

# tss CONNECT™

Turner Syndrome Society  
of the United States  
Fall 2017



2017 TSSUS Conference

New TS Resources - 6

History of Butterfly & TSSUS - 15

  
Turner  
Syndrome  
Society  
of the United States



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 2017

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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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## Message from the President

This time of year inspires me to daydream about new opportunities. School has started, and whether you're a parent, student or both, September is a month of preparing. I find myself rejuvenated and inspired by those I recently met at the conference, either for the first time or those who feel like family to me. I daydream about how I'll react when the 1,000th person fills out the Turner Syndrome Research Registry (TSRR) survey; how the community will respond when we announce the first researcher project for the TSRR; how someone's doctor will read the new *Clinical Practice Guidelines for the Care and Treatment of Girls and Women with Turner Syndrome* (TS Care Guidelines) and provide better care; and how those in Atlanta will feel meeting someone with TS for the first time at a TS Days event. I am anxious and excited to have both of my children away from home at college, after sweaty move-in days and a home that is now too quiet.

Whatever this time of year holds for you, enjoy and take a little time to daydream about the good things coming your way.



### TSSUS Updates:

My title has changed from Executive Director to President of TSSUS; Carol Crawford's title has changed from Board President to Board Chair, and Emily Havrilak's title has changed from President-Elect to Chair-Elect.

The conference was a huge success! Be sure to read the highlights in the centerfold here.

The record-breaking number of almost 800 indicates that receiving quality information from TS experts, connecting with others, and leaving feeling positive and empowered is of great value to the TS community. I want to point out that almost 400 girls and women with TS attended the conference and had the opportunity to create lifelong support systems.

The Turner Syndrome Research Registry now has 545 completed surveys. This month, a data analyst will review the information entered and carefully determine if there are any mistakes. For instance, someone accidentally entered her age as "1" instead of "21", and a few parents created records for both themselves and their daughters. We expect that researchers may begin accessing information in the TSRR as early as September. This is exciting news!

The Healthy Heart Screenings performed by Dr. Silberbach and his volunteer team of echocardiographers and staff performed 107 ultrasound scans on attendees' hearts at the TSSUS Conference. They identified issues of concern with 5 individuals, and consulted with them and/or their parents about issues that needed to be followed up on by their personal cardiologists.

Videos of recorded sessions from the conference will be available soon, graciously sponsored by the TSSUS Minnesota Chapter. This year we'll add captioning for the hearing impaired on select videos. Videos from past conferences are available for you now in the resources section of our webpage at <http://www.turnersyndrome.org>.

We announced the location and dates of both the 2018 and 2019 conferences so that you may start planning ahead to attend this invaluable event!

Sincerely,

*Cindy Scurlock*

Cindy Scurlock, TSSUS President

# Recent Accomplishments

TSSUS works tirelessly to support the TS Community. As evidenced in the release of our 3-year Strategic Plan, TSSUS advances knowledge, facilitates research and provides support for all touched by Turner syndrome. Here are some highlights of our recent accomplishments:

## Expanding evidence based TS Research through the Turner Syndrome Research Registry (TSRR)

Participating in the online registry (TSRR) empowers you to make a difference.

In 2014, TSSUS identified the need for a national TS registry and made it a reality at the July 2016 Conference. TSSUS, along with other endorsing organizations, have encouraged 545 participants to enter their personal Turner syndrome health information. The registry is unique in that patient's control who may have access to their personal information, now and for years to

come. Online questionnaires are created by TS researchers, and then patients and families enter their responses. The TSRR allows researchers to learn more about TS and recruit participants more easily, which advances TS research – a priority for TSSUS.

### What we have learned so far:

- 69% of participants are under 5 feet tall
- 40% have a heart abnormality
- 40% have a hearing impairment
- 38% report having a 45X karyotype
- 36% have a visual impairment
- 32% have a vitamin D deficiency
- 3% are 5'4" or taller



**“Evidence-based medicine is the integration of best research evidence with clinical expertise and patient values.”**  
Sackett D et al.

In addition to the registry, TSSUS supported eight TS research studies through participation, promotion, and funding assistance.

TSSUS initiated and coordinated the TS Patient Advocacy Survey that will soon be published in medical journals.

TSSUS Conference attendees participated in research studies resulting in two key journal articles: *Describing Lymphedema in Turner Syndrome* and *Aortic Dimensions in Turner Syndrome*.

## Supporting the Turner Resource Network (TRN)

TSSUS meets monthly with TS researchers, physicians, and patient organizations to advance TS research. Recent accomplishments of the TRN include:

- Revised *Clinical Practice Guidelines for the Care and Treatment of Girls and Women with Turner Syndrome (TS Clinical Care Guidelines)*

- Collaborated to create the Patient and Family version of the *TS Clinical Care Guidelines*

TSSUS co-presented the Health Needs Survey of the TS community to 60 TS experts to ensure those with TS were viewed as individuals and not just subjects

TSSUS co-coordinated and sponsored the highly successful 2016 International TS Symposium. The 2½ day meeting hosted the most knowledgeable physicians, researchers and patient advocates, from Europe and the U.S., to discuss the latest recommendations for health care and well-being for the TS community.

## Serving You as the Premier Source of TS Information & Connections



- Served as the TS lifeline by responding to more than 5000 calls and e-mails.
- TSSUS website supported more than 186,500 different people.
- TSSUS online Professional Directory listed 200 TS providers and TS clinics by state.
- More than 385 people attended 44 TSSUS local meetings in 21 cities.
- Supported 19 TSSUS local groups with guidance and resources to hold events and meetings.
- Offered \$9,500 in scholarship funds for college, conference, enrichment opportunities and memberships.

**“I entered the dance party with two girls around my age who I just met at dinner... the room was transformed into an exclusive dance club only for girls with TS. It was in that transformation that I gained a new sense of pride and confidence about being a girl with Turner Syndrome.”**

**Elsa 2016  
(TSSUS conference)**

- TSSUS presented at the 2016 International Turner Syndrome Society Conference in Cancun, Mexico.
- Created awareness to more than 1,500 people through the *Chasing Butterfly Walks* for TS.
- Collaborated to create “Understanding a TS Diagnosis” with Lettercase, (a project funded by the NIH).
- Co-host the TSSUS and TSS of Canada message boards, supporting 912 users.
- Served more than 600 people at the 2016 Conference and almost 800 at the 2017 Conference, with many of the conference session videos available online.
- Issued three *TSS Connect* Newsletters to support our membership and entire online community.
- Two (2) TSSUS TS Days are planned for 2017 in Atlanta and Houston, with multiple cities in the works for 2018.
- Three (3) Turner Topic Patient Guides are available on lymphedema, growth, and gynecological needs related to TS.

# Introducing the TSSUS *Butterfly Society*

An exclusive monthly giving program for supporters of Turner Syndrome research, education, awareness, and support programs.

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

The TSSUS *Butterfly Society* is an exclusive group of supporters who believe that every woman, girl, and family touched by Turner syndrome should have access to cutting-edge, up-to-date information, resources and clinical care guidelines, as well as the opportunity to connect with others in their area through organized social and educational gatherings.



## Why Give Monthly?

**IT'S AFFORDABLE.** By giving monthly, you invest what makes sense for you 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:**

- Quarterly 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
- Tickets to exclusive *Butterfly Society* receptions at future Annual TSSUS Conferences
- Complimentary TSSUS Membership for one year (at the \$10/month level and above)

## **Monthly Gift Levels**

\$5 • \$10 • \$20 • **\$30** • \$50

TSSUS is celebrating 30 years of serving the TS community. Please consider making a \$30 monthly gift in celebration of our anniversary, and join the TSSUS *Butterfly Society* today.



## **Appreciation Gift**

While the *Butterfly Society* will be an ongoing philanthropic program of TSSUS, founding members are being accepted until December 31, 2017. All founding members who participate at the \$10 per month level or above will receive an exclusively – commissioned, one-of-a-kind, hand-painted, decorative butterfly stone as a token of our appreciation.



**TSSUS Butterfly Society  
Founding Members**

**Monthly Donors**

Renee' Ailes-Casper  
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Anonymous  
Jolynn & Christopher Backes  
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Becky Barnes  
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Founding Members**

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**TSSUS Staff**

Becky Brown  
Deborah and Jimmy Rios  
Cindy and Billy Scurlock





# 10 Tips for a Successful School Year

## with Nonverbal Learning Disorder or Social Processing Deficits

Mysti Harrison, MS, TSSUS Board Member, Parent At Large

The start of school can be a stressful time for both parent and child. This stress can be magnified when your child has struggles with acquiring knowledge and understanding through thought, experience, and the senses. Nonverbal learning disorder, otherwise known as nonverbal learning disability (NLD or NVLD), is characterized by verbal strengths as well as visual-spatial, motor, and social skills difficulties. In short, NLD is a set of strengths and struggles that may not appear when your child begins school, but may reveal itself as the demands of education increase.

Your child may have great vocabulary and verbal skills, but may struggle with non-verbal communication like sarcasm, social nuances, and facial expressions. They may have poor motor skills (difficulty riding a bike, tying their shoes, handwriting and mathematics). Additionally, your child may display struggles with change, novel situations, and may experience anxiety and low self-esteem.

So, how can you help your child start off the new school year on the right track? Try these 10 tips and see how they work for you:

### 1. Educate your child's school on TS and NLD

Write a letter to your child's teachers and school staff explaining her strengths and challenges and how she best learns. You know her best. You may suggest they read the *Clinical Practice Guidelines for the Care of Girls and Women with Turner Syndrome* section on neurocognition and behavior.

### 2. Ensure your child is tested by the school to identify challenge areas and struggles (such as dysgraphia: a struggle with writing; or dyscalculia: a struggle with calculating) that can affect her learning

These struggles can be discussed during the IEP (Individualized Educational Plan) process. This will ensure the school understands your child's learning differences and how to best teach her. She may also qualify for ancillary services such as occupational or vision therapy.

### 3. Get organized and stay organized

Make sure your child's learning space at home is comfortable to her. Store homework and school supplies out in plain view. Find an organization system that works for her, and stick to it! This could be a binder with dividers, a folder system, or an accordion portfolio. Color coding is also very helpful. Help your child organize papers in the right area or binder daily.

### 4. Encourage the use of a planner

Many schools require students to use a planner, but filling the planner out weekly from the board in the classroom can be hard when you have special organizational issues. Ask your child's teacher to provide a hard copy of the week's expectations, and spend time helping her transfer that information into her planner, one-on-one.

### 5. If your child struggles with handwriting, speak to your school about typing and dictation programs

Often the IEP will identify special accommodations to support or supplement weak handwriting skills. There are several dictation and typing apps available that are free or inexpensive. These are especially helpful for projects.

### 6. Practice the layout of your school prior to the first day

Learning the lay-out of a new school can be especially challenging. Before the first day, visit the school and rehearse where the classroom's, bathroom's, nurses' office, gym, principal's office, library, and cafeteria are located. If your child has a lock for their locker, practice opening it. You may want to request a keyed lock instead of a combination lock for ease of use.

### 7. Ask for an alternate testing environment, and/or untimed testing

Not all students need or want this accommodation, but it may be very helpful. Some schools may simply allow a child to sit in a location that is more quiet than where she usually sits, or she may receive permission to sit in the library or a quiet room nearby, while other schools may require an IEP plan.

### 8. Monitor your daughter's grades online or by email with her teacher(s)

This can help you identify subjects or areas of study she may be struggling with immediately so that there is time to make adjustments before report cards are issued.

### 9. Communicate!

Communicate with your child, her teachers, the staff that work with your child's IEP or RSP services, and others in the school environment. Have frequent meetings to stay abreast of things that are going well and things that may need added attention or adjustments. Speak with your child about what is going well and what she feels she is struggling with. Encourage your daughter to talk to her teachers about her needs, when age appropriate.

### 10. Be positive

School can be difficult. Between the social interactions and the learning demands, it can be a daunting task. Be positive with your child, and make sure she knows you're a team and that you're going to work hard to make this year the best year yet!

Remember, your daughter with Turner syndrome may have some unique struggles, but she also has unique strengths. Use your daughter's strengths to overcome her struggles. Struggling with memorizing multiplication facts? Try 'School House Rock'. Struggling with social skills? Practice at home in fun and silly ways as you 'pretend' to be her peer and work through situations together.

If you have any questions, feel free to email me at [mysti@turner-syndrome.org](mailto:mysti@turner-syndrome.org). I would be more than happy to help!



# The Creator's Butterfly

By Katie and Nikki Rinkliff

(Dedicated to all the lovely women  
with Turner syndrome like me)

I want you to know, My love,  
My precious butterfly,  
That I have always loved you.  
I've seen every tear you've cried.

You are not a genetic accident,  
mishap, or mistake.  
You are not some type of error  
that humans tend to make.

See, I knitted you together  
within your mother's womb.  
I designed every part of you  
as on a master's loom.  
Because . . .

You are created in My image,  
a reflection of My glory.  
I have not forgotten you.  
I am the Author of your story.

When your body seems against you,  
and your fight is all but gone,  
I will never leave you,  
and My arms are always strong.

From medicines to hospitals,  
and doctors day after day,  
I will be your comfort.  
All you have to do is pray.

When you find yourself locked down in fear,  
and scenarios fill your head,  
Take them all and lay them down  
at My feet instead.

Anxiety can feel like torture.  
It is the devil's greatest game.  
But I will hear your anguished cries  
calling out My name.  
Because . . .



You are created in My image,  
a reflection of My glory.  
I have not forgotten you.  
I'm the Author of your story.

You may not think you're glamorous,  
But you are the apple of My eye.  
Your beauty is transcendent.  
You don't even have to try.

Beloved, I know you mourn the loss  
of the children you cannot bare,  
But I will grant you countless ways  
to show the world your care.

So whether you have one, two, three, or four . . .  
or maybe no children at all,  
I still designed your family.  
Take heart. Be glad. Stand tall.

And know you are My masterpiece,  
A treasure I call "Mine",  
There's not one hair I do not know.  
I made you special by design.  
Because . . .

You are created in My image,  
A reflection of My glory.  
I have not forgotten you.  
I am the Author of your story.

# Chasing Butterflies Walk

Cassopolis, Michigan



by Brandy Shelby

On December 11, 2015, my sweet girl was diagnosed with Turner syndrome. As you all know, along with the diagnosis come the “what ifs” the endless, sleepless nights researching, the ultrasounds, the echoes, the blood work, the MRI’s, the doctors, and prayer ... lots and lots of prayer. I prayed God would bring peace to the storm, and that He would protect and care for Leah. I prayed He would bring



answers, acceptance, and guidance in this diagnosis.

The Turner Syndrome Society of the United States was a large part of this answered prayer. Shortly after our first

rounds of doctors’ appointments, we learned of a TSSUS *Chasing Butterflies* Walk in Fort Wayne, Indiana.

We attended, and the underlying theme I heard there was that “God doesn’t make mistakes.” We met with other women who have also had the diagnosis, and listened to all of their stories. Now, in May, five months into the diagnosis, I was finally not afraid. God brought answers and acceptance, and He was guiding my heart to be more involved.

In July, we hosted our own TSSUS *Chasing Butterflies* Walk in Cassopolis, Michigan. Family and friends went above and beyond in their support for Leah, and the local community did not hesitate to lend a helping hand. Deborah Rios and the TSSUS team were wonderful, helpful, and very patient. If you



have not attended a walk, I strongly encourage this.

Leah has made friends that understand what it’s like to attend so many doctors’ appointments. She talks about the BIG discussion. GROWTH HORMONE SHOTS. They have discussed heart surgeries and failed hearing tests.

It was so precious to hear Leah say, “**Mom, it is awesome to see other girls just like me.**”

We love to hear what other little girls are doing to raise awareness and to be able to talk to other moms that understand

and can calm your fears. It is so beneficial to talk to other women to get advice on hormone replacement therapy and the road that lies ahead. It is a great feeling when you come to the place where you can be that voice others are praying for in their new diagnosis they had just received.

Hosting a walk is a great way to bring awareness and raise money for a cause that is so dear to our hearts.

This year we held our second annual TSSUS *Chasing Butterflies* Walk in Cassopolis, Michigan on July 8th, 2017. TSSUS went above and beyond in supporting our efforts. We are beyond thankful for the Turner Syndrome Society and the instrument you are that is used to bring peace. From the bottom of our hearts, thank you.

## Coming to a City Near You

*TS Days*™ are local TS community events coordinated by the national office of the Turner Syndrome Society of the United States. They will be launched in cities across the country beginning with Atlanta, Georgia on September 16, 2017 and in Houston, Texas on October 14, 2017.

*TS Days* are free, local, one-day events that include an educational presentation by physicians, health care providers, or a panel of peers, as well as a social opportunity to create friendships within the TS community.

*TS Days* events are the perfect opportunity for parents and newly diagnosed girls, teens and women with Turner syndrome to come together to learn and laugh in a welcoming and warm environment.

TSSUS is committed to local events and creating opportunities for the TS community to make meaningful connections across the country.

### We are considering host-cities for 2018 now!

What we’re looking for:

- Cities/regions with a high number of TSSUS members and supporters
- Cities/regions with lead volunteers on the day of the event
- Cities/regions with suitable and wonderful places to host a *TS Days* like a park, zoo, or an indoor entertainment facility with meeting space

If you would like to talk about volunteering or suggest a location, please reach out to Stephanie Kirksey, TSSUS Events & Program Manager at [stephanie@turnersyndrome.org](mailto:stephanie@turnersyndrome.org)





# 30th Annual TSSUS Conference

The 2017 Turner Syndrome Society of the United States Conference in Denver, Colorado was an astounding success!. We had almost 800 people attend, with hundreds of new faces. There were 40 break-out sessions on topics ranging from Orthodontics to Fertility with more than 20 presenters and panelists. We would like to recognize the TSSUS Minnesota Chapter for sponsoring the video recording of many of the sessions, which will soon be available for all on [www.turnersyndrome.org](http://www.turnersyndrome.org).

Dr. Michael Silberbach and his team conducted the Healthy Heart Project study for the 13th year offering 107 free echo cardiograms to conference attendees, and identifying five individuals with issues that required immediate follow up or monitoring with their cardiologists. Please join TSSUS in thanking Leaping Butterfly Ministry for sponsoring the Healthy Heart Project at the conference this year.

Dr. Dean Mooney of the Maple Leaf Clinic offered 30-minute complimentary consultations with conference-goers on living with nonverbal learning disorders, and was a presenter in several break-out sessions, including the yearly favorite, For Dads Only.

In the General Session, we were all treated to a performance by YouTube sensation Cimorelli. Band member Amy Cimorelli has Turner syndrome,

and she, her sister Katherine, and mother Lynn were at the conference all weekend and had a great time with our community. Amy and Lynn even emceed the talent show!

TSSUS President, Cindy Scurlock, Board Chair-Elect Emily Havrilak, and Board Treasurer Sarah Sullivan presented the Society's Annual Report in the Annual Meeting Saturday morning. Becky Brown, TSSUS National Director of Development and Communications, appealed to TSSUS membership to come on board as donors in the newly-founded TSSUS *Butterfly Society* monthly giving program, and is pleased to report that 86 conference attendees answered the call!

80s Karaoke Night was a big hit, with attendees belting out tunes from Dolly Parton's "9 to 5," to "Footloose." The Saturday evening *Time of My Life* dance party had everyone on the floor reliving the 80s with Michael Jackson, Journey,



## TSSUS Minnesota Sponsors Conference Sessions Video Recordings

TSSUS would like to thank the TSSUS Minnesota Chapter for sponsoring the video recording of several sessions at the 2017 Turner Syndrome Society of the United States Conference in Denver, Colorado. One of the key tenets of TSSUS is to extend the educational reach of the annual conference by providing professionally recorded sessions for publication on [www.turnersyndrome.org](http://www.turnersyndrome.org) so that everyone can benefit from this valuable information.

Julie Leon, TSSUS Minnesota Chapter Leader shares "Our chapter has grown tremendously, and through our fundraising efforts we've been able to bring a lot of girls and women from Minnesota to the TSSUS conferences. We want our support to reach beyond those that can attend the conferences so that this valuable information can reach as many people as possible."



# Conference Raises the Bar!

Bon Jovi, and more, while the quieter Coffee Shop allowed attendees to visit while listening to softer live music.

Mandy Thomas and her team at Gallery on the Go provided attendees with fun and relaxing painting experiences with their make-and-take exhibitor booth, Thursday and Saturday evening Butterflies and Brushes Paint Nights, and by sponsoring four Intentional Art break-out sessions for women and teens with TS. We would like to give big "thank you" to Mandy and her team for their sponsorship this year.

Conference Coordinator, Shawn Wier, shocked the ballroom of almost 800 people Saturday night when she announced

not only one, but the next TWO locations for the Turner Syndrome Society of the United States Annual Conference. The 2018 conference will be held in Arlington, Virginia (Washington, DC), from July 13-15, 2018, and the 2019 conference is heading to Nashville, Tennessee from June 28-30, 2019.

The Turner Syndrome Society of the United States would like to recognize Lilly as a major supporter of this event, and would like to additionally recognize NovoNordisk and Genentech.



## A Family's Experience

by Jessica Hynes

This year, our family attended the 2017 Turner Syndrome Society conference all together for the first time. My husband, Jeff and I, usually try to make it a special event by attending only with Clare (our TS girl). I was surprised at what an impact the conference made on our other 4 children, especially the older ones. Not only did they have a TON of fun, but they also told me how much they enjoyed seeing how other girls and women with Turner syndrome were having fun and loved hearing them sing, seeing them dance and enjoy spending time with each other. They loved seeing Amy Cimorelli and how talented the girls in the band are. My second daughter also said it was so neat to see Clare bond and play with other girls with TS.

Clare is so lucky to have 3 sisters and a brother that love her unconditionally, and who really don't see her as any different than them. They just loved supporting her and her fellow TS sisters at the conference and will continue to do so hopefully every year. We will continue to try to attend the conference as a family, when possible, since it makes such a positive influence on both Clare's life, and the rest of our family. Thank you for the great efforts you all make to put on such wonderful event every year! It is greatly appreciated!

# Golden Butterflies Interview at the TSSUS Conference.



By **Becky Brown**

We sat down with Dorothy Baume, Barb Flink, Linda Kalb and Donna Rice at the recent 30th Annual Turner Syndrome Society of the United States Conference in Denver to chat about how these conferences have enriched each of their lives over the years.

These ladies have attended almost of all them, and are considered the Golden Butterflies of TSSUS.

**TSSUS: Ladies, can each of you share your thoughts about how the TSSUS conference has helped you or improved your life in some way?**

**DB:** The friendships I've developed, meeting other women who I have something in common with – all so very valuable. The sessions have provided valuable information as well as contacts that I've benefited from.

**BF:** Because of TSSUS conferences, I am much more confident, I know some wonderful people, and I have more medical knowledge.

**LK:** They have given me great guidelines for my health. They also continue to provide me with updates for my health when things change. They have introduced me to wonderful friends, expanded my social connections greatly, and they keep my skills sharp when I work as a volunteer on committees.



**DR:** Every time I come home from a conference, I bring something new. It might be a new piece of medical information, or I might have met someone who encouraged me in some way. I always feel like I come back motivated to follow through on something.

**TSSUS: Why do you think it's important to attend year after year?**

**DB:** Each year I find I meet new people and build on old friendships. I communicate with some of the women often - and have even found friends to travel with. I continue to learn new things every year that I take home and share with my care providers. Conference is definitely like a family reunion. I always participate in the research opportunities that are offered. They are so important in helping my fellow sisters advance medically in the future.

**BF:** To see my Golden Butterfly Buddies, and to stay involved!

**LK:** To keep informed of medical updates and the discovery of new information. To meet new people and make new connections – both medical and social.

**DR:** There is always something to be learned. You never know who you might meet (or meet again) who will touch you in a very special way. Each conference has a different “feel,” and the social aspects are (to me) just as important as anything else.

**TSSUS: What is your fondest memory from one of your conference experiences?**

**DB:** Learning that I have encouraged or been a role model of sorts by sharing my story. It's truly amazing how small this world is - and through helping others, it gets even smaller.

**BF:** Relaxing by the pool after the conference in San Diego in 1994, and sightseeing in San Francisco before the conference in 1998.

**LK:** I have two. The first was at the very first conference in 1988 in Minneapolis. My mother has always been a wonderful support for me, and she was with me. We met two ladies in the baggage claim area right after getting off the plane. They are the first women with TS I'd ever met. One had written the article my father read in a newspaper that led me to TSSUS – her name was Dru Davis, and the other was the second President of the Society – Barbara Tiemann. My second fondest memory was after the Denver conference in 1992 when I connected with a whole bunch of friends on the East Coast after the conference. We decided then that we would always add a vacation to the end of conference. It was a turning point for me.

**DR:** It was seeing Trudy McCarthy (former Board President) carrying in our flag at the 2000 International conference.

**TSSUS: If you could talk to your 15-year-old self, what would you say?**



**DB:** I certainly wish my family and I would have known about this when I was younger. Being born in 1953 I had no idea TSSUS was there until the mid to late 90's. I am so glad I took the time to become a part of this group that has so much added to my life, and helped me become a better person, as well as the knowledge I share with my care providers... that on top of the support I have received is just priceless.

**BF:** Don't worry so much about what other people think of you. You don't have to “try so hard.” You are okay. You are just as capable as everyone else. Not everything that happens to you is because you are short. Those well-meaning adults that tell you “Don't worry, you'll grow” ARE WRONG! Don't stop taking estrogen hormone replacement therapy until you are well into your 50's. Take probiotics and Imodium for your digestive problems.

**LK:** I would say “you will find the name of the condition you have when you enter college. You will discover it for yourself in a college text book.” I would also say “your father will read a newspaper article when you are 33 years old that will mention TSSUS – this will be your introduction to TSSUS and the very first conference in Minneapolis in 1988.”

**DR:** Be patient with yourself, and demand that you at least try your best. You have a lot going for you - don't be afraid to show everyone! Try new things.

**TSSUS: What advice or encouragement would you offer to a young girl with Turner syndrome?**

**DB:** Reach for the stars! There's nothing you can't do. I didn't have the advantages that the girls have today, such as growth hormones,

ear tubes, etc. Use having TS to your advantage. Learn about your body and listen to it - be aware and listen to your doctor to make sure they are listening to you. After so many years, YOU do know your body best.

**BF:** Be yourself. Not everything that happens to you is because of TS: You can be whatever you want to be.

**LK:** Live life to the fullest. Keep informed with TSSUS conferences. Make as many friends at the conferences as possible with TS, and at home with non-TS people. Keep pushing to be your very best that you can be

**DR:** You are a gift to all who know and love you. Make use of all you have to be amazing!



**TSSUS: When you meet a parent with a daughter who was recently diagnosed with TS, what do you usually share with them?**

**DB:** I find they usually want to know about my experience ... when was I diagnosed, what was I able to accomplish - what kind of life have I lead. I mention TSSUS to them and encourage them to be part of our family. We are there for support, we are there for information and wonderful resources.

**BF:** Have the same expectations for your daughter with TS that you would have for any other daughter. Your feelings about your daughter's infertility, and how you deal with it, will greatly affect how she will deal with it.

**LK:** I would explain that TS has a variety of different conditions that their daughter may or may not have in varying degrees. Follow the TSSUS *Clinical Care Guidelines* for check-ups and come to conference.

**DR:** I suggest they have the same concerns for their daughter they'd have for any child, medically and psychologically. Expect her to have challenges, but they may be different even among "average" Turner girls. I also tell them my own parents treated me as normally as they could, expecting me to "at least try."

**TSSUS: Now, most importantly ... will we see you in Arlington, Virginia in 2018?**

**DB:** You betcha!!!

**BF:** Absolutely!!!!

**LK:** Yes, as long as my mom's health continues!

**DR:** Arlington? 2018? Like I'd miss it!



## Family Conference First-Timers



This was our first TSSUS conference and it really was life changing. We gained so much information about TS and how to help our daughter be successful in life, not to mention the new friendships we gained. The TSSUS Conference was such an incredible experience for our family!

Brooke & Andy Long

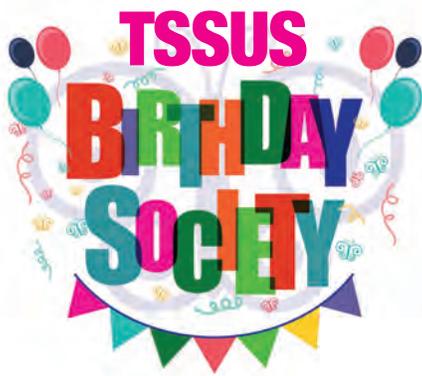
## Blue Jeans for Butterflies

TSSUS *Blue Jeans for Butterflies* is coming soon. This turn-key fundraiser makes supporting TSSUS fun! We're looking for team leads to organize *Blue Jeans for Butterflies* single-day events in their workplace or school, starting late Fall.

This is a great event for Turner Syndrome Awareness Month in February. TSSUS will have BJFB kits available online soon that include everything you need to host your own BJFB event. E-mail [becky@turnersyndrome.org](mailto:becky@turnersyndrome.org) for more information.



Turner Syndrome Society  
of the United States



# Birthday Society Winners!

Have you registered for the TSSUS *Birthday Society*? This fun new program celebrates you on your special day! All you have to do is register online at [www.turnersyndrome.org](http://www.turnersyndrome.org) by either updating or creating your profile.

Each month, one winner will be selected by a random drawing and will receive a box of Baked by Melissa bite-sized cupcakes delivered to their front door.



May 2017: Zara Rivett



August 2017 Winner:  
Ellie Bekkerus



July 2017 Winner:  
Madylin Walker



June 2017 Winner:  
Kelly Emmett

## My TS Story – Gabriella

I was 12 years old when I found out I had TS. I was not diagnosed when I was born. I was a preteen getting ready to enter high school. I was old enough to know how this would affect my life and that it would be something that would make me “different” from the rest of the world. When you are 12 years old, the last thing you want to be is “different.”

I was mortified that this would now define me everywhere I went. I thought I might as well be wearing a sign on my forehead saying “Hi everyone! I have Turner syndrome!” I cried for days after I found out. But then, as time went by, I started to realize something. This doesn’t make me so different from anyone else. Sure, I am on the shorter side, and it may take me a little longer to grasp certain academic subjects (math specifically). HOWEVER, I didn’t have to share the fact that I had TS with everyone I met, and it was not something someone was automatically going to know just by looking at me.



If I wanted to share this piece of me with someone, I could. But otherwise, I didn’t have to tell anyone anything. This is just something that makes me, *me*. I can still do the same things other girls my age do. I can still have the same conversations and like the same things. Having Turner syndrome is part of me, but it does not define me. And, truth be told, I love that I have it. It is what makes me unique and special. It has also helped me love myself more, as well as others for who they are. It has honestly, I believe made my heart grow 10 sizes.

This will have been 6 years since I’ve been diagnosed, and will be a first time college student this fall at Naropa University. I have jumped over so many hurdles to get here. So yes, it is possible for girls with TS to succeed and go to college, or write a book or become a veterinarian. Whatever it may be, you can do it. This is such a special community of strong, powerful, beautiful women, and I am so honored to be one of them. Go get em! Keep on shining, butterflies.

by Gabriella Bauduy-Salinas

# History of the Butterfly as a Symbol for Turner Syndrome

by Becky Brown

Today, the butterfly is recognized around the world as the symbol for Turner syndrome. We even refer to ourselves as butterflies, butterfly sisters, and golden butterflies. Many people ask how this came to be.

In 2010, the Turner Syndrome Society of the United States decided to update the organization's logo. The four circles of the original logo represented 4 cells dividing. One of the things we often heard from the community was that the logo looked like a butterfly.

The four circles of the former logo have evolved into the wings of the iconic butterfly of the Turner Syndrome Society of the United States logo known around the world you see today. This evolution connects our past to our present. The butterfly is feminine yet

strong like our members. Butterflies fly on their own, which is what we hope all of those with Turner syndrome will do with TSSUS forever providing support.

The Turner Syndrome Society of the United States is proud to have created the connection between the butterfly and Turner syndrome so well known today.



The Butterfly Symbol is a registered trademark of Turner Syndrome Society of the United States, and may not be used without the expressed approval and written permission of TSSUS.

## My TS Story – Kim

My name is Kim DuBoise. My story is still being written, literally and figuratively. Really! I have begun writing about my life with TS. Needs a lot of work, though! I am so glad to be able to share with you just a little bit



about myself. I was diagnosed before birth, and had to have open heart surgery at age three. While on the operating table, I had a near-death experience where I saw myself on the table and I was floating above it. I could see out of the room into the hall and hear people talking. Remembering this experience and focusing on

what it means to me has shaped my life in many ways. I struggled with esteem issues and shyness growing up.

I still do not like crowds. I have had a time with doctors understanding what I want and why, in regard to hormone therapy, bone density scanning, etc. So frustrating! Now I am writing and subbing in primary grade classrooms. I taught preschool for ten years and now want to make writing my way to express myself and support myself. I have self-published books of poetry, am co-author in several books, and have made peace of mind and self-acceptance my priority. I love to travel with my husband, to write, and cook. I have learned to accept all of myself and embrace my journey, and it has not been easy. It is my hope that girls with TS learn to embrace their gifts and share their heart and their talents with others. That's my story, so far!

by Kim DuBoise



**A BIG thank you to the 31 people who signed up at our 2017 Conference in July. We have hit our first goal of more than 500 completed surveys. Hurrah!**

We have 200 people who have started but not completed their registration. Are you one of them? Email [Natalie@turnersyndrome.org](mailto:Natalie@turnersyndrome.org) to find out.

How many people would we like to have register for the TSRR? As many as we can!. In the next six months, we would like to see another 2,000 participants join. We easily have that many people in our database, so if you are reading this and you haven't yet signed up, please do. There are approximately 80,000 girls and women in the US who have Turner syndrome. We would love to reach half of that number.

If you need any help with the TSRR, please call the national office at 832.912.6006 or 800.365.9944, or email [Natalie@turnersyndrome.org](mailto:Natalie@turnersyndrome.org). There is also a Step-by-Step Guide on the TSRR page at [www.turnersyndrome.org](http://www.turnersyndrome.org) website for help filling out the registry, along with Frequently Asked Questions. We are here to help.

Look for updates on Facebook and in the bi-weekly e-newsletter describing what we have already learned from current participants.

by Natalie Bonfig



# Membership in TSSUS



by Becky Brown

For thirty years, TSSUS has been empowering, educating, and supporting the Turner syndrome community through a variety of programs, resources, research, local events, our comprehensive website, and the Annual Turner Syndrome Society of the United States Conference. Our mission is to advance knowledge, facilitate research, and provide support for all those touched by TS. Our vision is that every woman and girl will have cutting-edge health care, ensuring the best quality of life.

You can be a part of this mission by becoming a member of the Society. TSSUS membership is available in three levels: Individual, Family and Professional.

## As a member, you:

- Become a part of the TSSUS Member Directory, which allows you to connect with other members who live near you or have shared interests
- Become eligible to apply for a variety of scholarships, including the Annual TSSUS Conference, hearing aids, and life enhancement (which can include anything from a summer camp or high school trip to guitar or cooking lessons), become a voting member for at-large board of director positions, and become eligible to run for a position on the Board of Directors.
- Receive a significant member discount on the Annual TSSUS Conference registration fee
- Receive a 20% member discount in the TSSUS online store

## But your TSSUS membership does so much more than that

Consider the woman approaching middle-age who has never met another with Turner syndrome, and attends the TSSUS Annual Conference for the first time and feels a sense of belonging unlike anything she has ever felt.

Consider the pre-teen who is yet to be diagnosed. Her mother searches the internet for “short-stature” and finds our website, which leads her to a diagnosis in time to find a significant cardiac issue.

Membership in the Society is about more than the benefits you receive directly. It’s about the girls and women your support allows TSSUS to reach; it’s about the Research Registry; it’s about others with TS out there who are looking for a connection with a community of friends and supporters. It’s about someone being there – for thirty more years.

Please visit our website for more information about becoming a member of the Turner Syndrome Society of the United States at [www.turnersyndrome.org](http://www.turnersyndrome.org), or call 800. 365. 9944

## The Unseen Benefits of Your TSSUS Membership:

“Thank you for the creation of a wonderful website that shows the possibilities for those living with Turner syndrome. My husband and I have been trying IVF with preimplantation genetic testing following 4 early pregnancy losses. We hoped this would reduce our heartache with future pregnancies. We were recently asked to sign consent for the clinic to destroy the embryos that had chromosomal issues. Something stopped me from blindly consenting, and I requested to see the results showing which chromosomes were affected. In amongst the mix of abnormalities that weren’t compatible with life, I found one Turner syndrome embryo. It’s the first time I’ve heard of the condition, and I set about looking on the internet for information. I have to admit that reading the Wikipedia entry scared me a little. But coming back today to look for more information led me to your website. To see so many happy smiling faces of young girls, combined with the eloquent firsthand accounts in your newsletter, brought such a human touch to our decision. Thank you for opening my eyes to the possibilities of life with Turner syndrome.”

a visitor to our website August 18, 2017



# The Changing Landscape of TS nonprofits and the Turner Syndrome Society of the United States

The Turner Syndrome Society of the United States (TSSUS) got its start in 1987 as a nonprofit organization focused on bringing the TS community together. Our focus was then, and still is today, to support communities across the country with TSSUS resources, opportunities, local groups, and volunteers. As a national organization, our aim is to be a resource for everyone in the Turner syndrome community across the country. TSSUS advances knowledge, facilitates research, and provides support for all those touched by Turner syndrome.

Based on questions I receive on a regular basis from our supporters and the TS community in general, I wanted to spend a moment to add clarity to this subject.

Much has changed in the last 10 years with respect to some organizations that began as TSSUS affiliated groups. Several of the volunteer leaders of these groups disaffiliated with TSSUS and created wholly separate nonprofit organizations, with varying mission statements and focus areas, while often relying on the resources and supporters gained when conducting official TSSUS business.

This means that financial support for Turner syndrome from traditional funders has become quite fractured. Some of our donors and supporters have expressed confusion, and even some have sent donations to other organizations thinking they were supporting TSSUS.

In the interest of clarification, the Turner Syndrome Foundation, Walk for Ferriall, Turner Syndrome Global Alliance, Turner Syndrome Colorado, Turner Syndrome of the Carolinas, and the Turner Syndrome Kaleidoscope Walk, are not affiliates of the Turner Syndrome Society of the United States.

Collaboration is a key tenet in the TSSUS Strategic Plan. We recognize that there is a great deal of work to be done, and that there are several organizations in the TS community with whom to collaborate to advance our mission. We will continue our dedication to working with others in the TS community who share our spirit of reciprocity, financial transparency, and dedication to advancement of Turner syndrome treatment, support, research, and quality of life for all touched by TS.

As a 501(c)(3) nonprofit organization, we hold ourselves to a very high standard. Thoughtful and considerate stewardship of our donors' dollars is of the utmost importance. We are dedicated to transparency, and invest in a thorough financial audit each year. It is in this spirit that we make this audit and our IRS Form 990 available on our website at [www.turnersyndrome.org](http://www.turnersyndrome.org).

If you have any questions about TSSUS, our history, our mission, our strategic plan for the future, our financial transparency policies, or how you can support our work, please contact me. I welcome the interaction and feedback.



*Becky Brown*

Becky Brown, TSSUS National Director of Development and Communications

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# Our Graduates

Please Join TSSUS in Congratulating these Butterflies Who Recently Graduated from High School or College

**Katherine Sierra Go** was born fighting! She has slain many giants in her life and continues to overcome challenges with the grace and poise of an “old soul.”

This past May, Katherine graduated from the Go Christian Academy. She qualified for the dual credit program at Lone Star College, and plans to attend Lone Star college full time in the Fall. She plans to pursue a degree in either pediatric nursing or special education.

Katherine has a life-long love of working with children. She’s been involved in serving others through a local food pantry/clothes closet, Sunday school, various mission trips, singing in choirs and serving as a camps counselor. She spent the summer working as a children’s swim coach for her swim league, which she loves! In Katherine’s words, “Go Class of 2017!”

My name is **Emily Mosher**. I was diagnosed with Turner syndrome when I was three. Nineteen years later, I graduated from Central Washington University with a Bachelors degree in interdisciplinary studies. My goal is to use my degree to become a social worker. I am looking forward to what is coming my way in the future.

Congratulations to Arizona Resource Group Leader **Kelly Shea Jasper** on her graduation from Arizona State University. Kelly graduated Summa Cum Laude with a Bachelor of Science Degree in Integrative Health from The College of Nursing and Health Innovation.

**Kylee Hay** graduated from West Broward High School in Pembroke Pines, Florida. She will be attending Palm Beach Atlantic University in the fall with plans to study secondary education and musical theatre. She is received honors for GPA, Chorus, and Thespians.

**Shelbi Weible** is a 2017 graduate of West Hardin High School. She lives in a small town in Southeast Texas. Diagnosed with Turner syndrome in 2013, Shelbi plans to attend Lamar University.

**Toni Farrell** graduated from the University of Miami in 2017 with a Bachelors of Science - Microbiology & Immunology, a Bachelors of Arts - Economics, with minors in chemistry, biology, health sector management and olicy and dance.

Toni graduated with departmental honors. In microbiology. Her family is incredibly proud of Toni’s accomplishments. She was diagnosed at age 10 with mosaic Turner syndrome. Toni has never let her diagnosis stand in her way as she pursued her dreams and ambitions. In addition to her high academic achievements, Toni is also a champion Irish Dancer and has competed at the national and world level. Toni is currently applying to Medical School, and her family is excited about where her dreams will take her.

**Carly Wubben** graduated from Iowa Falls-Alden High School. She plans to attend the SAVE program at Iowa Lakes Community College this fall.

**Morgan Parsons** graduated from Cypress High School in May. She is ready to further her education in college and make a positive impact on the world!

**Lena Marie Nanasy Hull** - When my beautiful daughter was born in 1982, I was immediately told something was wrong. I received so much bad news and back then things were more grim than they are today, thank God. But my daughter has grown into a very smart and beautiful lady. I hope all the new mothers get better news these days and all the negativity has been stopped. God Bless every woman, especially those with Turner syndrome.

**Lizzie Kunesh**, a graduate of Jay M. Robinson High School in Concord, NC, will be attending UNC-Chapel Hill in the fall where she plans to double major in Peace, War & Defense and Contemporary European Studies. Lizzie’s dedication to Girl Scouting earned her the Norma Cannon Hayes scholarship, having completed her Gold Award project in 2016. Lizzie is an AP Scholar with Distinction and has held her #1 academic rank through her high school years. Lizzie enjoys playing clarinet, singing and theater and looks forward to joining the Marching Tarheels in the fall.



# Tribute Ads

Express yourself with a heartfelt message to someone you love and admire.

For details, email [becky@turnersyndrome.org](mailto:becky@turnersyndrome.org)



*Brooke Kaczynski*

So proud of you, enjoy your sophomore year of college and "Be your best you!"

Love Mom, Billy and Ally



*Madi Harrison*

**Happy Sweet 16 Madi!**

Mom and Dad are so proud of you. We love you!

*Alicia Graham*



**Happy Birthday Sweetie!**

You'll always be our miracle! Love Mom & Dad

**We ♥ Our Volunteers.**

**Thank you, Dorothy**



**In loving memory of Cheryl Foust**  
TSSUS Board of Directors



Happy Birthday,  
**Janet!**

You'll always be our miracle!  
Love, Mom & Dad



I'm so proud of you

*Clare!*



Love, Daddy.

**Congrats!**

**Jenn**

**We love you!**



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