

TSS CONNECT

SPRING 2017

Just in Time for Mother's Day!

"THOSE MAGICAL WORDS"

Article by Courtney Strauss

AND OTHER STORIES FROM
TS MOTHERS INSIDE!



Turner
Syndrome
Society
of the United States



The Turner Syndrome Society advances knowledge, facilitates research, and provides support for all persons touched by Turner syndrome.

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OUR SOCIETY IS PREPARED FOR THE FUTURE

Celebrating our 30th Anniversary!



This year, we celebrate the 30th anniversary of the founding of TSSUS. As I look back on the history of our Society, I can't help but feel nostalgic about how far we've come since 1987. Skimming through the bulging white binders labeled "Newsletters" and "Conference Brochures," one overarching theme becomes apparent: making connections. People sharing experiences initiated our Society, caring about our health and the needs of others keeps us focused, and our united strength advances us. The mission of the Society has evolved to meet more ambitious goals over the years, but our sincere support of the TS community never changes.

In 1989, TSSUS introduced the first *TS: A Guide for Families* and *TS: A Guide for Physicians* and distributed these free resources to everyone who needed them. The *Guide for Families* continues to be

the most popular TS publication available. TSSUS committed \$10,000 to the professional symposium in 2016 to support the revision of the TS Clinical Care Guidelines for use by physicians managing TS. A TSSUS newsletter from 1989 called the "Turner's Syndrome News" highlighted summer picnics, presentations held by groups, research opportunities, conference updates, and even letters and pen pals. It's amazing that the services and events that were valued by the TS community years ago are still requested in 2017.

Twenty years ago, in the Spring edition of TS News, "FDA Clears Growth Hormone Therapy for TS" was the cover story. TSSUS helped Lynn Tesch, Susan Jennings, and Jessica Stout bravely testify in court to the Food and Drug Administration (FDA) that growth hormone therapy positively affected their lives and should be approved for use in Turner syndrome cases.

Today, 30 years later, our Society continues to significantly support the TS community. Because of changing times, coupled with our unwavering commitment to the TS community, we have updated our guiding statements.

Our mission:

"TSSUS advances knowledge, facilitates research, and provides support for all touched by Turner syndrome."

Our vision:

"Every woman and girl with TS will have cutting edge health care, ensuring the best quality of life."

I believe the Society's newly-drafted and recently-released Three Year Strategic Plan will interest you, as it explains how we intend to meet the needs of the TS community moving forward.

Here are a few of the exciting things we are currently working on:

- Registration for the July conference in Denver is underway
- More than 1,000 people are inspired by others with TS on the TSSUS online message boards
- The TSSUS-funded Turner Syndrome Research Registry (TSRR) has 575 participants
- TS Days are being finalized in cities around the nation
- Turner Topic Patient Guides are being created
- TS Clinical Care Guidelines revisions for physicians will soon be released
- A new patient friendly version of the Clinical Care Guidelines is being developed

In between issues of TSS Connect, we will continue to announce opportunities and progress updates through emails and the Society's Facebook page. Thank you for being such a key part of the Turner Syndrome Society of the United States.

Sincerely, 
TSSUS Executive Director



THOSE MAGICAL WORDS

- Courtney Strauss

Ever since I was a little girl, I have only ever dreamed of being two things: a teacher and a mom. As I got older, my life started falling into place. I got my first teaching job, married my best friend, and bought a house. Yet, something just seemed like it was missing—a baby.

When I was diagnosed with mosaic Turner syndrome, the doctor told my parents that I wouldn't be able to have children. Both for my parents and myself, this was very hard to hear. Fast-forward 23 years to 2016, when my amazing husband and I embarked on the biggest journey we've ever been on, IVF. After consulting with our knowledgeable and supportive team of doctors, we decided to do a frozen embryo transfer using a donor egg.

Our IVF journey was the most amazing, emotional, rewarding thing we have ever done. We had our first transfer May 17, 2016 and found out two weeks later on May 31, 2016, that the transfer had worked and we were pregnant! We had waited so long to hear those magical words; we were both shocked and thrilled! On January 12, 2017, I gave birth to our healthy, beautiful baby girl, Olivia Grace Strauss.

Olivia filled in the missing piece of our life. She completes our family. She is truly a blessing and we are thankful for her each and every day. ♦



While infertility is a very painful reality for many women with Turner syndrome, a small percentage are able to conceive naturally, and a growing number are conceiving and giving birth with the help of egg donation and in-vitro fertilization. Still, others are becoming parents through the gift of adoption.

The stories shared in this issue are meant to give hope and share in the joy of these women in our community, while in no way minimizing the pain of those who are living with infertility.

MIRACLES CAN HAPPEN

- Ashlea Danberry

My name is Ashlea Danberry, and I was diagnosed with mosaic Turner syndrome at the age of ten. I am now 33 years old. Words cannot begin to describe how lucky my husband and I have been. With the help of modern medicine, I have been able to give birth to two boys and even breastfeed them! For women with TS, one of the biggest concerns with pregnancy is making sure that your blood pressure and heart can handle the stress. My story is no different.

I underwent a fresh 5-day donor egg IVF embryo transfer on 6/13/2013. For this cycle, I solicited the assistance of the Center for Reproductive Medicine in Minneapolis, MN. I walked into the clinic already armed with cardiac MRI results from a few months prior, knowing full well that the test would be requested. Sure enough, it was one of the first questions asked of me: "How is your heart?"

Upon pregnancy verification, I was released to my regular OB/GYN. She, of course, referred me to the maternal/fetal medicine department at the University of Minnesota. From there, I saw a cardiologist every trimester. I also had another echo six months after he was born. Everything still looked fine at that point.

Interestingly enough, I did show signs (around 33 weeks of gestation) of preeclampsia. Normally, my blood pressure is on the lower side (100/70), but it shot up around 150/100. They monitored me closely at that point, and I delivered him at 36 weeks and 2 days gestation (only because my water completely ruptured). My son was born on February 3, 2014. My blood pressure returned to normal very soon after that.

With that initial round of IVF, we were also blessed with two additional viable embryos. We, of course, opted to cryopreserve those embryos and underwent a frozen embryo transfer on January 11, 2016. This resulted in my second son. I carried him to 38 weeks and 1 day gestation. This time around, I showed no signs of preeclampsia; but again, they did an echo on my heart during my second trimester. I also had another MRI at 31 weeks. I have to admit, lying on your back in that confined tube for nearly an hour while 31 weeks pregnant was insanely uncomfortable. I should have had the MRI done just prior to the frozen embryo transfer, and then the cardiologist probably would have been satisfied with a second echo in lieu of the MRI during my third trimester.

My second son was born on September 15, 2016. With him, my cardiologist ordered an echo 48 hours after birth and then again one month after he was born. Both showed no abnormalities. She also requested I have another MRI done this fall (one year after his birth), which I will do.

Another concern is the stress labor itself (mainly pushing) can cause on the heart. My first son was born cesarean, but it was because his heartrate began to drop. It had nothing to do with me. My second son was a VBAC (vaginal birth after c-section) birth.

I hope that my story is encouraging to other TS butterflies—my two sons are proof that miracles can happen! ♦



MOTHER'S DAY STORIES

Happy Mother's Day!



PHOTO

Carissa and her mom, meeting some of the football players from the Chicago Bears!

My name is Carissa Caulum. I am 22 years old, and I was born with Turner syndrome. My mom is Melissa Caulum and we live in LaCrosse, Wisconsin. Ever since I can remember, my mom has gone to almost every doctor's appointment with me. When I started attending conferences, she went with me. I think sharing these experiences is why we are so close now. When we go to

conferences together, I feel our bond grow closer.

Since my open-heart surgery in Fall 2009, I have regular appointments at the Children's Hospital in Milwaukee. My mom and I have a tradition. We go to Dave and Buster's to eat dinner and play games, then we go to the Cheesecake Factory to get cheesecake and take it back to our room to eat. It's the part of going to the Children's Hospital that I always look forward to. For me, this tradition helps me escape and just live in the moment. Also, this tradition is a time when my mom and I relax and have fun together. My mom is a very special person to me and would not be who I am today without her. ♦



PHOTO

Lynda Taylor and her daughter, Brittany.

When the adoption agency called us to ask if we would take a little baby girl with Turner syndrome, we didn't hesitate, even though we knew nothing about TS! Over these 21 years, we have had trials, struggles, frustrations, and many happy and exciting times too. But more than that, we have rejoiced at the blessing Brittany has been in both our lives and those of many others. We have celebrated every one of her

accomplishments, ranging from finishing 14 years of nightly growth hormone shots, to two proms, to graduating from high school with her Early Childhood Certification, to playing soccer in high school, to her years in college, and now having her first job! Each new phase (bringing both challenges and joys) has been a wonder to be a part of and God has been faithful to provide everything we have needed.

Brittany and I enjoy our mother/daughter times together, or "GNO's" as she calls them (usually a Salad Works and movie night!) She is her daddy's girl and is still learning that she will always be his little girl who he wants to care for. She loves spending time with her brother, and as protective as he is of her, he loves to spend time with her also. They go to the movies, or the nearby 2nd & Charles store, or spend time at his place, or even at a Star Wars event.

As her mom, I am so thankful and honored that the Lord has entrusted me to help bring her up into the young lady she is becoming. What a great reflection for Mother's Day! ♦



PHOTO

A warm embrace by her grandparents at Houston's highschool graduation.

My name is Houston Whitson. I am 25 years old and have mosaic Turner syndrome. I lost both my parents before I was 15 years old. After my mom passed away, her parents - my grandparents - had the task of raising my siblings and I. They took really great care of us.

I noticed I was shorter than the other girls in my class; I was always the runt of the crowd. So, we went to the doctor to find out why. The doctor didn't have answers, so they referred us to Wake

Forest Baptist Medical Center. That was where our adventure began. It was there, when I was around 13 or 14 years old, that I was diagnosed. After the diagnosis, we spent a whole day running tests and getting blood work and ultrasounds. My grandmother took me to every appointment. We have special memories about our favorite breakfast spot, where we went after my appointments every 6 months. She is very special to me, and my best friend. She managed my appointments and any contact or calls with my doctors. She always made sure I had proper care. She is still my rock and has been such a big supporter of me through my struggles with Turners.

Thank you, and I hope our story is the one you are looking for! ♦



PHOTO

Debra Veazey and her daughter enjoying the day together.

What I have to say is far less like a story and far more like a bumpy journey. It's a journey that has my daughter and I on a road that goes on for miles! There are many bumps on this road, but I try my best to add joy and laughter along the way.

My beautiful daughter Madison was not diagnosed till the age of 7, even though I knew there was an issue even while she was still in my womb. So many doctors told me that I was just worrying too much. But what mother watches her daughter not growing, not eating as an infant,

falling so far behind on her growth chart, and being told she has a kidney disorder, and not worry?

My wish for her is to always feel like having Turner syndrome is a not a stigma or a negative status, it's a special quality that makes her unique! She is the kindest soul and no matter what, she will remain that way! I will always be there for her. She has taught me to be a better person. For every other butterfly, you are all special and unique and may God bless you forever! ♦

MY JOURNEY TO MOTHERHOOD

- Rebekah Hill



Growing up, there was never a doubt in my mind about what I wanted to be: I was going to be a teacher and a mom. I wasn't going to let the fact that I was diagnosed at birth with mosaic Turner syndrome (45X, 47 XXX,) prevent me from doing just that. I met Jon, my husband of 15 years, during my freshman year in college. We dated for two years, and got married two days after I finished my student teaching. We moved to Nashville, TN and I got a job as an elementary teacher. When we had been married for 4 years, we decided it was time to look into having children.

I researched IVF (in vitro fertilization) for hours on end. In January 2005, I went through my first cycle of donor egg IVF. It was unsuccessful. My doctor made a few medicine adjustments, and in May 2005, I went through my second cycle of IVF using frozen embryos. I wasn't supposed to, but I took a pregnancy test at home before I went in for blood work to see if the cycle

was successful. It was positive. I was speechless. My blood work that day revealed I was pregnant with probable multiples. I went in for an ultrasound a few weeks later. They saw twins with two strong heartbeats and the spot where a third baby had started developing but didn't keep growing. My twin pregnancy was uncomplicated until 33 weeks, when I developed preeclampsia. My healthy twin girls were born at 34 weeks and 5 days. After a short NICU stay to gain some weight, my girls, Cambrie and Haley, came home. Cambrie and Haley are now 11 years old, and even though they are polar opposites (both in looks and in personality) they are best friends.

When my twins were preschoolers, I went through two more cycles of IVF using our remaining frozen embryos. Both of those cycles resulted in unexplained miscarriages. I immediately started looking into adoption. We knew we wanted to adopt a newborn baby boy. I got the name of a social worker and we began the home study process. When our home study was complete, the social worker told us about a new adoption agency that worked nationally, that was looking for adoptive parents. I didn't waste anytime contacting and signing on with that agency. We put together our family profile, and a few weeks later, we were active! Just four months later, on January 18th, 2006, I got a phone call. It was our adoption agency wanting to know if we were interested in a baby that was going to be born the next day in South Carolina. We immediately said YES! The agency didn't know gender, health, race or anything else. A few hours later, the agency called us back and confirmed everything with us.

We kissed our girls goodbye, (they stayed with my parents,) and jumped in the car with nothing more than a car seat, a pack and play, and some white onesies. We arrived at the hospital early the next morning. We were quickly ushered into a waiting room with no explanation. Five minutes later, we were walked through an unmarked side door into the hospital nursery. There was one baby in the nursery. The nurse looked up and said to us,

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OWNING MORE THAN YOU NEED COMES WITH CONSEQUENCES

- Lori Firsdon



For my birthday this year, my husband surprised me with a mini vacation. While we relaxed by the pool, a young boy went running past our chairs. His mother called out, "No running, stop running!" He didn't slow up one bit. In fact, he started laughing and picked up his pace. He continued to run because he was unaware of the consequences he could suffer by running around the pool.

His mother knew them. He could slip and hit his head, stub a toe, or fall into the pool and drown. If someone explained the consequences to him beforehand, he may have slowed his pace when his mother reminded him not to run. This poolside incident reminded me of the many people who share with me how they feel like they are drowning in their homes, surrounded by the accumulation of stuff they collected over the years. They filled their homes to near capacity because they weren't thinking about the consequences they would suffer as a result of owning more than they could care for.

When you think about the consequences of keeping too much stuff, you can change your behavior. Knowing the drawbacks of being emotionally attached to stuff, will help you wean your-self from objects and stop the drowning feeling.

As you read through the consequences listed below, think about how you are being affected by your stockpile of stuff.

Wasted time. Wasting time looking for things in your home takes you away from doing things you enjoy. You're also stressed as you try to find what you are looking for.

Emotionally drained. Are you tired of thinking about all you've amassed and worried about how you are going to get out from under it all? Are you losing sleep from this anxiety?

Physically challenged. Are you constantly frustrated while trying to perform the simplest of tasks because extra stuff is in the way? Do you feel like you are walking through a complicated maze to get from one room to another?

Bullied by others. Do people make fun of you because you're disorganized?

Exhaustion. Do you avoid coming home because dealing with all your stuff is stressful? Your home should be a place you retreat to, not run from.

Arguments. Are your relationships in danger of ending because your loved ones no longer have the patience to deal with it all?

Socially isolated. Do you feel lonely, but wouldn't dare ask anyone over for fear of them judging how messy your home is?

Wasted money. Do you waste money buying more things because you can't find what you already have?

Misdirected energy. Is your emotional energy being spent coveting possessions instead of spending time with your loved ones?

Lost opportunities. Do you have trouble acting quickly when unexpected opportunities present themselves?

Refer to this list as you look through your things and determine if what you own are life jackets that keep you buoyed in life or anchors that hold you under.

Once the mother caught up with her son, I could hear her explaining the consequences of running by the pool. He didn't run for the rest of the afternoon. Look over this list. What changes can you make to lessen your consequences? ♦

Lori Firsdon owns Forte Organizers in Centerville, Ohio. She does onsite organizing and speaking engagements. For more organizing tips, visit www.ForteOrganizers.com. Reprinted with permission.



Turner Syndrome
Research Registry



UPDATE

Thank you to everyone who has signed up for the TSRR! Our TSSUS Community is coming through as always! We have 570 registered participants, but approximately 147 have not started or finished the survey. You may have received an email recently asking you to finish the survey. We need at least 500 *finished* surveys to attract researchers.

If you need any help with the TSRR, please call the National Office at 1-800-365-9944 or email Natalie@turnersyndrome.org. There is also a "Step-by-Step Guide" on the TSRR page on the TSSUS website for help filling out the registry. We want to help!

- The registry is a highly secure site therefore you may only access it from a computer. *Smart phones are not secure enough.*
- You may go to www.turnersyndrome.org to find out more about the Research Registry and sign up. *If you would like personal assistance, such as registering by phone, please call us at 800-365-9944.*
- Spread the word! We need to reach outside the TSSUS community so please share our posts.

Participating in the TSRR empowers you to make a major difference. TS researchers and health care providers cited the TSRR as essential to advancing TS research! ♦



Join Us at the

30TH ANNUAL TURNER SYNDROME EDUCATIONAL CONFERENCE

Celebrating

THE PAST

PREPARING

FOR THE FUTURE

Bringing back the 80s!

**Celebrating 30 years of Creating
Awareness, Promoting Research,
and Providing Support for all those
touched by TS.**

DENVER, COLORADO

July 21-23, 2017

More information on our website!



Birthdays are a special time of year,
and the
Turner Syndrome Society of the United States
wants to help you celebrate!

Find out more on our website!



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ARIZONA RESOURCE GROUP

- Kelly Shea Jasper



TOTAL RAISED \$5,000

Team Captain Bethany Wood, total raised: \$640

Team Captain Cosette Dover, total raised: \$175

Team Captain Heather Austin, total raised: \$50

Team ZoZo, Team Captain Teresa Minarsich, total raised: \$40

My name is Kelly Shea Jasper and I am the leader of the Arizona Resource Group. Recently, we had a Chasing Butterflies Walk for Turner Syndrome on March 4, 2017 at the Phoenix Zoo. It was a beautiful, sunny, 80-degree day in the valley of the sun. The event was great and everyone told us they had a really good time. All registered walkers got Zoo bracelets and were able to enjoy the rest of their day at the Zoo. It was great to see so many people making connections.

I gave some opening remarks, and then introduced Professor Leah Randolph from Arizona State University who spoke on behalf of the President of ASU, Michael Crow, and Teri Pipe, the Dean of the College of Nursing and Health Innovation. I would like to take this opportunity to thank Professor Randolph, as well as the following people:

- Raul from Golden Key International Honor Society ASU Chapter
- Katie Thorson, our Bronze donor
- Karina Palomino, leader of the Business Planners at West team ASU club, and the ASU volunteers who came with her
- Glenda and Jim Reid, who ran our walk-up and sales table
- Amy Howard and her assistants at the Phoenix Zoo
- Alexis Friddle from ASU, who served as our medic
- Sarah Lamp for facilitating an interview at Channel 12 on Arizona Midday with Destry Jetton about Turner Syndrome and our Chasing Butterflies Walk

This event was truly a volunteer effort. We could not have done this without them. Our volunteers also brought water, fruit, donuts and protein bars. We raised about \$8,389.50 in total donations this year including \$2,315.00 from Fuiil Celtic.

In February, for Turner Syndrome Awareness Month, I was happy to receive a proclamation from the Governor of Arizona, Doug Ducey, making February Turner Syndrome Awareness Month and March 4th, the day of our walk, Turner Syndrome Awareness Day. This was a first-ever proclamation for Arizona.

It's been a very busy last few months of TS Awareness and fundraising in Arizona. As for me, I am preparing to graduate in May Summa Cum Laude with a BS in Integrative Health from ASU's College of Nursing and Health Innovation.

Always remember, Butterflies, you can do anything you set your mind to do because we rock! ♦

FLORIDA RESOURCE GROUP

Chasing Butterflies Walk in Ft. Walton Beach, Florida.



The Florida Resource Group held their walk on February 25, 2017.

TOTAL RAISED \$6,056
Hosted by Carrie Odom

Team "Chasing Butterflies" with Brianna Wolfle

TOTAL RAISED \$1,145
Team Captain Sharon Wolfe

SEEDS OF FAITH CELEBRATION

A benefit gala for Leaping Butterfly Ministry.

On February 23rd, during National Turner Syndrome Awareness Month, Leaping Butterfly Ministry in Houston, Texas hosted its 4th annual Seeds of Faith Celebration fundraiser. The evening's theme was An Evening in the Garden and it was held at The Woodlands Country Club. The night included dinner, cocktails, and dancing, along with a raffle, and both a silent and live auction. Speakers for the program were mothers of TS daughters: Ashley Pope, Kim Graham, and Cindy Scurlock, with a video presented by Emily Markowski, Rosemary Morris, and Debbie Browne.

Over 100 were in attendance, along with many wonderful sponsors, including:

- Circles of Hope Foundation
- Turner Syndrome Society of Texas, Gulf Coast Chapter
- John and Ashley Pope
- Kelly and Cindy Parker
- Dean and Draper Insurance

The evening grossed \$87,000.00. This has given Leaping Butterfly Ministry the opportunity and blessing to award:

- 26 scholarships to TSSUS' 2017 Summer Conference in Denver, Colorado
- 7 sets of hearing aid scholarships
- Programs for those attending the conference
- Partnership with Texas Children's Hospital for their Echocardiogram Room
- Funds for research and awareness to TSSUS

Please join us at our next celebration on Thursday, February 22nd, 2018. If you are not able to attend, then we invite you to visit www.LeapingButterfly.org to learn more about us.

Help us help others. ♦



CALIFORNIA RESOURCE GROUP

Over 100 people attended the Chasing Butterflies Walk in Sacramento, CA!



TSSUS Chasing Butterflies Walk

Hosted by Erica Bautista

TOTAL RAISED \$4,900

Team Tatiana Super Crew, Team Captain

Jessica Morales raised: \$1,080

Team Ceded, Team Captain Erica Bautista

raised: \$550

Team Captain Jacqueline Woolridge

raised: \$510

Team Captain Dana Elizabeth raised: \$400

Team Captain Amy Jimenez raised: \$470

Team Captain Kimberly Jordan raised: \$310

Team Captain Rosemary Morris raised: \$310

Team Madam Monarch, Team Captain

Lea Harris raised: \$120

Team Captain Shannon Mullings raised: \$120

Team Captain Brandy Greening raised: \$94



DID YOU KNOW?

You can set up your own personal fundraising page to support the Turner Syndrome Society!

It's easy to set up, and you can share your link with others via e-mail, text message, or social media within minutes.

To learn more about how YOU can make a difference through Social Fundraising, contacts:

shawn@turnersyndrome.org or
deborah@turnersyndrome.org



JOIN THE CHASE

Upcoming Walks in 2017!

Newark, DE 4/29
Claysville, PA 5/6
Vancouver, WA 6/24
Cassopolis, MI 7/8
Walk Syracuse, IN 7/15
Shippensburg, PA 9/16

More Walk info on our website!
www.turnersyndrome.org
> Take Action/Chasing Butterflies

WELCOME BECKY BROWN

TSSUS has a new staff member!

In February, Becky Brown enthusiastically began working as the TSSUS Director of Development and Communications. In her role, she will focus on increasing financial support for the organization, as well as on crafting clear and powerful communications that add value to our members, supporters and the TS community as a whole. Becky is passionate about servicing the TS community and has more than 20 years experience in senior leadership as a director in the nonprofit sector. Most recently, she lead the development efforts at Target Hunger and Shriners Hospitals for Children -Houston & Galveston.

Becky shares, "One of the biggest challenges facing nonprofit organizations today is the notion that one must be among the extremely wealthy to be a philanthropist. We all have the capacity to support the charities advocating for the issues closest to our hearts. At TSSUS, our greatest potential philanthropists are our volunteers, the TS community, the medical and professional community and our members who may not think a \$10 monthly donation matters. It's the seemingly small donations that can change the world." ♦



PHOTO
Left to Right
Rosemary Morris, Mysti
Harrison, Jeff Hynes,
Elizabeth Fontenot, and
Becky Brown

MY JOURNEY TO MOTHERHOOD

continued from page 5

"Here is your son." Unbeknownst to us, he had been born just ten minutes before. After the shock wore off, we were able to give him his first bath, hold him, and feed him his first bottle. We named him Brandt Micah. We were able to stay with him in the hospital because his birthmother requested a closed adoption (no contact.) Brandt is now 6 years old. He is all-boy and the light of our lives. Two years after Brandt was born, I came across an article on a news website. It was the story of Dr. Catherine Melver, and how she and her husband adopted a little girl from China who also has TS. The wheels in my head began turning. I sent out an email inquiry to some international adoption agencies that worked with China. A handful of agencies emailed me back and said that Turner syndrome is rarely diagnosed in China. Most cases are diagnosed after the child is adopted.

But I tend to be stubborn, and I don't like to be told no. I immediately emailed TSSUS to see if they had heard about any girls with TS that needed a family. TSSUS forwarded my inquiry to Dr. Melver. Dr. Melver sent me a link about an older child with suspected TS who lived in China. I contacted the adoption agency that she was listed with and requested information about her. I took

one look at her file and knew she had a sex chromosome abnormality, but knew it was slightly different from Turner's. Jon and I decided to proceed with adopting her because we knew she didn't have many more chances to find a family due to her older age. A ton of paperwork, and nine months later, we flew to China and brought home Alina Jie. Once home, we immediately began medical testing. It turns out that Alina has a variant of Turner syndrome. Her sex chromosome abnormality is similar, but distinctly different from TS. We immediately began her on growth hormone. Almost three years later, at the age of 14, she is 7 inches taller, speaks English, and is on the honor roll at school. According to her bone age and her endocrinologist, she will hit 5'0" and possibly be 5'1" (taller than me!) Pretty good for a little girl who was 4'0" when she came home and didn't start growth hormone until she was 12!

I live a crazy and busy life with four kids and a husband. Like everyone else, I have been through lots of ups and downs. I happen to have Turner syndrome, but Turner syndrome has never had me. ♦

THANK YOU DONORS

January 1, 2016 through March 31, 2017.

TSSUS would like to recognize and thank the following donors who generously made a financial gift in support of our work to advance knowledge, facilitate research and provide support for all touched by Turner syndrome.

If we have inadvertently omitted or made an error in the listing of your name, we apologize. Please contact us at tssus@turnersyndrome.org to correct your record.

INDIVIDUAL DONORS

Kenneth Acres	Amy Barnett	Peter Bowman	Krislyn Carlson	Michael Costigan	Jolene Dehond
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Catherine & Zoe Melver
Abby Montag
Rosemary Morris
Morgan Murphy
Ellen Muschany
Cheryl Nathan
Adeline Nolan
Vivian Nielsen
Melissa Olmsted
Jordyn O'Neil
Sarah Page
Gracelyn Parpart
Camryn Parsons
Lauren Patris
Emily Pawlowski
Jessica Peters
Evelyn Pobuda
Allie Pope
Winnifred Powell
Cordel Queathem
Leah Rigley
Virginia Ward and Stan Root

Cece Russo
Allison Schwartz
John Seltzer
Leah Shelby
Jennifer Shewell
Sydney Short
Kaitlain Sietzier
Marilyn Silveria
Isani Singh
Lexie Smith
Karissa Snodgrass
Kinsley Stavinoha
Maria Suhon
Sydney Svagerko
Brittany Taylor
Bella Terence
Alexandra Terry
Madison Thompson
Erin Timmermann
Dana Tucker
Gracie Umbarger
Emily Underwood
Alexis Vaxman
Emmalynn Verdoorn
Eliza Wahlers
Brenda Walker
Grace Ward
Emeryelle Grace Warford
Agustin Whamond
Thea Wier
Megan Willeford
Caroline Winterhoff
Brianna Maddison Wolfe
Bethany Wood
Zoe Woods
Jacquelyn Wooldridge
Sydney Worthy
Sophia Zambrano



THANK YOU DEBBIE

On April 5, 2017, Debbie Browne, the Founder and President of Leaping Butterfly Ministry, presented Cindy Scurlock, TSSUS executive director, with three checks totaling almost \$25,000.

These funds will be used for 27 scholarships to the TSSUS Annual Conference, 7 hearing aid scholarships, conference programs, and general support for the Society. Thank you, Debbie, for everything you do for the TS community and for the Turner Syndrome Society of the United States.



Do you have a photo or event you would like to share with the TS community?

Please send your photos and event highlights to newsletter@tssus.org!



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*All smiles at last year's
annual education conference.
Don't forget to sign up
for this year's!*