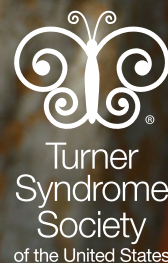


# tss Connect™

Turner Syndrome Society  
of the United States  
Fall 2018



Recent Accomplishments

2018 Conference Recap

Top 6 Things

Symposium Highlights





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

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### TSS Connect • Fall 2018

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

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## 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 we grant wishes and fulfill dreams. I hope the communications from TSSUS allow you to have a window into the difference 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.

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 a luxury to slow down and reflect and dream, it's a necessity. I hope you have had time to relax this year and count your blessings.

Sincerely,

Cindy Scurlock

Cindy Scurlock  
TSSUS President



## 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.

• **Symposium:** The planning, coordination and funding of the *Turner Resource Network (TRN) 2018 symposium Turner Syndrome Science in the 21st Century*.

• **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.



Leading up to the TSSUS Minnesota Chapter's Chasing Butterflies walk, Ellie Bekkerus operated a lemonade stand to raise funds and awareness for Turner syndrome. Her goal was to beat the funds she raised for the walk last year, which was \$500.

Ellie did a great job, and raised \$727.87 for TSSUS. She was even interviewed on her local news station!

Way to go, Ellie!



If you have been on Facebook, or have received the monthly TSSUS e-blast, you may have heard about the new TS community support program called "TS Days." You may have even attended one of the six events held this year and the end of 2017. Knowing that not everyone has the means to make it to the TSSUS National Turner Syndrome Conference, we wanted to provide an opportunity for people to get connected and have access to educational programs within their local areas and regions. So far, we have seen amazing results.

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 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





# TSSUS Chasing Butterflies Walks for Turner Syndrome



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](http://tssus.org) to find a walk in your area, or call Deborah Rios at 800.365.9944 or email [deborah@turnersyndrome.org](mailto:deborah@turnersyndrome.org) about planning one in your community today.



## 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

## 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





# 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 Butterflies and Brushes paint night on Thursday evening.

On Friday we kicked off the conference with a welcome from National Event and Resource Manager, Shawn Wier. After lunch, the TSSUS Board of Directors and President, Cindy Scurlock, shared about the mission and vision of the Turner Syndrome Society.

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 Dessy, 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!

TSSUS was fortunate to receive a generous grant and product donation for the conference youth program from the Arbonne Charitable Foundation. They provided each of our pre-teen and teen girls with a product kit valued at \$169, which included some skin care items as well as some fun cosmetic products. Former TSSUS board member, TS mom, and Arbonne Executive District Manager, Kim Graham, was instrumental in securing this donation. Thank you, Kim!

Sunday morning featured a delicious breakfast buffet and more educational breakout sessions, but as always, it was hard to say goodbye to friends old and new. After a group outing to the Spy Museum, our mission was complete. Until next year ...

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.

This activity is supported by a contribution from Lilly.

**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 through 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 TSSUS 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](mailto: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 seen 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.



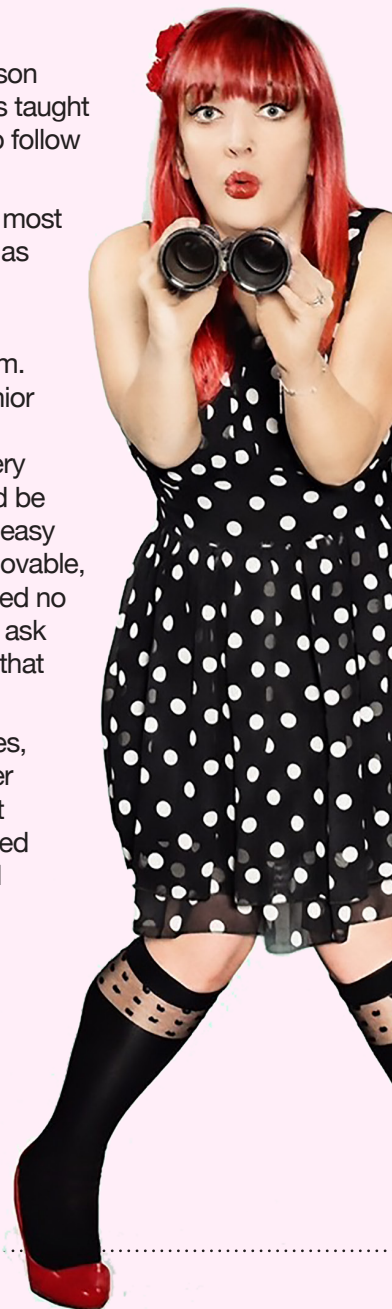
## Volunteer Appreciation

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!





# Top 6 Things to do When Caring for a Sick Loved One

by Natalie Brobin Bonfig

An endocrinologist spoke these words to my husband over the phone. Our three-year-old daughter wasn't growing. She was wearing the same clothes she'd been wearing the whole year before. One doctor told me it was because of the open-heart surgery she'd had at birth and another said it was because of her many ear infections. I knew we were missing something. Finally, her cardiologist pointed out that she hadn't gained any weight in a year. I knew that and asked, "What are we going to do next?"

That's how we ended up at the endocrine clinic. A few tests later, the doctor diagnosed our daughter with Turner syndrome. I was relieved to understand why she wasn't growing, but now I had hundreds of new questions. What would we do? Which doctors did she need to see? Would she have a good quality of life?

Through trial and error, I learned how to care for my daughter and manage the team of doctors. It wasn't easy, but I would have done anything to improve her health. I always wished someone had given me some practical advice to make things easier. Although this is by no means a complete list, my hope is that it can help you if you find yourself in a similar situation.

1. Get organized
2. Do your own research
3. Know which medical specialists to see
4. Become a medical expert
5. Follow your intuition
6. Find your tribe

**♥ Get Organized** Start simple. Create a "to do" and "contact" list. Write down contact information for all of your loved one's physicians and other medical personnel such as their specialties, phone numbers, and their office addresses. Open your "to do" list at every appointment. Take notes on new diagnoses, appointments to make, tests to schedule and anything else required for your loved one's care. For example, I use a multi-subject notebook organized by specialist for taking notes at every doctor's appointment. I also have a folder on my computer for documents regarding my daughter's health issues such as test results, published studies, articles and more. Getting organized allowed me to access the information that I needed quickly, and helped me feel more in control of a situation where feeling out of control had become the norm.

**♥ Do Your Own Research** Knowledge truly IS power. You need to do your own research online so you know what questions to ask the doctors. Start by finding and reading the Clinical Practice Guidelines on your daughter/husband/parent's medical diagnosis. Search online for "Clinical Practice Guidelines, the diagnosis." As you extend your online research, stick to reputable websites such as the Mayo Clinic, Family Doctor, Drugs.com, and MedlinePlus. If you can get to a conference run by an organization that specializes in your loved one's diagnosis, get there! The more you know as a caregiver, the better you can help your family member. For example, I attended yearly conferences on my daughter's genetic disorder. I would get first-hand knowledge of updates in cardiology and other relevant specialists. I often went to appointments armed with information that was more current than my daughter's doctors!

"Your daughter has a genetic disorder."

**♥ Know Which Medical Specialists to See** One of the most overwhelming parts of a new diagnosis is identifying which physicians who are considered the "experts" and who to see. In the beginning, you will probably depend on the first doctor who diagnosed your family member to lead the way. After a while, you may find your own experts through other caregivers and doctors. If you are lucky, you have a doctor who oversees and coordinates care with the various specialties. More often, like what I found out, you will become the coordinator for all the doctors. Many times, there are so many specialists involved that none of them has a complete body of knowledge and understanding of a complex medical condition. I did the research and learning necessary to decide which specialists to see when my daughter had a new health issue, such as when her cardiologist saw scoliosis on her heart x-ray. I made an appointment with a spine expert without consulting our primary doctor. It can save you lots of time to go directly to a specialist. Keep in mind that your insurance company may require a referral.



Coley and Natalie Brobin Bonfig

**♥ Become a Medical Expert** As the main caregiver of your loved one, you need to become a medical expert on his/her diagnosis so you can make the right decisions for him. You keep track of everything from blood work, test results, and notes from visits at numerous specialists. You do your research to understand your loved one's health problem. You know exactly what to look for in the test's results. Over time, I knew what to look for on the echocardiogram that my daughter had every six months. I took on the title of "Medical Mom" early on because that's what I was!

**♥ Follow Your Intuition** If a physician or other medical professional tells you something that feels wrong, listen to your intuition. In caring for my child, I learned that doctors do make mistakes and that it was important for me to be in tune with and to trust my own intuition. My husband and I were both uncomfortable with our daughter's first cardiologist and his advice. Our daughter was having symptoms of heart failure, and the doctor we saw dismissed our concerns. Upon pursuing a second opinion, we found ourselves facing emergency cardiac surgery for our infant daughter. After that experience, I was selective and outspoken with doctors. If I was not comfortable with a given doctor, I would find another one. I recognize that we live in a large metropolitan area and not everyone has that luxury of choices. In any case, don't be afraid to question the expert, or speak up as often and as directly as necessary until you feel heard.

**♥ Find Your Tribe** You will need support. The unique stressors of caring for a loved one with a chronic or serious illness cannot be understated. Many people in your life will not be able to relate to what you're going through. It's not their fault—it's true that walking a mile in your shoes is necessary to appreciate the full picture. Those who are in a similar caregiving role are the ones who can fully appreciate your experience. This is your new or extended family. There are support groups everywhere! If it's a more common illness, you may find one at a local hospital. Another great place to look is with a patient advocacy organization related to their condition. I found the Turner Syndrome Society of the United States (TSSUS) early on and found moms and dads who completely understood what our family was going through. Facebook groups are another great place to find support.

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## Many Thanks to Our Donors & Members

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

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

### Individual Donors Jan 1 - Sep 1, 2018

Cynthia Abrams  
Teresa & Doug Acrea  
Jacqueline Adsit  
Wendy Agricola  
Barb & Wally Alaspa  
Jessica Aldrich  
Jason Altvies  
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6 Things, continued from page 12

Much of the knowledge I have shared here, I learned in moments of desperation during the past 22 years. I began to see what a difference my research made in my daughter's life, so I kept going. She is an amazing young woman who does not let anything stop her, certainly not her health conditions. She will soon be a college graduate, and she has an exciting future ahead of her!

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 these six important things:

1. Get Organized
2. Do your own research
3. Know which medical specialists to see
4. Become a medical expert
5. Follow your intuition
6. Find your tribe

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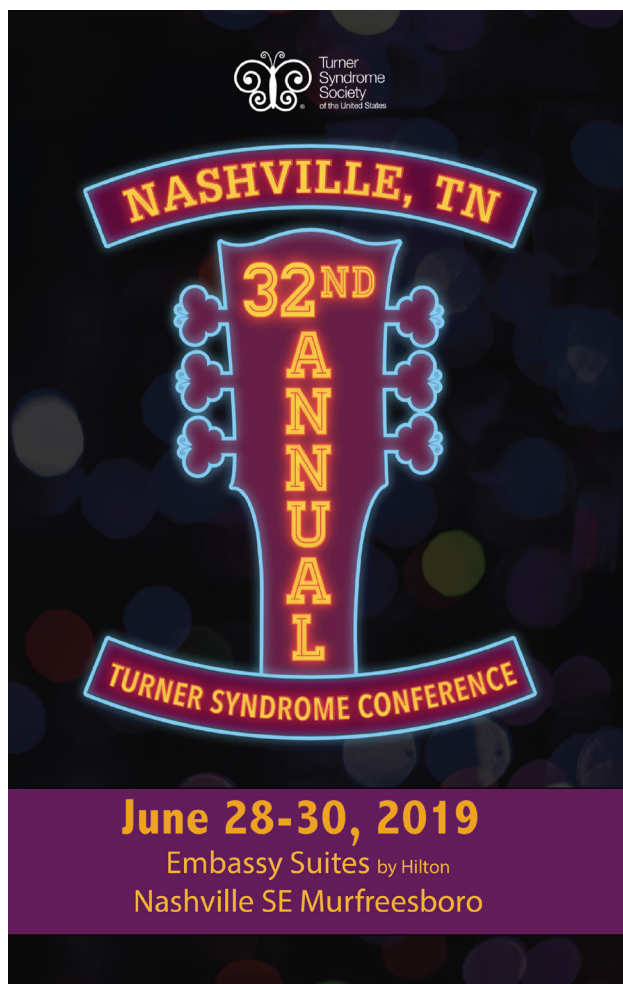
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