerful, and year after year parents, and people with Turner syndrome of all ages tell us, "this has been a life-changing experience."

TSSUS offers conference payment plans to TSSUS members. If you'd like to submit an application for consideration, please contact Deborah Rios at deborah@turnersyndrome.org or 800.365.9944.

TSSUS provides conference scholarships. The application period opens on October 1, 2019 and closes on February 1, 2020. You must be a member of TSSUS to apply for all TSSUS scholarships.

Professional audio recordings and audio recordings synced with slides are available for anyone to purchase for a limited time. We are proud to extend the knowledge of expert speakers to the entire TS community. - To order, please visit <https://store.resoundingvoice.com/collections/2019-tssus-national-turner-syndrome-conference>.



2019 TS Choice Awards

Outstanding TSSUS Volunteers

– these volunteers were honored for their dedication and service to the TS community during the last year.

Stephanie Thompson – Stephanie is a long-time TSSUS volunteer. She donates her time to the TSSUS conference, TS Days, and local events. She is an ardent TSSUS supporter, a constant social media presence, an advocate and mentor



Lynda Taylor

Stephanie Thompson

who answers questions, offers support, and grieves with expectant parents through loss. Stephanie is a mom on a mission, spreading awareness wherever she goes!

Lynda Taylor – Lynda is full of energy and excitement, and she serves her local community with love as the TSSUS Resource Group leader in Delaware. She enthusiastically coordinated a local Chasing Butterflies walk that was a top fundraiser for TSSUS, she volunteers each year at the conference, and she consistently helps Deborah from the national office.



Outstanding Individual Fundraisers

Top Peer-to-Peer Fundraisers: these individuals raised significant funds from their families and friends to support their Chasing Butterflies Walk team.

Rio Barrere-Cain– Rio single-handedly raised \$3,000 from her circle of support for the Los Angeles Chasing

Butterflies walk. Rio is a recent graduate of UCLA and is currently working in a biology lab and applying to combined MD-PhD programs to continue biology research. In her career, she hopes to combine her curiosity for biology with a holistic understanding of what research will most give patients a sense of agency and improve quality of life. Rio continues to reflect on how Turner syndrome has contributed to her identity and interest in biology. Rio's walk participation was supported with donations from family, friends and colleagues.

Denise Fisher – Denise was instrumental in coordinating the Chasing Butterflies walk in Dillsburg, Pennsylvania last year, which was the top grossing fundraising walk for TSSUS. Denise worked diligently to procure sponsors and in-kind sponsors that provided everything from characters in costumes to bounce houses and firetrucks on walk day. She received sponsorship donations from several local businesses – from her hair salon to her home builder!



Kara Navarro – Kara worked with her employer, Argon, to provide more than 200 Adidas backpacks and supplies to those who attended the Los Angeles and Alameda, California walks. She volunteered her time and talents, along with her sister's catering, to make the Los Angeles walk one of the most successful this year!

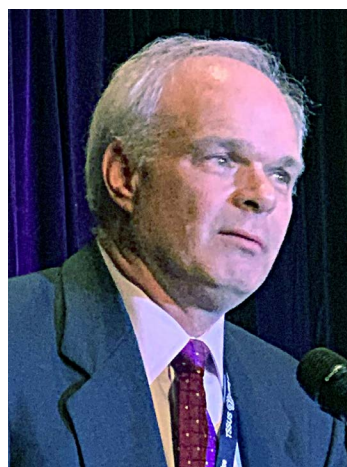
Thank You



Natalya Winters – Natalya coordinated a walk in Birmingham, Alabama this year with more than 150 registered walkers – that's almost a record breaker! She created an enormous amount of awareness in her community by employing grass roots efforts like passing out flyers in the local park and appearing as a guest on local TV news programs.

Outstanding Independent Fundraiser

Circles of Hope Foundation – 2018 marked the 10th anniversary of the Circles of Hope Foundation Annual Golf Tournament benefitting the Turner Syndrome Society of the United States. In this landmark year, the Stavinoha Family's donations exceeded a lifetime giving total of \$200,000! Parents Chrissy and Troy Stavinoha and grandmother Debra Alexander Algeo work tirelessly each year to make this golf tournament the success it is, and have had such a positive impact on so many with Turner syndrome. We are honored and grateful, Circles of Hope Foundation!



Outstanding Professional

Dean Mooney, PhD, LCP – Dr. Mooney was honored for his outstanding professional dedication and service to the TSSUS and the TS community. He has spent much of his life supporting girls and women with Turner syndrome through his

knowledge of Non-Verbal Learning Disorder. He has helped countless girls and women with TS through his sessions and private consultations at TSSUS conferences, and has spoken at TSSUS events for more than a decade. His compassion knows no bounds, and he works late into the night every night at conference trying to help as many people as he can. In fact, we had to interrupt a private consultation to present this award to him! Dr. Mooney is a valued member of the TSSUS Professional Advisory Board (PAB), and is the founder of the Maple Leaf Clinic in Vermont.

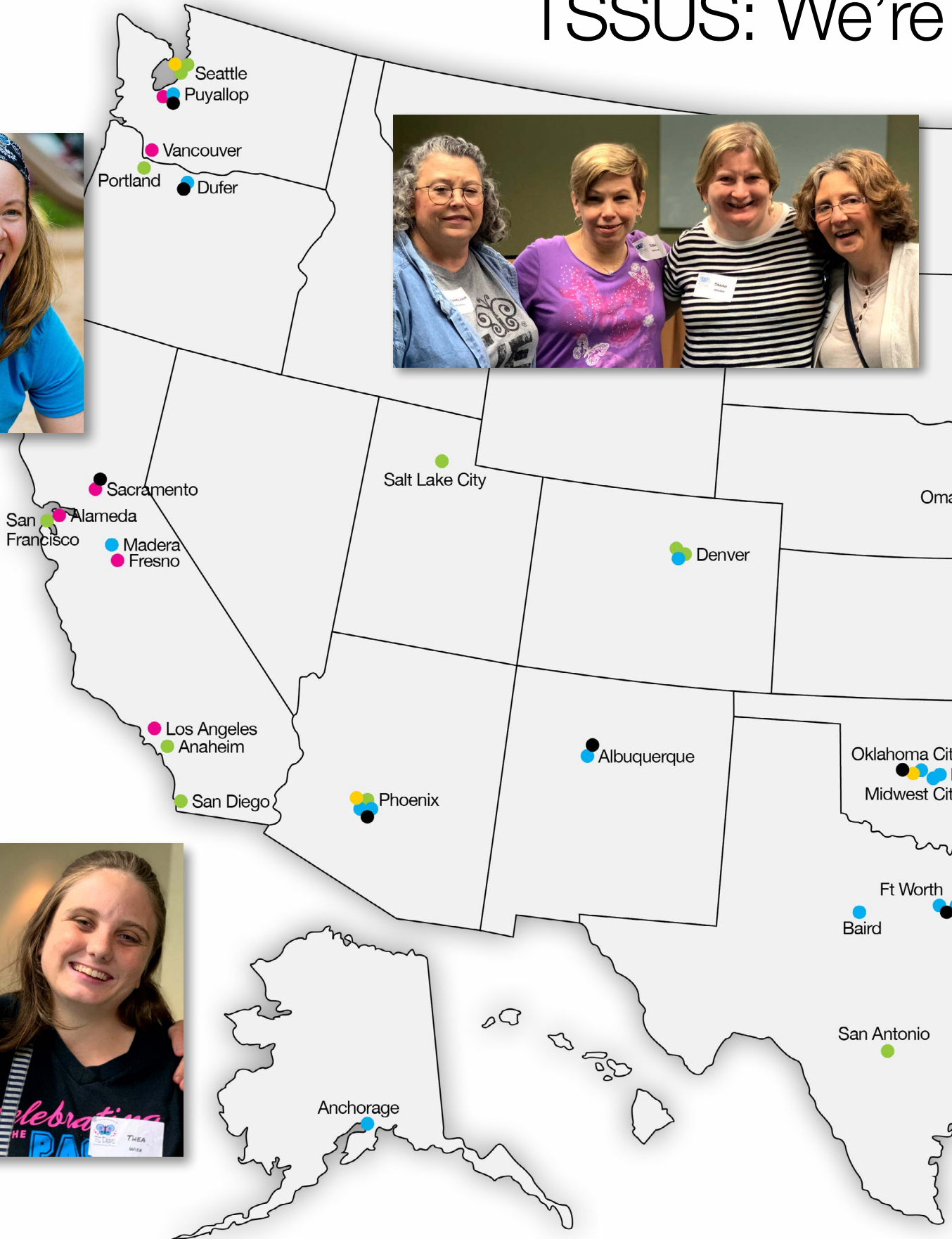
Outstanding Butterfly Award

(Voted on by the TS Community)

Tammy Kozak - Tammy has been a member of TSSUS for decades. She founded and emceed the TSSUS Conference Talent Show until her health prevented her from traveling. She also founded the TSSUS Choir which performed at the conference for years. She volunteered as a chapter leader in New York and governed the society as a former board member. Tammy's strength and positive attitude throughout her life is inspirational. She's a true friend and mentor to many butterflies, and we are proud to recognize her for a lifetime of service.

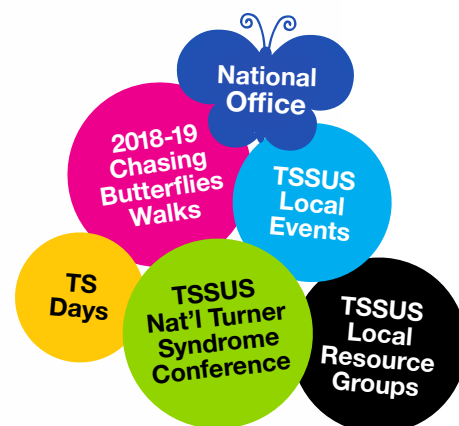


TSSUS: We're



Your Community

The Turner Syndrome Society of the United States brings programs, services, and empowering events to cities across the country. **Our “local” community is virtually everywhere you are.** With 19 Local Resource Groups, local educational/ social events in 35 cities, the National TSSUS Turner Syndrome Conference, 20 Chasing Butterflies Walks, and 4 TS Days, we bring the TS community together for meaningful connections, learning, and support.



It's been a busy and fantastic 2019 at the Turner Syndrome Society of the United States! We had a great conference in Nashville, TN at the end of June, several TS Days events across the country, and lots and lots of Chasing Butterflies Walks and TSSUS local events in communities from coast to coast, with several happening in the coming months.

TSSUS Chasing Butterflies Walks

Each year, the Chasing Butterflies walk program is expanding. Local volunteers come together to host a fundraising and awareness walk in their communities. As a national signature event, Chasing Butterflies walks raise funds for the local community and the national initiatives of TSSUS.

2019 Walk Events

- 🦋 **Fresno, CA, March 9, 2019**
Walk Coordinator - Rosemary Morris
- 🦋 **Los Angeles, CA May 18, 2019**
Walk Coordinator - Rosemary Morris
- 🦋 **Birmingham, AL, May 23, 2019**
Walk Coordinator - Natalya Winters
- 🦋 **Lynchburg, VA, May 25, 2019**
Walk Coordinator - Iris Nicole Campbell
- 🦋 **Vancouver, WA, June 8, 2019**
Walk Coordinator - Glenna Gibson
- 🦋 **Alameda, CA, June 22, 2019**
Walk Coordinator - Haley Rodden
- 🦋 **Cassopolis, MI, July 13, 2019**
Walk Coordinator - Brandy Shelby
- 🦋 **Grand Rapids, MI, August 17, 2019**
Walk Coordinator - Katie Visner
- 🦋 **Dillsburg, PA, August 24, 2019**
Walk Coordinators - Denise Fisher and Audrie Noll
- 🦋 **Plymouth, MN, September 7, 2019**
Walk Coordinators- Colleen Daman and Billi Jo Sielaff

Upcoming Walks

- 🦋 **McKinney, TX, October 5, 2019**
Walk Coordinator - Kimberly Prince
- 🦋 **Wooster, OH, October 12, 2019**
Walk Coordinator - Branon Workman
- 🦋 **Sugar Land, TX, December 7, 2019**
Walk Coordinators: Becky Brown, Charity Cox, and Deborah Rios

TS Days

TS Days are having an important impact in the TS communities we visit. Now in it's second year, TS Days bring people together to learn vital information about their health care, and provide people with Turner syndrome of all ages the opportunity to come together to socialize and support one another.



TS Days 2019

- 🦋 August 24, 2019 - Seattle, WA
- 🦋 September 21, 2019 - Chicago, IL
- 🦋 October 19, 2019 - Phoenix, AZ
- 🦋 November 16, 2019 - Ft. Lauderdale, FL

Providing Important Resources

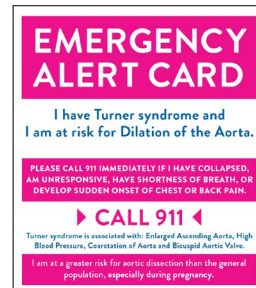
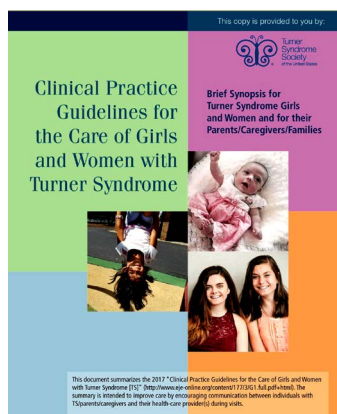
TSSUS believes that everyone in the TS community should have access to resources and tools to help you become your best healthcare advocate.

This year, we released the Cardiac Emergency Alert Card (CEAC) and offer it without cost to those with TS and/or their parents/guardians.

We continue to offer the patient and family friendly summary version of *The Clinical Practice Guidelines for the Care of Girls and Women with Turner Syndrome* through our online store at no cost. This vitally important

resource helps guide you through all recommended testing and screenings over the course of a lifetime.

Both resources can be ordered through the "Our Store" button at tssus.org.



TSSUS Membership Skyrockets!



Thank you to all who have become members of TSSUS through our 2019 Member Initiative. This program has increased TSSUS membership by almost 45%! Thank you for supporting our work with your membership. Exclusive member t-shirts are still available in most sizes for \$5 each. From now until the end of the year, TSSUS members may order up to five (5) per membership at \$5. Please order yours today.



Donate your birthday on Facebook!

Did you know you can easily create a fundraiser on Facebook for your birthday, wedding, anniversary or any other special occasion? It's easy! You simply click the "create fundraiser" button, select the Turner Syndrome Society of the United States as your charity, and ask your friends and family to make a donation in your honor.

The top Facebook fundraiser each month will be awarded a TSSUS swag bag filled with TSSUS branded merchandise. Contact Becky Brown, National Director of Development & Communications if you have questions about how to set this up! becky@turnersyndrome.org.



TSSUS Offers Compassionate, Knowledgeable Support Around the Clock

At TSSUS, we are always just one phone call or one click away. We understand that navigating a new TS diagnosis or working through some of the challenges that come with TS can be daunting. Sometimes, you just need someone to talk to, or you have a complicated question you need help with. If we don't have the answer, we'll reach out to our network of experts for assistance. You can find us on our Facebook Page (<https://www.facebook.com/turnersyndromesociety/>) and our Facebook Group (https://www.facebook.com/groups/TSSUSGroup/?source_id=30264154034) around the clock, and by phone during standard office hours at 800.365.9944.

Let's Get Social!

 [Facebook Page](#):

"Turner Syndrome Society of the United States"

 [Facebook Group](#): "Turner Syndrome Society of the United States Group"

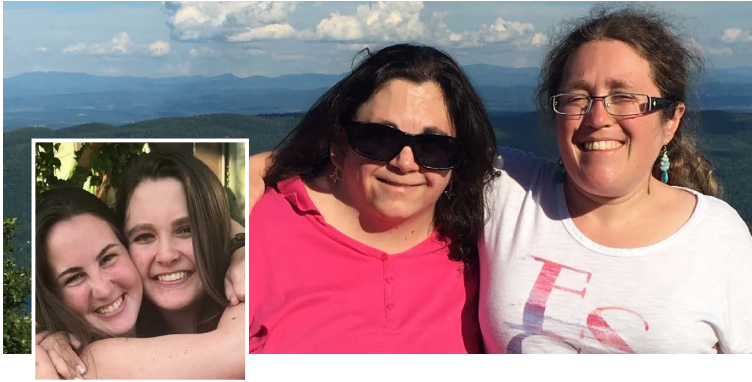
 [Instagram](#): @turnersyndromesocietyus



Join the TSSUS
Birthday Society" here:
[turnersyndrome.org/
birthday-society](https://turnersyndrome.org/birthday-society)

Butterfly Society

The Butterfly Society is an exclusive monthly giving program for supporters of Turner syndrome research, education, awareness and support programs.



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 woman, girl 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?

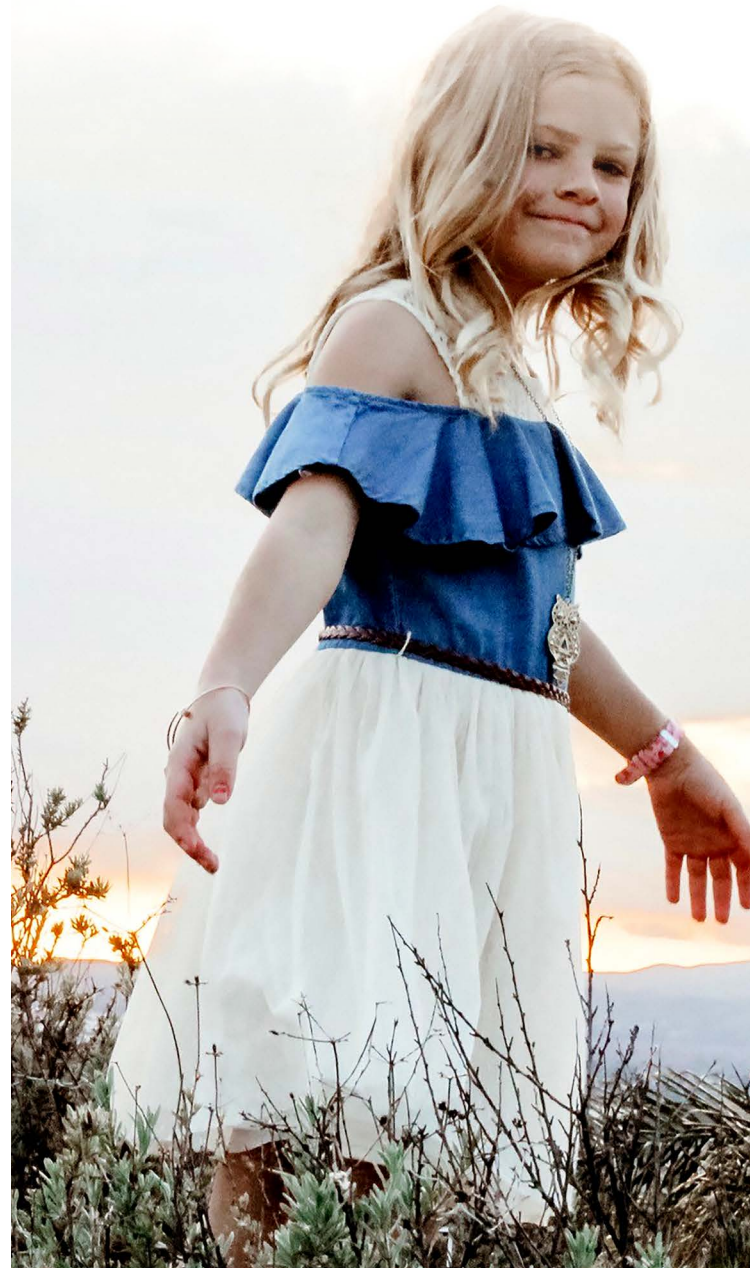
IT'S AFFORDABLE. By giving monthly, you invest what makes sense for you, while making an incredible impact over the course of your membership in the Butterfly Society.



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 EXCITING. You'll become an integral part of something bigger than yourself.





Butterfly Society Members Receive:

- An exclusive welcome gift
- A surprise end-of-the-year souvenir
- Your name listed as a Butterfly Society Member on the TSSUS webpage, in the TSS Connect Newsletter, e-newsletters, and at the TSSUS National Conference.
- Tickets to the exclusive Butterfly Society receptions at the TSSUS Annual Conferences
- Complimentary TSSUS Membership for one year (at the \$10/month level and above)



Monthly Gift Levels: \$10 • \$20 • **\$30** • \$50 • \$100

Are You Currently a Monthly Supporter?

Thank you for recognizing the significant impact the TSSUS Butterfly Society and your generous monthly gifts have on the work we are able to do in support of our mission. As the Butterfly Society enters its 3rd year, we are respectfully requesting that each of you consider increasing your monthly contribution by an amount that fits your budget.

If 200 Butterfly Society supporters increased their monthly donation by just \$5, that would represent an annual increase of \$12,000 for TSSUS programs and services.



Becky Brown, National Director
of Development & Communications

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turnersyndrome.org



Many Thanks to Our Donors & Members

At the Turner Syndrome Society of the United States, our members and donors are our lifeblood. Without the support of those of you whose names are represented here, we would not be able to provide vital resources, exciting, supportive educational events, and contribute leading support and directives for Turner syndrome research.

Every dollar, every membership, and every donation counts. Whether you are a TSSUS Butterfly Society monthly donor, a Chasing Butterflies Walk participant, a TSSUS member, or one who donates during the Annual Campaign, your donation impacts those living with Turner syndrome and their families each and every day. Thank you for your support and generosity of spirit.

Individual Donors

(Mar 21-Sep 23, 2019)

Roxanna Askam
Trionne Barnett
Miriam Barrere
Dorothy Baume
Erica Bautista
Brandi Baybak
Liz Baybak
Kaylie Bekkerus
Diane Berkowitz
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Corporate/Foundation Donors

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Ridgeview Middle School
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