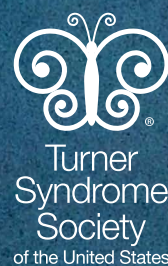


tss Connect™

Turner Syndrome Society
of the United States
Spring 2018



My TS Stories

Mission Possible: 2018 Conference

My TS Days • Butterfly Society

Volunteer Spotlight



July 22-30, 2018 • Teens 12-19 years

Camp with us in Los Angeles!

HOLLYWOOD



Program Highlights

- Theater Workshops: A specially-designed program by Debra De Liso, Actor and Faculty, University of Southern California
- **Tour of Universal Studios Hollywood Theme Park**, including World of Harry Potter
- Swim in our beautiful campus pool • Beach Days • Museum Visit
- Presentation by Mitchell E. Geffner, MD, Professor of Pediatrics, Division Chief of the Center for Endocrinology, Diabetes and Metabolism Children's Hospital Los Angeles
- Counselor-Led Rap Sessions • Theater Excursions
- Salon Day at Vidal Sassoon Academy • RNs at Camp



Mount St. Mary's University, Doheny Campus
10 Chester Place, Historic District, Los Angeles, California


**THE NATIONAL
TURNER SYNDROME
CAMP, INC.**

Our 22nd Year

Register now at
NTScamp.org/registration/

The National Turner Syndrome Camp, Inc.

Beverly Daley, PhD • Beverlyd4tscamp@outlook.com • 818.209.2220 • NTScamp.org

The National Turner Syndrome Camp, Inc is a non-profit 501(c)(3) organization dedicated to enabling teens and young women (12-19 years) with Turner Syndrome to gain confidence and realize their potential. The camp provides a fun-filled experience and a safe community that facilitates long-term friendships, exploration of the arts, and healthy living. Tax ID: 47-149407



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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Designed by n8 marketing
TSS Connect Editor
Becky Brown, National Director of
Development & Communications
becky@turnersyndrome.org

TSSUS Staff:

Cindy Scurlock, MA, President
Deborah Rios, Member Services Director
Becky Brown, National Director of
Development & Communications
Shawn Wier, National Events &
Resource Manager

TSS Connect • Spring 2018

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

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.

EIN 41-1596910
United Way #021953
Combined Federal Campaign #11561

Message from the President

On Monday, I left the office with a happy heart and feeling exhausted! Here's a quick snapshot of what a day at TSSUS is like because of the support your membership and donations allow us to provide the TS community.

- An email read: "My 5 year old has TS. It isn't common where we live. She's going through some things right now I don't understand, and I don't know what to do or where to turn for help. Please, is there anyone that can help me as a parent of a child with Turner's? I am depressed and anxious and don't know where to turn."
- A father of a college freshman called to become a member and to get involved in the TS community. We joked about how much we worry about our girls in college, even though they are doing so great!
- A woman with TS called to sign up for the Spy Museum tour at the conference. She mentioned the butterfly habitat at the Smithsonian Museum in Washington D.C.
- A 9th grade teacher called requesting resources for a Spanish speaking student's family. Teachers are the best!
- The TSSUS Oregon group leader called requesting paperwork for a grocery store donation for a Chasing Butterflies Walk she is coordinating.
- A mother called for support for her 29 year old with nonverbal learning disorder who is having difficulties with employment. We talked for a while, and I referred her to the excellent videos on the subject available on our website from prior conferences.
- A mom and adult daughter called about applying for a conference scholarship.
- A mom of a 33 year old daughter and I chatted for a while. She called out of concern because her daughter is so shy and has high liver enzymes (which is common in TS). We laughed about her daughter's shyness, yet she's looking forward to dancing at the conference. Funny how people shine when the lights turn down and the music turns up!
- A doctor's office called to order copies of the Patient Version of the Clinical Practice Guidelines to distribute to patients.
- A sweet donor called and donated \$270 to cover the cost of someone needing a TSSUS conference registration.
- My brain was tired and as I began packing up. A young couple called on their way home from a 2-month checkup where they just received their daughter's diagnosis. The pediatrician's office did an excellent job of offering information. They had a lot of questions and wanted to connect with a local parent. They felt overwhelmed with the appointments they needed to schedule and were crying as they thought of the possibility of their daughter being able to have children. My advice is generally to take things one day at a time.

One person at a time is how we serve the TS community. Everyone's needs and stories are important, and we love the connections we make every day.

Sincerely,

Cindy Scurlock, TSSUS President



Chasing Butterflies Walks

In March we made a HUGE announcement about the TSSUS Chasing Butterflies Walk program. TSSUS will match up to 50% of funds raised through Chasing Butterflies Walks.

This means that walk coordinators or a local TSSUS representative may request funding to support TS Butterflies in their area for needs that align with the TSSUS mission. Current walk coordinators are excited about offering scholarships for limited medical needs, conference, or planning events that benefit their local Turner syndrome community.

Now is a great time to start planning Summer and Fall Chasing Butterflies Walks for Turner Syndrome. Anyone can coordinate a walk – you don't have to be a group leader – you just need to be passionate about helping those with TS.

Contact us for more information about this new and exciting opportunity. Deborah Rios at 800.365.9944 or by email at deborah@turnersyndrome.org.

Chasing Butterflies Walk – Alameda, California

Walk Coordinator: Haley Rodden, February 3, 2018

On February 3, 2018, high school senior Haley Rodden organized her first TSSUS Chasing Butterflies walk in Alameda, California at the Harbor Bay Ferry Terminal. Haley has Turner syndrome, and wanted to help support others with the condition and raise awareness, while raising funds for TSSUS programs. More than 70 people came out and enjoyed a beautiful day by the water, including Alameda Mayor, Trish Herrera Spencer. Haley is off to college this Fall, but is planning the 2nd Annual TSSUS Chasing Butterflies Walk in Alameda next Summer when she'll be home on break. Great job, Haley!

Chasing Butterflies Walk – Sacramento, California

Walk Coordinator: Rosemary Morris, March 10, 2018

Southside Park in downtown Sacramento, California was ablaze with butterflies on March 10, 2018 as the TSSUS Northern California Resource Group hosted its 5th Annual Chasing Butterflies Walk. TSSUS Board Member and Group Leader Rosemary Morris co-coordinated the walk with a

wonderful team of volunteers including Brandy Greening, Emily Torres, Jacqueline Wooldridge, Dana Tucker, Kersten O'Malley Doll, and Erica Bautista. Dr. Mitchell Geffner of Children's Hospital Los Angeles traveled up to Northern California to speak and participate in the walk, and Jared Patton was on hand representing Novo Nordisk, a long-time sponsor of the event.

The Northern California Resource Group Chasing Butterflies Walk always hosts a super star event with lots of wonderful components, including Brandy Greening as the DJ and emcee, guest speaker Emily Torres, the Fancy Feet Dance Troupe and the TSSUS Butterfly Store. Congratulations on a job well done!

Upcoming Chasing Butterflies Walks:

Brooksville, Florida, October 6, 2018, Host: Shannon Rodgers
Cowarts, Alabama, May 5, 2018, Host: Kathryn Berry
Vancouver, Washington, June 6, 2018, Host: Glenna Gibson
McKinney, Texas, June 16, 2018, Host: Kimberly Prince
Cassapolis, Michigan, June 23, 2018, Host: Brandy Shelby
Zionsville, Indiana, August 8, 2018, Host: Kelsey Cavanaugh
Houston, Texas, October 13, 2018



Chasing Butterflies Walk – Sacramento, California



Chasing Butterflies Walk – Alameda, California



MISSION:

POSSIBLE

UNCOVERING THE SECRETS OF TURNER SYNDROME

Registration for the 2018 National Turner Syndrome Conference is well underway!

With an impressive lineup of expert speakers and exciting activities, you won't want to miss this year's event.

We have designed a diverse educational program for women with TS and their spouses/significant others, parents and extended family members, children, and teens.

This year, all conference information can be found on the conference website under "Events>National Conference" on the TSSUS website menu. Details will be added as they become available, so be sure to check back often.

A detailed session schedule will be available in mid-May or early June. The hotel block is filling up, so be sure to reserve your hotel room if you haven't already.

You can do this under the "Hotel" tab on the conference website. "Push the button" to go to the reservations page, or call the local number to reserve your room by phone.

Sunday's Mission

**SPY
MUSEUM**

July 15, 2018
13:30-16:30 pm



TOP SECRET



In recognition of Turner Syndrome Awareness Month this February, we wanted to celebrate you – the girls and women who live with Turner syndrome every day, and the moms and dads and people who love them.

We received so many powerful and moving stories; stories of triumph, heartbreak, challenges, obstacles and strength, we are still publishing them on our blog. We are sharing just a few of them throughout this issue of the TSS Connect.

We are grateful to those of you who have bravely shared your story, and encourage everyone to visit the TSSUS blog to read the entire series – more are added weekly. If you haven't shared your story yet and would like to, you can do that at www.turnersyndrome.org/share-your-story.

I Wouldn't Change Things If I Could

By Holly Peterson

My name is Holly, and I'm a 22 year old college student. I was diagnosed with Turner syndrome at 18 months old. The first time I met another person with TS, I was twelve and had just moved away from my hometown.

I went to a Turner Syndrome Society of the United States (TSSUS) National Conference for the first time, and found myself overwhelmed with the number of people surrounding me that were just like me. Seeing that I was not alone, and that there were so many other girls my age who were experiencing the same things I was, with the same worries and concerns, made everything so much easier. I knew I could reach out to these new friends I had made when I needed support, and they'd know exactly what I was going through.

I have also gotten the opportunity to get involved with my local TSSUS Resource Group and help volunteer at TS events. I'm lucky to get to meet a lot of people with TS and their families because of this. One of the most important lessons I've taken away from having Turner syndrome is that none of us should ever be underestimated.

Of course, some things may be challenging for us, but as many of our friends and family members know, people with TS are motivated, dedicated and driven to achieve what we put our minds to. I am extremely impressed and proud to see the things people in the TS community accomplish and overcome. We sometimes have to work a little harder to get people to take us seriously and listen to what we have to say, but in the end, this makes us stronger and surer of what we have to say. As I said, never underestimate us.

Statistics may predict that someone with TS will have difficulties socially, struggle with math, and that their brain may function a

little differently than others. But those expectations don't have to limit us. I have met some brilliant scientists with TS that use math every day. We are more than statistics, and more than expectations put on us. Because often, people with Turner syndrome exceed those expectations and work incredibly hard towards their goals.

I know now that I wouldn't change things if I could, since having TS has made me a much stronger person, and has brought incredible people into my life that I wouldn't know otherwise.



Holly pictured in center.

Working in the Theater, On the Way to Independence

By: Emily Limbach

My name is Emily Limbach and I have Turner syndrome. I was diagnosed before birth when my birth mother had an amniocentesis after the doctor noticed a cystic hygroma on the back of my neck.

When the diagnosis of TS was confirmed, my birth parents had difficulty accepting this information. I was born six weeks early and had some medical problems related to my prematurity. I was discharged from the hospital to my foster mother who also became my adoptive mother. She is a neonatal nurse practitioner, and was delighted to take me home and care for me with my TS. She also said I was very cute!

I took growth hormone for five years and am now almost 5'1" tall. I have a heart defect called "enlarged aortic root" and hypothyroidism. I take medication, but am very healthy and do not experience any problems from these medical issues.



As I continued to grow, my development was slower than most children. I didn't talk until I was four years old. I attended special education during all of my school years and graduated high school in 2016. Last year, I attended Project Search at Milwaukee Children's Hospital.

I now work at a theatre in Mequon, WI. I have asked my doctor's if my learning difficulty is because of my TS or something else. Most women with TS don't have the level of learning disability I have. The doctors don't know if this is related to TS or perhaps other genetics, because my birth parents also had learning difficulties.

Despite my learning challenges, I'm doing very well and enjoy my new job. I'm also starting to look for an apartment, so I can have more independence and responsibility.

My mother and I have been to two TSSUS conferences and are looking forward to going again in 2018. I hope to see many of you there!



There are now 6 patient-friendly, easy-to-understand Turner syndrome guides in the TSSUS Turner Topic series. Each Turner topic focuses on a unique aspect of health and wellness management for those affected by TS.

Turner topics are available for download at <https://www.turnersyndrome.org/turner-topics>



The TSSUS Butterfly Society

As we approach the one-year anniversary of the TSSUS Butterfly Society, we are pleased to share that 230 of you have become committed monthly donors and 415 have supported the Butterfly Society with a single gift. This includes 100% of our board members and 75% of our staff members!

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. Are you ready to be a part of something bigger than yourself?

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 EXCITING. You'll receive exclusive updates from TSSUS and key volunteers, as well as surprise gifts, and messages about those we have been able to help with your support.

Butterfly Society Members Receive:

- Progress updates including messages about those we have been able to help with your support.
- An exclusive welcome gift
- A surprise end-of-the-year souvenir
- Your name listed as a Founding Butterfly Society Member on the TSSUS webpage and in the TSS Connect Newsletter.
- Complimentary TSSUS Membership for one year (at the \$10/month level and above)



Butterfly Society members are invited to attend an exclusive reception Friday, July 13, 2018 at 5:00 pm at the TSSUS National Conference in Arlington, Virginia. All Butterfly Society members will receive this custom designed cloisonné pin at registration that serves as your ticket into the reception. The Butterfly Society pin will be mailed to supporters who are not at the conference.

Becky Brown

Director of Development & Communications

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

Office: 800.365.9944 • Mobile: 832.465.9388

becky@turnersyndrome.org • turnersyndrome.org



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The TSSUS Conference and the Healthy Heart Study Saved My Daughter

By Mysti Harrison

When we attended our first TSSUS Conference with our daughter Madison in Dallas we were immediately interested in the Healthy Heart Project (HHP), led by Dr. Michael Silberbach. We were in our early days of TS; my daughter had been diagnosed the year prior. This was the first time I had attended a TSSUS event, and the first time I had met anyone with TS.

I encouraged Madison, who was 10 at the time, to join the study, and explained her participation could help others. She could help make identifying heart conditions easier on the next round of baby butterflies. That's all it took! She's always like helping other people.

I was still overwhelmed at her cardiac diagnosis. I felt like we could brave every thing else, but the heart issues terrified me. She was diagnosed with bicuspid aortic valve and had widening of her aortic root. Her physicians didn't seem too concerned about it at the time. We were excited about helping.

Last Summer, we attended the TSSUS Conference in Denver. Now 16, Madi is a talented artist, cheerleader, dancer, an honor roll student (despite her struggles), and an amazing young woman all around, and I am a member of the TSSUS Board. We both took time away from conference activities and went to the HHP area.



They took her blood pressure and it was really high – higher than two years ago. Her endocrinologist noted her elevated blood pressure at her recent appointment and didn't seem overly concerned about it. He had us monitoring it at home and was

going to refer us to nephrology after the conference trip if her blood pressure was still high.

Then we entered the echo room. The echocardiogram was not right – I could tell. The mom gut I have been honing for the last 17 years knew it wasn't right. The tech was professional; her face didn't change, but I knew. I could see the aorta size was different. I can't explain how, but I could. Much the same way I knew something was 'different' about her and fought for her diagnosis. The technician allowed Madi to clean up, and I had her go rejoin her friends. I stayed to meet with the staff about the results.

We sat in a dark and private corner of the room behind a partition, and Dr. Silberbach's colleague told me her aorta had changed (for the first time in 7 years). He said effective immediately no pushing, no pulling, no lifting, and no exercise until she sees her cardiologist. This meant no cheerleading, and camp was only two weeks away. I was instructed to have a cardiac MRI immediately.



I had to work to even stand up to leave the room and compose the words to call my husband. I called my 'TS mom squad' and told them to make sure Madison stayed with the girls she never leaves the side of during conference. I explained I needed some time to process, and to not tell her anything.

She was 2 weeks away from turning 16 years old and her life changed. She was a flyer on the cheer squad. As a family, we spent our weekends backpacking, hiking, and rock climbing. This all changed in the blink of an eye.

I couldn't tell her at the conference; she needed to enjoy this weekend. This is the one time every year where she doesn't worry about her diagnosis, where her height isn't an issue, and where she is surrounded by women young and older who 'get' her. There are no words to explain the importance of this weekend to my daughter's mental and physical health.



When we arrived back home, her father and I told her about what Dr. Silberbach and his team had found and what they told me. She asked me, through tear filled eyes, if she was going to die. I had no answer. I explained we were going to do everything we could to ensure that she had the best team, the best care, and the most love we could provide her. This did little to ease her worry.

We called her coach and the director of athletics at her high school. They stated she had to have clearance to go to cheer camp, but they would modify anything and everything they could to keep her on the cheer squad.

Dr. Silberbach contacted Madi's cardiologist and shared the importance of an MRI. She was seen that week. They put a rush on the order, thanks to the insistence of the TSSUS Health Heart Project's team. The MRI was terrifying, but also informative. Her aorta width had increased to an 'at risk' size. The cardiologist concurred with Dr. Silberbach's recommendations. They agreed that as long as she did not engage in static exercise, did not lift, push or pull, and did not take any 'blows to the chest', she could still cheer.

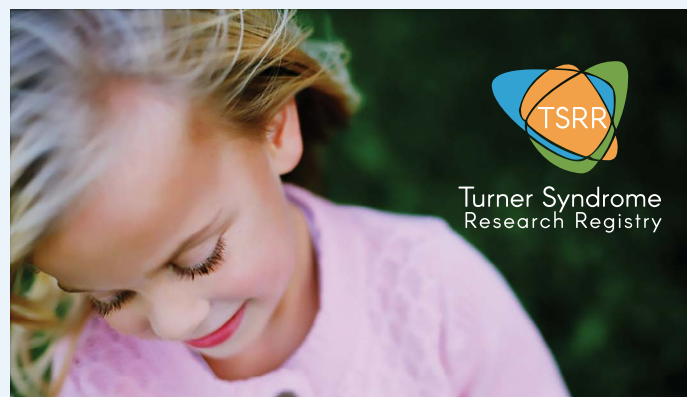
In the following months, Madi gained a nephrology specialist and many changes in hypertension medication. She had to stop 'training' for cheer, which translated to no vigorous exercise. Our family had to take a long, hard look at our activities, and now my daughter and I don't participate in hiking with the family.

The TSSUS Healthy Heart Project, Dr. Silberbach, and his team saved my daughter. It could have been months before we got the diagnosis, as we all know the referral process can be a daunting and lengthy task. Who can speculate how much more damage may have occurred in this time? This study and the team's persistence led to quicker diagnosis of my most precious treasure.

I couldn't be more grateful for TSSUS, Dr. Michael Silberbach, and his team. The dedication and effort they all have to our girls and women with Turner Syndrome is immeasurable and lifesaving. A huge thanks to them and everything they do.

TSRR Update

The Scientific Advisory Board (SAB) members will be the first researchers to access and publish a journal article utilizing the Turner Syndrome Research Registry (TSRR) data. The SAB will present information gained from the TSRR to the Turner Resource Network Symposium attendees this July as the first public announcement conveying the value of the TSRR to researchers.



Our current work includes "cleaning" and formatting the data (information entered by participants) to reveal our first snapshot of the health and wellness of our TSSUS community. We are excited to show how the TSRR can be a powerful tool for researchers and families to improve the quality of life for women and girls with TS. We encourage the entire TS COMMUNITY (those with a TS diagnosis) to go online, sign up and fill out the TS health survey at www.turnersyndrome.org/research-registry.

Members of the SAB include Michael Silberbach MD, Vaneeta Bamba MD, Aaron Dorman MD, Paul Kruska, MD, Gary Lorigan Ph.D., Siddharth Prakash MD, and Cindy Scurlock, MA (patient advocate).

About the TSSUS Healthy Heart Project

TSSUS and Dr. Michael Silberbach and his team offer the Healthy Heart Project at the TSSUS National Conference every other year. Dr. Silberbach reports that since 2003, 984 echocardiograms have been performed. Each year, important medical findings are made in an estimated 3 to 5 individuals. Over the course of the study, there have been more than 20 girls and women with Turner syndrome that have had new diagnoses made that required either a major intervention in the cardiac catheterization laboratory or a heart operation.

In addition, the data from the Health Heart Project has been the basis for 3 major scientific articles and has contributed to the cardiovascular recommendations in the 2017 Clinical Practice Guidelines for the Treatment of Girls and Women with Turner Syndrome statement.





Sami Smith

Do Not Label Me by Lois Smith

Do not label me Petite, Disabled, Small. Do not Label Me.
 I am Bright, Determined, Driven. See Me for who I am, not the Labels you give Me.
 Do not Label Me "Small". I am Compact, Capable, Surprising.
 I am Dynamite in a Compact Package.
 I will make My Own Way. My way may not be your way.
 My way may go up the rocky hill instead of around on the paved road.
 My way may hit snags and boulders too big to climb over, but I'll find another way.
 I ask you don't do it for me.
 Be there to sit with me a minute if I fall until I can get back up myself. To love me.
 My way is not your way.
 Oh, but the sights I will see going up that mountain!
 Watch my journey and live it with me.
 Do not label me.

Host a Blue Jeans for Butterflies Fundraiser

Blue Jeans for Butterflies (BJ4B) is an exciting new TSSUS signature fundraising program, where volunteers organize and host "wear jeans to work or school" events, called Blue Jeans for Butterflies day(s), in their office or school to raise funds for TSSUS programs.

On a specified day, you and your co-workers will make a donation to TSSUS in exchange for dressing down and wearing jeans. We suggest a \$5 donation for offices, and perhaps a smaller donation in the elementary school environment.

Order a BJ4B Toolkit

This is a ready-to-go fundraiser in a box. We've created a BJ4B Toolkit that includes everything you need to host a BJ4B event. If you're committed to supporting the TS community, visit <https://www.turnersyndrome.org/blue-jeans-for-butterflies> and order your toolkit today!



Avery is a Fighter: She's Our Hero!

By Megan Bell

After beating the odds with a large, septated, cystic hygroma, Avery Elizabeth was born in June of 2009. In the womb, Avery had many medical issues along with the hygroma, so our doctors didn't feel she'd make it to birth originally. However, the hygroma dissipated, and she ended up with a much better outlook!

Avery was born with coarctation of the aorta, and was kept in the NICU on medication to await heart surgery. She had surgery at one week old and recovered in the PICU for a few weeks.

At 7 months old, Avery was very sick again with her heart and needed aortic valve replacement surgery. While she coded at the onset of anesthesia, the surgery was a success, and she recovered well. We learned after surgery that Avery's aortic valve was unicuspid or "fused" as the surgeon said.

Avery still sees her cardiologist every six months and will need another valve replacement in the near future, but she is doing really well! She is eight years old and in the second grade. Due to medical issues and her size, we chose to hold Avery back in preschool to allow her to catch up some before beginning Kindergarten.



Avery was given an IEP, and she was labeled "Developmentally Delayed." Avery struggled initially, but she got the hang of things and ended up doing quite well by the end of Kindergarten. She did have hearing issues. Her ears always seemed to be clogged, and something wasn't right.

After getting hearing tests and working with our ENT, it was decided that Avery needed hearing aids for mild to moderate hearing loss. Avery had gotten tubes placed in her ears at a year old, which really helped her to become more verbal. We repeated the surgery to place tubes in her ears ever since then, and her ENT feels she will need them well into the future.

Avery got her hearing aids at the beginning of 1st grade, and they have helped her SO much! Avery has also had surgery to



pin her ear back some too. She was having tubes replaced, and her doctor did it then. He pierced her ears while she was under, which she was very excited about.

Now in the 2nd grade, Avery does most of her work on her own. When it comes to deeper thinking, she sometimes struggles, and she gets extra help with math at times. She really surpassed our high expectations and has blown us away!

Avery loves to dance and sing, and she is very social and outgoing. She enjoys going to school and church, and she is a great big sister. She takes gymnastics and has always been strong and agile, with good coordination. She laughs and smiles and gets excited over the smallest things. She truly brings joy to everyone around her and people are drawn to her.

Avery does struggle with emotions sometimes, and she can become angry and have outbursts that are unwarranted. She also needs to know what to expect and likes a routine. She can be quite OCD at times, but we work with her to understand that things won't always go exactly as she thinks they should.

She is extremely bright and has a great memory.

Here are other things that Avery deals with due to her TS:

Hypothyroidism: just like most girls with TS, Avery has to take medication daily. Her endocrinologist recently increased her dosage due to issues she was having.

Ears/Hearing: Avery began getting tubes at one year old. She has had them replaced 4 times now. Currently, she only has one tube because she has a hole in one ear. We've always struggled with drainage and infection, and Avery's hearing has always been an issue. We realized at the end of Kindergarten that it really affected her at school. It was revealed that she had mild/moderate hearing loss, so Avery got hearing aids to start the 1st grade. They have helped her a great deal.

Allergies: Avery sees an allergist for an IGA deficiency in her blood which lowers her immunity. She wears a medical ID bracelet for emergencies because if she is given blood, it has to be modified first.

Celiac disease: About a year and a half ago we discovered that Avery is allergic to gluten and has Celiac disease. She never complained, which we attribute to a high pain tolerance, but internally, she was inflamed and had no cilia. Avery was not absorbing nutrients or gaining weight, but since starting the gluten free diet, she is really growing.

Growth: Avery was never on the regular growth chart and was extremely low on the Turner syndrome chart until we began growth hormone injections after she turned 2. She hasn't seemed to have side effects, but we did switch to morning injections because she was having trouble sleeping at night.

Avery is a fighter and she is our hero. She's shown us what true strength is, and we adore our beautiful, red-headed butterfly!

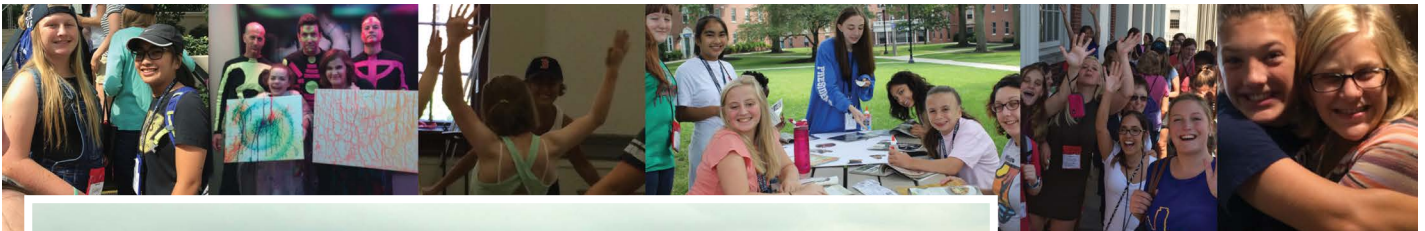
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Volunteer Spotlight – Rosemary Morris

If you've been involved in the Turner syndrome community and with the Turner Syndrome Society of the United States for any length of time, then you probably know Rosemary Morris.

Rosemary has been a dedicated advocate for those with Turner syndrome for 28 years and is one of the Society's most ardent volunteers. Rosemary was instrumental in starting what is now the Northern California TSSUS Resource Group. As the group leader, Rosemary has created key outreach programs that have been duplicated across the country in other TS communities. The TS Patient Family Education Day program she started in 1992 was the inspiration for the Turner Syndrome Society's TS Days – the new educational and social one-day event programs we have launched in cities across the country.



This year, Rosemary hosted and coordinated the 5th Annual Chasing Butterflies walk in Sacramento. The Sacramento walk is a model walk, and incorporates key elements that make it a success year after year.

In 2016, Rosemary was elected by her peers in the Turner syndrome community to serve in the Woman-at-Large position on the TSSUS Board of Directors. As a TSSUS Board Member, Rosemary contributes valuable insight and perspective to the board, and actively engages in governing the Society.

In case she wasn't busy enough, Rosemary came to us early this year to propose starting two more TSSUS Resource Groups in California. Recognizing that Central and Southern California have significant TS communities, and that California is a BIG state, TSSUS authorized Rosemary to start the Central and Southern California Resource Groups with hopes of mentoring local volunteers there.

Rosemary is a mentor to girls and women with TS across the country. She is an example of a life well lived, and always puts

others before herself. She has a giving heart, and a true spirit of service to others.

Rosemary and her husband of twenty-five years, Barry, adopted their 14-year-old son, Andrew, who has autism, at birth. Rosemary calls Andrew her Soul Child, and she is a dedicated and proud mother to this amazing young boy.

Please join TSSUS in thanking Rosemary Morris for her years of dedication to the TS community and for her countless hours and years of volunteer service to the Turner Syndrome Society.

If you know of a TSSUS volunteer in your community you would like to nominate for the TSSUS Volunteer Spotlight, please contact Becky Brown at becky@turnersyndrome.org.



Launched in 2017, "TS Days" is a new community support program of TSSUS. These one-day events provide girls and women with Turner syndrome and their families the opportunity to join others in their region to share experiences, have fun, and learn about recommended TS healthcare and available resources.

2018 TS Days will be coming to the following cities:

Nashville, Tennessee April 21

Omaha, Nebraska June 9

Dates still tentative

Oklahoma City, Oklahoma August 24

Minneapolis, Minnesota September 15

Boston, Massachusetts October 27

Boise, Idaho November 16

Kansas City, Missouri 2019





11250 West Road, Suite G
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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!