Dear Friends and Families with Turner Syndrome:

We are excited to announce our special Summer 2016 edition of the Turner Syndrome Clinic newsletter. You will hear from girls, women, friends, and family living with Turner Syndrome who attended the Turner Syndrome Society of the US (TSSUS) National Convention in Cincinnati and the Boston International Turner Syndrome Summit (BITSS).

This summer, the MGH Turner Syndrome Clinic was fortunate to have Caitlin Sullivan helping us in the clinic. Caitlin attends Saint Anselm College and is completing a baccalaureate degree in nursing. This newsletter is one of the many projects she has been involved with.

SPECIAL ISSUE: SUMMER IN THE CITIES, TS ON THE MOVE
Volume 3, Summer 2016

A Message from the Reporter:

Hi!
I'm Caitlin Sullivan. I am a 19 year old rising sophomore, and I have Turner syndrome! This past summer, I spent 6 weeks as an intern for the MGH Turner Syndrome Clinic. Besides learning more about Turner Syndrome, I learned about genetics in general.

This newsletter was my personal project. It was fun for me to ask others about the TSSUS conference, having attended 8 of them myself. The friends I have made through the meetings are some of my best friends- anywhere!

Hope you enjoy this as much as I enjoyed speaking with everyone!

2016 TSSUS Conference:
“Team Turner - Up for the Challenge!”

615 girls and women living with Turner syndrome and their friends and families gathered at the Turner Syndrome Society of the United States Conference from July 22-24 in Cincinnati, Ohio.

Everyone was excited about the sports theme, “Team Turner Syndrome”. During the 2-day event, there were talks from educators, physicians, and self-advocates (women with Turner Syndrome) discussing medical problems, physical characteristics, genetics and learning challenges. There were also innovative presentations on personal growth, career development, coping and lifestyle.

These conferences always emphasize having fun and socializing with old and new friends. Of course, we all learned so much.

The scientific symposium (Turner Research Network, TRN) followed the family meeting and brought together researchers from around the world to revise the current Management Guidelines. (Bondy et al., JECM, 2007)
Two Special Moms and Daughters

Sarah Sullivan is the Treasurer of the TSSUS, and you guessed it—my mom! When asked why she volunteers, she said: “Because I have a strong devotion to promoting a health plan for women and girls with TS and working with a group of people who share this passion. I have learned that I am not alone, and that everyone has different challenges. We share more than our differences; we treasure what makes each daughter special.”

And “What makes me special?” I asked key mom. “What is my strongest quality?” My mother replied, “My favorite thing about you is that you look at the world as a glass half-filled, always positive.” Like mother, like daughter!

Cindy Scurlock is the Executive Director of the TSSUS, and mother of Brooke. Cindy became Executive Director in 2007 and “oversees and executes what the board determines the needs of the TS community.” She first learned about Turner Syndrome the day Brooke was born. “At the time,” she remembered “the hardest part about the diagnosis was that Brooke would probably not have children. The rest of the diagnosis did not make sense to me, but that stuck in my mind.”

“What is your favorite thing about Brooke?” I asked. “What makes Brooke so special?” “Her optimistic attitude! She can find the positive in everything and everyone.”

Turner Resource Network (TRN) Symposium: Updating the Management Guidelines

Health care providers use guidelines to help them care for people with Turner syndrome. The most familiar are those published in 2007 by Dr. Carolyn Bondy of the NIH (and available on the TSSUS website). This summer, an international group of TS experts gathered in Cincinnati after the TSSUS Conference to update this information. Dr. Angela Lin, Co-Director of the MGH Turner Syndrome Clinic, was Co-Moderator of the Section on Genetics.

She was thrilled with the quality of information and the lively discussion among caregivers and researchers from around the world. An attempt was made to use evidence from research studies, in addition to personal experience. For the future, larger collaboration among centers will provide better data to make decisions. The new guidelines should be published in 2017, and of course, will be widely shared.

Conference in a Cocoon: What Fun!

“I enjoyed going to the session by Kathy Montag: Transitioning from Middle to High School.” –mom from MA

“I’m looking forward to the new experience, making new friends, and creating a good relationship between the Turner Syndrome Boards of the US and Denmark.”–woman from Denmark

“The dance is always a favorite.” –woman from TX

See you next year in Denver!
Daddy’s Girls

Everyone loved the father’s performance of “My Girl”. I asked a few dads what they believe makes their daughter special:

“I love her positive outlook on life.” – Father from MA

“She is such a persistent person. When she decides to accomplish a task, she will not be denied.” – Father from MI

These dads truly know and love their daughters.

The Butterfly’s Other Half

Love is in the air! I had the chance to speak to a husband from Alabama. “It’s kind of a funny story. One of my wife’s girlfriends and my buddy starting dating. Her girlfriend disclosed that her friend (now, my wife) had TS, so I learned about TS indirectly from my buddy.”

His favorite thing about his wife is her “bright outlook about the world that is infectious.” How sweet!

Sibling Love

“My sister is always fun and has taught me how to be brave.”–sibling from NY

“Living with a sibling with Turner Syndrome is not any different than living with anyone else because it’s what I’ve always known. Plus, I get to go to cool conferences every year!” –sibling from TN

Young Caterpillars Turn into Butterflies

“Anaheim was my favorite conference. It was fun because it was a girly theme and I was still a little girl.”– Teen from the South

“I liked just getting to meet other girls with the same thing.”– Teen from the Northeast

Every Butterfly Needs Friends to Help Her Fly

The bond that women with Turner syndrome share is incredible, beyond explanation. Among those attending the conference were the senior lady “veterans” who call themselves the “Golden Butterflies.” One told me that she loves “just being with other people who understand the connection and giving lots of hugs”.

If there is a downside, many women said they struggle with their infertility. A young woman from Illinois agreed that the hardest part of learning about Turner Syndrome was “hearing that I’m probably not going to be able to have kids.” Another insight was provided by my Texan teammate who noted, “the medical aspects are actually easier and not as obvious to the public. At least for me, the social challenges are what I struggle to deal with.”

This honest sharing is what makes the conference so special, and gives us support found only here.
Seven days at Boston University. Four mentors. Twenty participants.

The mission of Boston International Turner Syndrome Summit was to give teens with TS a chance to truly connect with their peers. This year’s BITSS attendees came from all over the world – one girl even traveled from “across the Pond” – and shared different experiences of living with TS. Despite the geographic differences, all looked forward to meeting other teens in their age group. Some of the highlights included movie night, Karaoke Night, and a Mocktail Painting Party. We learned how to apply winged eyeliner at a local cosmetics store, saw “Cuisine and Confessions” at the Emerson Cutler Majestic Theatre, and walked the Skywalk Observatory at the top of the Prudential Center. Taking advantage of Boston Harbor, we went on a whale watch tour, swam and hiked on Spectacle Island. More fun was spent visiting the Isabella Stewart Gardner Museum, Harvard Natural History Museum (where we sang the Moose Song in front of a giant Moose), eating out a lot, Zumba, meditation and yoga. And always, the fun of getting to know each other.

Whew. What a week. It’s safe to say, “Mission accomplished, BITSS!” See you next year!

About the author

Hi, everyone!
I wanted to introduce myself. I’m a senior in a Boston area high school who attended BITSS this summer. Loved every moment of it, especially “Cuisines and Confessions”.

In addition to enjoying my hometown, I have two Labradoodles. In my free time, I love to read and write. I hope to study psychology or secondary education with a focus in English in college.

I hope you enjoyed reading this as much as I enjoyed talking to everyone and writing this!

Your friendly BITSS reporter

What the BITSS campers have to say

“I loved meeting so many new, wonderful TS sistas.”

I made a lot of friends. Thanks so much!!! You changed my life.

This week was a memorable experience for me. I felt like I have gained independence and made new friends.

“I thought it would be a great way for me to gain more independence before I go off to college.”