Enjoying the View

During the first half of 2018, the staff at TSSUS felt like passengers on a fast train to an exciting destination, so fast in fact, the scenery resembled an abstract painting.

Preparing for local TS Days, the TSSUS National Educational Conference and the TS Research Symposium is in addition to our “everyday” important work. I am so proud of the staff for working at record speed for the last several months to create the best possible experiences and futures for girls and women with Turner syndrome.

NOW, we are forcing ourselves to work at a sustainable pace. Visiting with people in person we generally only speak with by phone and email re-energizes us, makes us question if our impact is large enough, wonder what we could do better and faster — and then we take a deep breath.

TSSUS is a business and we pride ourselves on meeting goals to improve lives. We have the amazing privilege of seeing and hearing from those who share that it’s not a luxury to slow down and reflect and dream, it’s a necessity. As exciting as it is to anticipate, prepare for, and enjoy the destinations, it’s comforting and inspiring to help people, one at a time. I’ve realized it’s not luxury to slow down and reflect and dream, it’s a necessity.

We have a window into the lives of others and through these stories and communication we’re learning it is what we need to do.

In the next few months, we’ll create resources from the conference presentations, we’ll determine which cities TSSUS will visit for next year’s TS Days as well as the 2020 conference. We’ll be listening to your ideas and needs, so share your thoughts with us! Please do us a HUGE favor, update your home and email addresses and phone numbers with us. We’ll be sending out Save the Date postcards and don’t want you to miss any opportunities.

Enjoying the View

Turner Syndrome Society of the United States
11250 West Road, Suite G
Houston, TX 77065
832.912.6006 800.365.9944

The planning, coordination and funding of the Turner Resource Network (TRN) 2018 symposium Turner Syndrome Science in the 21st Century. TSSUS is making too.

In the next few months, we’ll create resources from the conference presentations, we’ll determine which cities TSSUS will visit for next year’s TS Days as well as the 2020 conference. We’ll be listening to your ideas and needs, so share your thoughts with us! Please do us a HUGE favor, update your home and email addresses and phone numbers with us. We’ll be sending out Save the Date postcards and don’t want you to miss any opportunities.

Enjoying the View

TSSUS Recent Accomplishments

July 2017 - September 2018

Each year, the Turner Syndrome Society of the United States works tirelessly toward advancing knowledge, facilitating research, and providing support for all those touched by Turner syndrome.

We are proud to share our significant accomplishments with you here. TSSUS continues to be a key contributor to the TS community through our collaboration and founding role with the Turner Resource Network.

• Updated Guidelines: The Clinical Practice Guidelines for the Care of Girls and Women with Turner Syndrome are now up to date. Doctors and professionals use the guidelines to manage TS healthcare.

• Patient & Family Version of Guidelines: The patient and family summary version of the Clinical Practice Guidelines are available for the first time to assist people to effectively partner with their healthcare providers.

• TSSUS is providing printed copies of this resource to the TS community TSSUS members at no charge.

• Online Physician Directory: The online Professional TS Physician Directory has almost 200 healthcare professional listings.

• Research Registry: The Turner Syndrome Research Registry (TSRR) is utilized and endorsed by TS researchers and the TS community.

• Funding Research: TSSUS donated $58,300 to the Doernbecher Foundation of the Oregon Health Science University to support Dr. Michael Silberbach’s team for advancing TS cardiac research. The funding was made possible by the Ravelle Pitmann Research Fund of the Turner Syndrome Society of the United States, established by a generous donation from Elena Erenberg.

• Advancing Research: Assisted 8 Turner syndrome researchers in conducting studies of importance to the TS community.

• Scholarships: Provided 119 scholarships for membership, college, the TSSUS conference, and life enrichment.


• Legislation: Actively engaged in and supported rare disorder legislation.

• National Conference: Hosted, funded, and coordinated the TSSUS Annual Conference, which is the largest gathering of TS experts, women, and families in the world.

• TS Days®: Introduced regional TS Days® events, offering half-day educational and social opportunities in Houston, Nashville, Omaha, Oklahoma City and Minneapolis.

• Expert Website: 86,000 unique website users in last year.

• In the Community: Supported and funded 79 local TS events that allowed 2,024 people to learn and connect with each other and healthcare professionals at meet and greets, Chasing Butterflies® walks, medical and educational meetings, and social outings.

• Butterfly Society: Established the TSSUS Butterfly Society® monthly giving program, with almost 300 recurring monthly supporters to date.

• Turner Resource Network: Collaborated monthly with other key TS stakeholders in the Turner Resource Network (TRN) to review and secure the success of the Turner Syndrome Research Registry® TS regional clinics, and the TRN Professional Symposium.

• Making Connections: Connected women and families to experts, peers, and resources for health and well-being needs daily.

• Online Support: Actively engaged and supported the TS community through a strong social media presence through TSSUS social media channels, other TS social media channels, and the TSSUS Inspire message board.

• Phone Support: TSSUS staff members provide caring, knowledgeable phone support to members of the TS community Monday through Friday.

We are proud of the work we do each day and are grateful for the opportunity to serve the Turner syndrome community. Thank you for being a part of the Society and for supporting our work through your membership, donations, and event participation.
What’s your TS Story?

Sometimes just knowing someone has been through what you’re going through or finding others with a similar situation can be a great comfort. Whether you’re the parent of a newly-diagnosed baby, a middle-aged woman, a teenager in high school, or a “golden butterfly” senior woman with Turner syndrome, we want to hear your stories of challenge, inspiration, hope, and discovery. My TS Stories can be submitted online on the TSSUS website at: https://www.turnersyndrome.org/share-your-story

Can we count on you to advance Turner syndrome research?

The future of TS research is in powerful hands ... YOURS! Are you doing your part? By completing the questionnaire in the TSSUS Turner Syndrome Research Registry (TSRR), you are contributing to the future and helping advance TS research NOW. This process takes about 20 minutes, and you can complete the questionnaire online in your own home. Learn more on our website at https://www.turnersyndrome.org/research-registry, or call 800.365.9944 for more detailed information or assistance.

In 2018, TS Days have been held in Nashville, Omaha, Oklahoma City, Minneapolis, and Boston—in late October. Attendees have included parents, young girls with TS, teens with TS, siblings, and women with TS. We’ve even had a few “Golden Butterflies” (the name we lovingly give to those 55 and over). The majority have never attended any type of TS event before, and many have never met anyone else with TS. It has been a humbling experience to watch these women connect with others for the first time and to watch them tear up when they learn they are not alone in their struggles.

Each TS Day begins with coffee and donuts as attendees arrive and get checked in. The morning is spent having an educational session for adults, and fun activities for youth in a separate room. After a delicious lunch buffet and some prize giveaways, we spend the afternoon socializing and crafting. Attendees have also enjoyed visiting the Butterfly Store to purchase t-shirts, logo/awareness items, games, and resources.

There have been so many touching experiences at TS Days this year. One of these happened at the end of the Nashville TS Day, when a precious mom came up to me, and with tears rolling down her face, thanked me for the opportunity for her to meet other parents, and for her daughter to meet other girls with TS. She had felt so alone, and this event made a big difference for their family.

In Oklahoma City, as we discussed the Neurocognition section of the care guidelines summary, I could see tears welling up in the eyes of several parents and women. One young woman had never realized that her anxiety and other behaviors were because of the effect of TS on the brain. She was so relieved and encouraged to know that others in the room had the same struggles. She and two other women close in age spent the entire afternoon at their table talking and laughing as they shared their stories and got to know one another.

One of the things we covered in the discussion of the guidelines synopsis was the heart. One family was told when their daughter was born that her heart looked fine, and they did not need to bring her back. She is now nine years old and they were shocked to find out that she needed to follow up with a cardiologist regularly. Another woman had not had her heart checked since she was a teen. She has one of the things we covered in the discussion of the guidelines synopsis was the heart. One family was told when their daughter was born that her heart looked fine, and they did not need to bring her back. She is now nine years old and they were shocked to find out that she needed to follow up with a cardiologist regularly. Another woman had not had her heart checked since she was a teen. She has already made an appointment since the event. There are many more stories like this.

The girls have had a great time getting to know one another, sitting together during lunch, making crafts, and playing games. It has been so fun to watch them interact with each other as well as the women with TS.

Again, so far TS Days have been very successful! Several attendees have driven in from out of state, even as many as six hours, to attend these fun events. We are looking forward to planning where we will go in 2019! I hope you will be on the lookout for your city and make plans to join us.

By Shawn Wier, National Event & Resource Manager
Thanks to volunteers, group leaders, women with TS, families, and moms and dads across the country, TSSUS Chasing Butterflies Walks are happening in cities all over! Walks are a great way to bring the TS community together and raise funds and awareness for Turner syndrome and TSSUS programs and research.

We appreciate everyone who has worked so hard on 2018 Chasing Butterflies Walks so far, and for those yet to come. Remember, walk coordinators may request that 50% of funds raised at a TSSUS Chasing Butterflies Walk be used to support TS Butterflies in their local area for needs that align with the TSSUS mission. This could be scholarships for life experiences, limited medical needs, the TSSUS conference, or for planning local events.

Planning a walk is fun, and we can help you every step of the way! Check tssus.org to find a walk in your area, or call Deborah Rios at 800.365.9944 or email deborah@turnersyndrome.org about planning one in your community today.

2018 Chasing Butterflies Walks

- **Alameda, CA, February 3**
  Walk Coordinator: Haley Rodden
- **Sacramento, CA March 10**
  Walk Coordinator, Rosemary Morris
- **Cowarts, AL, May 12**
  Walk Coordinator: Kathryn Berry
- **Vancouver, WA, June 16**
  Walk Coordinator: Glenna Gibson
- **McKinney, TX, June 16**
  Walk Coordinator: Kimberly Prince
- **Cassopolis, MI, June 23**
  Walk Coordinator: Brandy Shelby
- **Grand Rapids, MI, August 18**
  Walk Coordinator: Katie Visner
- **Plymouth, MN, August 18**
  Walk Coordinators: Julie Leon & Colleen Daman
- **Dillsburg, PA, August 25**
  Walk Coordinators: Audrie Noll & Denise Fisher
- **Zionsville, IN, August 26**
  Walk Coordinator: Kelsey Cavanaugh

Upcoming Walks:
- **Brooksville, FL- October 6, 2018**
  Walk Coordinator: Shannon Rodgers
- **Newark, DE, October 6, 2018**
  Walk Coordinator: Lynda Taylor
- **Sugar Land, TX, November 3, 2018**
  Walk Coordinators: TSSUS - Deborah Rios & Becky Brown. TSSUS Texas Gulf Coast Chapter - Kim Graham & Charity Watson
- **Las Vegas, NV February 23, 2019**
  Walk Coordinator: Anna Salazar
- **Sacramento, CA, March 9, 2019**
  Walk Coordinator: Rosemary Morris
- **Los Angeles, CA, May 18, 2019**
  Walk Coordinator: Rosemary Morris
- **Pelham, AL, May 25, 2019**
  Walk Coordinator: Natalya Winters
- **Alameda, CA, June 22, 2019**
  Walk Coordinator: Haley Roden
31st Annual TSSUS Conference: Mission Accomplished!

The 31st Annual TSSUS National Turner Syndrome Conference was a huge success. Many attendees took advantage of the location in Arlington, VA, to visit the nation’s capital, Washington, DC. Some arrived a few days early to enjoy the area’s history, while others chose to hang around after the conference to enjoy some sightseeing. The hotel had convenient access to shops and restaurants, as well as the metro rail.

As people started to arrive, it was like a family reunion with hugs, smiles, and catching up. The energy could be felt by everyone. The hotel staff commented many times on how fun and exciting our group was compared to other conferences. The fun decorations helped to create the “spy” feel for our Mission: Possible theme.

Early arrivers enjoyed an evening of painting and fun at the “spy” feel for our Mission: Possible theme. The afternoon was packed with educational sessions, including a presentation by organizing expert, Alejandra Costello, who has appeared on multiple television programs, including Good Morning America. You can view her series of organizational videos at alejandra.tv.

Two of our speakers this year traveled from Europe to attend the professional symposium and speak to conference attendees. We appreciate Dr. Claus Gravholt (Denmark), and Dr. Asa Bonnard (Sweden) for sharing their knowledge and insights with us.

The ever-popular Talent Show and Fashion Show was on Friday evening. Everyone had a fun time watching our girls and ladies show off their fashion and talents in dancing, singing, and mime, just to name a few. As always, the dads brought down the house with their traditional rendition of My Girl.

On Saturday morning keynote speaker, Lance “Claysmile” Smith delivered an entertaining, but powerful message on overcoming challenges, finishing with a Celebrating YOU! segment, inviting attendees to come up on the stage and share their accomplishments.

The afternoon was packed with educational sessions, including a presentation by organizing expert, Alejandra Costello, who has appeared on multiple television programs, including Good Morning America. You can view her series of organizational videos at alejandra.tv.

Two of our speakers this year traveled from Europe to attend the professional symposium and speak to conference attendees. We appreciate Dr. Claus Gravholt (Denmark), and Dr. Asa Bonnard (Sweden) for sharing their knowledge and insights with us.

For the first time, we were able to offer a total of forty-two individual consultations, thanks to our wonderful speakers. We are incredibly fortunate to have coaches like Diane McLean, Barbara Bissonnette, Stephanie Flores, and Dr. Dean Mooney, who went above and beyond to provide attendees with one-on-one time to discuss executive functions, employment, relationships, and nonverbal learning disability. We hope to be able to offer more of these types of services in the future.

The highlight of the weekend was the Masquerade Party and Dance. It was so fun to see everyone don their masks and enjoy some music and dancing. This year, we enjoyed live music from local musicians, Power Source. The younger kids enjoyed a PJ Party, while the preteens and teens learned dance moves with Lance Smith at their own dance party.

The youth program was also a big success. One of the highlights, led by The Ingredient Guru, Mira Desaty, was Camp Chopped, inspired by the Food Network show. The youth worked in teams to create a snack or dessert from “mystery” ingredients. The results were some very creative dishes, judged by the youth program leaders!

The 2018 TSSUS Conference was generously sponsored in part by Lilly, NovoNordisk, Genentech, the Arbonne Foundation and the TSSUS Minnesota Chapter. We are grateful for their support.

Many thanks to all those who helped make this “mission” possible.

Volunteer Spotlight: Julie Leon, TSSUS Minnesota Chapter Leader

Julie Leon was acknowledged for her commitment to those in the Minnesota Chapter area. The MN chapter was the first chapter founded within TSSUS, not surprising since the national office was located in MN at the time. Julie is passionate about offering events to those with TS and each year speaks to medical students about her experiences as a woman with TS. This year, the MN Chapter sponsored the TSSUS conference in the amount of $5,000 and also provided scholarships to people in their community to attend the conference. Julie and the TSSUS MN Chapter also hosted a great TSSUS Chasing Butterflies Walk in September. Thanks for everything you do, Julie!
The 2018 Turner Resource Network (TRN) Symposium Highlights
by Dr. Michael Silberbach
Arlington, Virginia, July 15–17, 2018. The Turner Resource Network (TRN) Symposium was a working conference that convened thought leaders from around the world. Attendees presented important new research and reviewed what is currently known about all aspects of Turner syndrome. We expect that these scientists will be inspired by their co-presenters to become “evangelists” for Turner syndrome research in the years to come.

The objectives of the conference were to:
1) promote the biology of TS and develop research strategies that will benefit both individuals with TS and the US population in general;
2) support TS-experienced researchers’ interests and attract new investigators in a variety of fields who might find Turner syndrome to be a useful human model for their research area of interest;
3) address clinical research in Turner syndrome, to include pregnancy, hormone therapy, psychosocial issues, and the Turner syndrome phenotype in different ethnic groups and races throughout the world.
4) Unveil the newly formed Turner Syndrome Research Registry (TSRR) and to develop strategies to utilize the TSRR effectively.

The meeting was an unmitigated success. Attendance included 93 people, 1/3 representing professional researchers, 1/3 physicians/researches (including TS clinic directors) and 1/3 having TS or a family member. Our keynote speaker, Dr. Diana Bianchi, the Director of the National Institute for Childhood Health and Human Development, presented her pioneering work on prenatal detection of genetic conditions. She offered a glimpse into the future where she envisioned finding new treatments though personalized prenatal genetics; and then treating or curing these conditions even before the baby is born.

We will share all of the new knowledge about TS presented at this meeting in a special issue of The American Journal of Medical Genetics, expected to be published in March of 2019.

Current Research Opportunities

TS and the Ability to Understand and Work with Numbers
Dr. Joseph Baker at Stanford University is currently coordinating efforts with TSSUS to conduct a study of numeracy in children, adolescents, and adult women with Turner syndrome. The overarching goal of his research project is to learn more about how the brain responds to basic number challenges, and to use this information to help improve math education for girls with Turner syndrome.

Dr. Baker and his team will be attending future TSSUS events, where they will be recruiting participation from interested members of the TS community and collecting brain-imaging data on-site. If you are interested in Dr. Baker’s study and would like more information, you may reach him directly at numericalBrain@stanford.edu.

An App to Assist in the Facial Identification of TS
Dr. Kruszka of the National Institutes of Health is coordinating efforts with TSSUS for a current research study. The purpose of the research is to create a tool (app) that assists physicians in developing a resource for poor countries in the identification of those with TS through facial recognition. Dr. Kruszka will be utilizing the Turner Syndrome Research Registry to encourage approximately 50 participants with TS and diverse ethnic backgrounds (African American, Asian, Latin American, and Middle Eastern etc.) to participate. If you have joined the TS Research Registry online, you may be contacted about the current research opportunities.

My TS Story: Angie Neeves
I am a woman with Turner syndrome. It’s not a huge part of who I am, but it helped shape the person I have become. My name is Angie and I am 34. I’ve always known I have TS and growing up I was taught it wasn’t something that made me “less” than others, and not to let it be my whole life. I’ve tried to follow that advice, but growing up different is hard and sometimes that self-doubt creeps in.

Girls with TS are usually pretty short, the average is 4 feet 7 inches (I reached a very tall 4’9”), and most girls with Turner Syndrome will be infertile. This didn’t mean much to me when I was younger, but as I get older it’s something that does upset me sometimes. I try not dwell on things I can’t change.

This is the story about TS and my on-going journey to self-acceptance. I grew up in Edmonton, Alberta. My parents encouraged me to not let TS be my whole life; it is just a small part of who I am. It was an accepted fact, like having blonde hair and blue eyes. That all changed when I started junior high, and my being “different” lead to bullying that lasted pretty much until I graduated. I did take hormone replacements, so I developed as normally as I could, but I still felt like an outsider and very alone. I was confused about why I had to take pills to start something that was supposed be part of growing up. I was bullied badly and never really fit in anywhere. It was not an easy time for me, to say the least. I had no confidence and felt like I was ugly and unlovable, and that I would be alone forever. I didn’t date at all in school and sort of figured no one would want to be with me, so why bother trying? I had a few boys ask me out as a joke or a dare, and that really messed me up. Was I so hideous that the mere thought of dating me was a joke?

At 23, I tried the online dating thing, and after a few really awkwardly bad dates, I met my husband Darren. We hit it off right away and have been together ever since. I feel so lucky to have met such an amazingly supportive man. He wasn’t bothered by my TS and accepted me for who I was. I can honestly say he changed my life and made me realize I was loveable, and that I was worth it. He makes me feel beautiful every day.

I started pinup modelling to build my self-esteem and I am so happy I did. It has been a fun journey, and I am glad I didn’t let the fear of what people would think stop me. I know I don’t look like most models and that not everyone will like my look, but that is okay! I have been overwhelmed by the support I’ve received and the fact I have over 21,000 followers on my page is crazy! I am the most confident I have ever been. I’m proud to show other ladies with TS they can follow their dreams and that being different is beautiful and nothing to be ashamed of. This is something I wish I learned a long time ago. While I still struggle with my self-esteem, I try to remind myself of all the good things in my life and that Turner syndrome is something I have and not who I am.

Volunteer Appreciation
TSSUS would like to recognize volunteer Kim Graham for her many years of dedicated service to the Society and the TS community. Over the years, Kim has worn many hats at TSSUS. She’s been our newsletter editor, a board member, a conference speaker and volunteer, a fundraiser, and an event organizer. She also suggested the “LOVE” t-shirt design this year, which has been our best-selling t-shirt ever! Most recently, Kim was instrumental in sponsoring and securing a product and cash grant from the Arbonne Charitable Foundation in support of the teen program at the TSSUS Conference – the charitable arm of Arbonne International, with whom Kim is an Executive District Manager.

Additionally, she and her husband Adrian are TSSUS Butterfly Society supporters, as well as major donors to the organization.

Thanks, Kim Graham!
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 resources, financial support, and education that improve the quality of life for our families each and every day. Thank you for your support and generosity of spirit.

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 our upcoming Annual Campaign, your support is critical to the program that reaches out and supports our families each and every day. Thank you for your support and generosity of spirit.
It's not easy being the caregiver of a loved one, and it takes a lot of work and emotional stress. Make it easier on yourself by doing the following:

1. Get Organized
   - Set up a daily schedule
   - Create a family calendar

2. Know which medical specialists to see
   - Research the best specialists in your area

3. Do your own research
   - Stay informed about your loved one's condition

4. Find your tribe
   - Join a support group
   - Connect with other caregivers

5. Know your insurance
   - Understand your coverage
   - Keep track of your medical bills

6. Take care of yourself
   - Exercise regularly
   - Eat a healthy diet
   - Get enough sleep
   - Manage stress through meditation or therapy

Remember, it's important to take care of yourself in order to be able to care for your loved one effectively.
Membership in TSSUS

Now more than ever, your membership is making an impact on the lives of those with Turner syndrome and the people who love them. The Turner Syndrome Society is advancing knowledge, facilitating research, and providing support for all those touched by TS.

When you renew your membership or become a member of TSSUS, you become a vital part of our mission. TSSUS membership is available in three levels: individual, family, and professional, starting at $45/year.

Visit www.turnersyndrome.org to become a member today!