A New Look for the New Year!

"YOU ARE PERFECT JUST THE WAY YOU ARE"

Article by Karen Freedle

AND MORE INSIDE!
I am excited to be starting my role as the President of the TSSUS Board of Directors after 5 years serving on the board. Our family had been very active in TS locally after Abigail, my 15-year-old, was diagnosed with TS. However, as always happens in life, I was busy with other things and became less involved. In 2010, Brenda Gruwell, whom I had met at local Atlanta Chapter meetings, called to say that one of us should consider a board position. At first, I was unsure, but I thought about how much the society had meant to me when Abigail was diagnosed and how wonderful it has been to meet other parents and women with TS in Atlanta, so I decided I needed to give back. It was one of the best decisions I have ever made. In 2011, I began serving the TSSUS Board as Treasurer. While I like to think that I’ve made positive contributions to the Society during my service, I know that the Society has made innumerable positive contributions to me, Abigail, and all of us in the TS community.

When I was less involved in TSSUS, I lost sight on the larger picture – the need for more TS research, more community support and better clinical guidance on issues Abigail and other women with TS may face in the future. I also lost sight of the connections we all make in the TS community – friendships and bonds that last a lifetime. TSSUS had not lost sight and I feel lucky to now be able to contribute to this work. Looking back on just the 5 years I’ve served on the board, I can see how much TSSUS has continued to grow. What excites me most is looking at our strategic plan and seeing the exciting work coming up to support our 4 primary goals:

- Ensuring that all girls and women with TS receive quality healthcare regardless of age, location, or finances
- Supporting patients, families, and professionals to ensure successful adjustment to all stages of TS
- Expand the knowledge about TS through research
- Facilitate a heightened awareness and understanding of TS, its effects, and possibilities

Each day so much work occurs in the office supporting these goals – from answering the phones, to helping local groups have meetings, working with the professionals on new TS guidance, helping setup Chasing Butterfly walks, putting on the TSSUS conference, or getting ready to roll out the new TS Registry. The hard work of Cindy, Deborah, Shawn, Stephanie, Cheri, and Barb cannot be overstated – these women are truly dedicated to our TS community.

If you have any questions about TSSUS or the TSSUS Board, please feel free to reach our directly to me at CarolCrawford@turnersyndrome.org. Your board is here to serve you, do not hesitate to reach out to me or any board member.

Carol Crawford
TSSUS President

RECENT NEWS

Kinsley Stavinoha, of The Circles of Hope Foundation, hands Cindy Scurlock a $20,000 check to benefit TSSUS. Their foundation held their 1st Casino Night.

COVER PHOTO

Clare enjoys herself at a TS Annual Event while being held by mom. She will be turning 3 this year - how time flies!
TSSUS 29th ANNUAL CONFERENCE 2016!
JULY 22-24, 2016 | CINCINNATI, OHIO

The Turner Syndrome Society of the United States cordially invites you to join us for our 29th Annual Turner Syndrome Conference. This year, our theme is “Team Turner: Up for the Challenge.” Emphasis will be placed on overcoming obstacles of TS and becoming a champion for your own healthcare.

TSSUS members! Watch your mailboxes in early March for an informational brochure highlighting the weekend’s activities, along with information on the hotel, transportation, youth program and more!

Be sure to regularly check the conference page at www.turnersyndrome.org for more detailed information as it becomes available!

PHOTOS FROM LAST YEAR’S NATIONAL CONFERENCE IN KANSAS CITY
Left: Three Butterflies pose after their Thursday evening dinner at Union Station.
Center: The sibling group enjoyed a visit to Science City after decorating t-shirts.
Right: The Lilly Exhibit full of activities.
SOCIAL COMMUNICATION
A brief overview of the 4 Steps of Communication. Compiled by Beckham Linton M.A., CCC-SLP.

Social communication is a complex, multifaceted concept that begins simply with a shared thought. Most people initially think social communication is all about ‘talking’, but it is a lot more than just talking. It involves looking, thinking, moving, listening, and regulating ourselves based on the thoughts and feelings of others. The process of social communication has at least 4 basic steps. These steps, defined by speech language pathologist, Michelle Garcia Winner, (Think Social Publishing) are as follows:

1. Think about the people with whom you want to communicate.
2. Use your body to communicate your intention.
3. Use your words to relate to people when you talk to them.
4. Use your eyes to connect with people as you relate to them.

These steps happen in order when we first meet someone, but we process and respond to the information we gather about a person through these steps simultaneously as the relationship grows. Let’s look at each of these steps more closely.

Step 1: Think about the people around you and what they might be thinking.
Have you ever met someone who just won’t stop talking about themselves or who only responds to you with very short answers, i.e., ‘Yep’, ‘I don’t know’. Do you know people who are perpetually late or who laugh too loudly or too long? Do you have friends or family members who stand too close or interrupt others in the middle of their conversation? If you answered ‘yes’ to any of these questions, you may know someone who is experiencing social communication challenges.

Step 2: Use your body language to communicate your intention.
Physical presence sends the message that we want to communicate, others are feeling comfortable or anxious, whether we are open or closed-off to the conversation. If we see a group of people whom you admire and would like to get to know better, it’s important that you know at least one person with whom you have a positive connection in that group before attempting to join that group. Otherwise, they may not willingly accept you into their conversation.

Step 3: Use your words to relate to people as you talk to them.
Commenting on what we observe going on around us: People walking out of the group, therefore you must make sure your own strengths or interests match those of the people in the group you are wanting to join.

Step 4: Use your eyes to connect with others.
Once we read the thoughts and intentions of others around us, use our eyes to connect with others, our language helps us know people who are perpetually late or who talk too loudly or too long. If we consistently stare at someone from across the room without any directed and constant eye gaze at work communicates a sense of not being interested. Conversely, too much eye contact can leave the wrong message with others. Understanding that everyone has strengths or interests is an excellent resource written by Michelle Garcia Winner.

This book would be very helpful for anyone who struggles with Nonverbal Learning Disability and wants to learn to overcome these challenges. The format also lends itself to a group discussion. Local TS groups might enjoy working through this together.

BOOK REVIEW: COMMUNICATING NONVERBALLY
- Thea and Shawn Wier

Communicating Nonverbally: A Practical Guide to Presenting Yourself More Effectively is an excellent resource written by Kathryn Sue Young and Howard Paul Travis. It would be very helpful for anyone who wants to improve their communication skills.

POSITIVE ELEMENTS:
* Provides practical, real-life examples and gives solutions for working through various situations.
* Reviews and explains different types of nonverbal communication, such as body language, touch, and personal space.
* Gives the reader, through workbook format, the opportunity to think through and analyze their own communication skills.
* Text is very straightforward and easy to understand.
* Includes chapters on nonverbal communication in an educational setting, professional setting, and in interpersonal relationships.

This book would be very helpful for anyone who struggles with Nonverbal Learning Disability and wants to learn to overcome these challenges. The format also lends itself to a group discussion. Local TS groups might enjoy working through this together.

Find it at textbooks.com for only $12!
PERFECT JUST THE WAY YOU ARE
- Karen Freedle

My story is really pretty typical. I grew up in the suburbs of Boston in a very loving and supportive family. They gave me my love of learning, deep religious faith, optimistic attitude, commitment to serving others, and confidence to be independent.

Unlike most Turner Women, I grew up not knowing I had Turner syndrome. My life proceeded in an ordinary fashion. I loved my family, my church, and school. Learning was fun for me, and I was, and still am, a voracious reader and learner. In elementary, middle school, and high school most subjects came easy to me, with the exception of Geometry.

I always knew that I was slightly different from other people. I found interacting with my peers a little awkward, and sometimes found it difficult to make friends. Although I did have select close friends growing up, with whom I am still in touch today. I was, without a doubt, the shortest person anywhere I went, and was very often teased and bullied for it, too.

I remember being brought to the Height & Weight Clinic at Boston Children’s Hospital when I was a young child, as I was nowhere to be found on the growth chart. It’s funny, because I remember them offering to put me on growth hormone (at that time growth hormone was desiccated pituitary), but the doctors changed their minds, saying that I would eventually “catch up” to my peers. My reaction was, “Right... I’m never going to grow.” I guess I was just that perceptive, even as a kid.

Adolescence hit, and I kept waiting for the expected changes, which seemed to take forever. They finally happened at about 16 years old with normal breast development and very light and extremely irregular periods.

Life continued, and I decided on a career in health care, and was encouraged by my family to enter a career in Nursing at the University of Virginia. My first semester there, I threw myself into my studies. Always an overachiever, I took a Master’s level history course, and a business “weed-out” course in statistics. I didn’t do well. I failed the Master’s level history course and the statistics course. This was pretty hard on me, as I’d never failed in school in my whole life. But, in true Turner syndrome determined fashion, I picked myself up and moved on, and did very well the rest of my time in college. Incidentally, my college roommate, who was also a nursing student, also had Turner syndrome.

After graduation, I took a job working on a Medical Surgical Unit at New York University’s Tisch Hospital. Within 9 months, I realized my calling was actually in the field of medicine, so I took a risk and returned home to Boston to take pre-med courses. I took to them like water, earning a nearly perfect 4.0 in the pre-med classes, but the damage to my GPA had already been done due to that first semester in college. My undergraduate advisor told me I would never become a physician, especially not one at a University like I had hoped. He advised me to apply to off-shore medical schools. In some ways, he was right, but again in true Turner determined fashion I was not discouraged. I applied to every medical school and Doctor of Osteopathy school in the United States, but did not receive a single interview. Still undeterred, I then applied to off-shore medical schools and enrolled in Ross University in Dominica, West Indies in August of 1995. Living in a third-world country was a true culture shock, but I did pretty well there both academically and socially. I helped start a tutoring program and a Catholic Students Association, which, I’m happy to say, is still in existence today.

One of the proudest and most defining moments of my life was in February of 1999 when I took the Hippocratic Oath, was hooded, and became a Doctor! This was the culmination of a life-long dream and the beginning of my career in medicine. I also decided that I was meant to dedicate my life to the care and welfare of children, and entered Pediatric Residency in 1999. During Residency, I noted that I had to work a little harder at communication and social interactions than some of my peers. Networking and such things came so easily to them, but I had to work at it. I also realized that I struggled somewhat with physical procedures like blood draws, lumbar punctures, and suturing. Again, I had to practice to do well at what seemed to come so easily to others.

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NEW ECHOCARDIOGRAM ROOM AT TCH

Two Turner syndrome fundraising groups in North Houston, Leaping Butterfly Ministry and Circles of Hope Foundation, have partnered to sponsor the Echocardiogram Room for Texas Children’s Hospital. TCH is building a new hospital in the area and their sponsorship will spread awareness of Turner syndrome to everyone who enters the room with a dedication plaque and artistic mural.

TS RESEARCH PUBLISHED IN JOURNAL OF LYMHOLOGY

“Describing Lymphedema in Females with Turner Syndrome” was published in the Journal of Lymphology, Volume 48, Issue 3 in December, 2015. This has been the culmination of research beginning in 2013, when Jana Rothbauer, OTR, CLT-LANA, attended the Dallas, Texas, TSSUS conference. The study gathered information through an online survey about lymphedema as it is experienced in girls and women with Turner syndrome. There were a total of 219 participants from the United States, United Kingdom, and Canada, creating an international representation.

The article may be viewed in its entirety at http://www.u.arizona.edu/~witte/lymphology.htm.

TS RESEARCH REGISTRY TO LAUNCH IN 2016

We’re so excited about launching the TS Research Registry this year!

A registry is a place where official records are kept. The Turner syndrome registry will store answers (provided by patients and families) and allow TS researchers to access them. The unique part of the registry is that the person that fills out the information owns the information. That means that you get to share your answers with as few or many researchers as you choose.

The Turner Syndrome Research Registry is part of a larger registry system called PEER, which stands for Platform for Engaging Everyone Responsibly.

The new Turner syndrome registry will be the one place that the entire TS community can use to support TS research with personal records. The Turner Resource Network will approve researchers and support the goals of the registry. The Turner Syndrome Society of the United States will fund the registry needs. Much more information will follow as we get closer to launching the registry survey the first half of 2016.
The 2016 Turner Resource Network International Symposium will take place immediately following the TSSUS conference, on July 24-26, 2016. The TS community is invited to attend the symposium.

The purpose of the symposium will be to update the Turner Syndrome Clinical Practice Guidelines. This is the document that health professionals should follow to ensure quality care for their patients. The guidelines will be expanded to include important topics that were not included in the previous guidelines, and an additional document will be created so that patients and families will be able to understand the standards of care without having to get a medical degree.

Dr. Philippe Backeljauw, TSSUS professional advisory board member, and Dr. Claus Graveholt, of Denmark, are chairing the symposium. More than 45 professional and advocacy delegates will convene to determine the best treatment options for those with Turner syndrome. The Turner Syndrome Society and the Turner Syndrome Global Alliance are working together through the Turner Resource Network to co-sponsor the 2016 symposium.

DID YOU KNOW?

Hearing loss affects a large percentage of the TS population. There are two types of hearing loss that girls and women with Turner syndrome may experience.

The TSSUS website has added NEW RESOURCES on hearing loss! It includes college scholarship information for the hearing impaired, hearing aid financial assistance programs, and learning about hearing loss.

To access these resources, simply visit www.turnersyndrome.org and select ‘Resources’ from the menu bar.

TS PROFESSIONAL AND PATIENT RESOURCES

TSSUS will be mailing out informational cards to you to give or mail to your physicians as a reminder that various TS resources are available!

WHAT IS THE TURNER RESOURCE NETWORK?

The Turner Resource Network (TRN) is the result of a collaborative effort of scientists, clinicians, and TS advocates (individuals with TS and family members), aimed at improving the quality of health care for those with Turner syndrome. The TRN’s goals include establishing TS guidelines and promoting excellence in health care delivery, determining which TS research studies will be coordinated with the Research Registry, and supporting regional centers to provide quality healthcare and research opportunities. The success of meeting TRN goals is dependent on the collective efforts of the Turner syndrome community (such as advocacy organizations, providers, and researchers) to identify objectives and collaborate on projects that support the timeline and needs within the TRN.

The TRN program can be viewed as an umbrella program assisting in coordinating multiple individual projects that are independently sponsored by a group or person.

Current projects coordinated through the TRN include:

- The Turner Research Network Registry (TRNR), a patient-powered registry which aims to be a large database containing, demographic, clinical, imaging and genetic information formed by combining 4 existing TS cohorts as well as limited self-reported data from the TS community.
- In 2017 the registry will aspire to import researcher-obtained data back into the TRNR.
- Quality TS Resource Centers
- Quality care documents for Professional TS Care Providers
- The 2016 International TRN Symposium with the goal of revising the TS Clinical Practice Guidelines.
**FALL REGIONAL CONFERENCE**

*Held in North Carolina This Past October*

The Turner Syndrome Society's North Carolina Chapter held a regional conference, "Bloom, Grow, Blossom" at the end of October in Charlotte, NC. There were over 110 attendees from all over the east coast including Pennsylvania, Maryland, and Florida.

The children's program included more than 30 participants. They learned about TS and social acceptance. After lunch, 20 girls enjoyed an afternoon of bowling.

Speakers included Dr. Jessica Lord Bean, Courtney Strauss, Dr. Jennifer Law and several of her colleagues involved with the TS Clinic at UNC-Chapel Hill. Some topics presented were TS & Cardiac Effects, Executive Function, Self-Image, and Auto-Immunity & Infections in Turner Syndrome.

**NEXT YEAR'S REGIONAL CONFERENCE WILL BE HELD IN RALEIGH, NC!**

Information can be found on our website beginning in March at www.tsnorthcarolina.wordpress.com or the TSSUS events page at www.turnersyndrome.org.

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**PATIENT EDUCATION DAY IN SUNNY CALIFORNIA**

The Central and Northern California Turner Syndrome Resource Group hosted their yearly TS Patient Family Education Day on Saturday, November 14, 2015, at Peace Lutheran Church in Sacramento. There were approximately 60 TS girls, women and their families in attendance to listen to Mitchell Geffner, M.D., of Children’s Hospital of Los Angeles speak on growth, diabetes and metabolism in Turner syndrome.

The other speakers included Catherine Devine, Genetics Counselor, who spoke on “The Genetics of Turner Syndrome,” and Mysti Harrison, Parent-at-Large Board Member, who spoke on non-verbal learning disability. Our members also enjoyed a wonderful catered lunch, and this event was made possible by generous funding from Eli Lilly, Genentech, Novo Nordisk, Pfizer, and Sandoz.

These TS Patient Family Education Days have been held over the past 25 years at Lucile Packard Children’s Hospital at Stanford, Valley Children’s Hospital in Madera, and Sutter Memorial in downtown Sacramento. The resource group tries to move these information days around to various locations, so that all of our members can enjoy attending and listening to the various speakers. These information days were originally started about 25 years ago by Rosemary Starr Morris, and were first held at Lucile Packard in Stanford.

**FAMILY FUN DAY**

The Northwest Panhandle Resource Group celebrated their 2nd Annual Family Fun Day with smiles while raising awareness.

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**HB CARES EVENT**

TSSUS President-Elect, Emily Havrilak (right) and Dianna Fuller (left) at the HB Cares event in Minnesota.

Dianna, who works with Helms Briscoe, is instrumental in helping us locate and secure our annual conference hotels. Thank you, Dianna, for supporting the TS community!
CELEBRATING THE SEASON TOGETHER
Good food, good friends, and lots of hugs and smiles!

PHOTOS ABOVE
The Middle Tennessee Support Group celebrated at The Gondolier, in Murfreesboro, TN. Along with conversation and laughs, the ladies enjoyed a "dirty santa" gift exchange.

PHOTOS ABOVE
Ladies from the Northwest Florida Panhandle Resource Group enjoy each other's company at their holiday party, while remembering Amber Gallo.

PHOTO ABOVE
The ladies from the Orange County Chapter enjoyed an evening of holiday festivities!

PHOTOS
The Kansas City Chapter enjoying an evening of fun, accompanied by a plentiful pot-luck feast!

PHOTOS
The ladies from the Orange County Chapter enjoyed an evening of holiday festivities!

HOLIDAY PHOTOS
Cover model Clare, and Mom pose for Holiday photos. Clare is now two years old and happy as ever!
Fundraising

THE NATIONAL WALK
Chasing Butterflies: The Walk for Turner Syndrome

TSSUS helps individuals organize walks in their own communities to bring awareness to Turner syndrome. These walks benefit the initiatives of research and support and the national office receives 100% of the proceeds after expenses.

We are excited that twenty-one walks were held in 2015, resulting in over 1400 participants and about $80,000 in registration fees and donations! Because of these wonderful coordinators, TS is more known in these communities and the proceeds were so great. We are grateful to each one, including their teams of volunteers and all the participants.

Ashleigh Dorfman with Nation’s Capital R.G.
Sarah Shutt with Central Virginia R.G., Fredericksburg, Virginia
Ashley Abbott, The Villages, Florida
Brittany Rayoum with St. Louis R.G., Belleville, Illinois
Cathy Neely, Lebanon, Ohio
Cheri Svêgerko, Conference Walk in Kansas City, Missouri
Darlene Hay with Butterflies of S. Florida R.G., Pembroke Pines, Florida
Deanna Corey with Western Oregon R.G., in Auburn, Washington
Erica Bautista, Sacramento, California
Erica Melman, Elk Grove Village, Illinois
Glena Gibson with Oregon R.G., Portland, Oregon

Jennifer Viscaino, Redlands, California
Katie Vissker with West Michigan Chapter, Grand Rapids, Michigan
Kelley Valenzuela, Monahans, Texas
Kelly and Lisa Jasper with Arizona Resource Group, Scottsdale, Arizona
Kristina Reeb, Newark, Ohio
Lynda Taylor with Delaware Valley R.G., Newark, Delaware
Mikaysa Espista, Bryan, Texas
Patty Collins with Boston R.G., Boston, Massachusetts
Penny Sheets, Wilksboro, North Carolina
Sarah Sandven, Ft Dodge, Iowa
Tamyka Campbell, Davie, Florida

R.G. stands for Resource Group (formerly known as Support Groups.)

CHAPTER WALKS

Some TSSUS Chapter Leaders also held walks in their communities in which 80% of the proceeds after expenses remained with the Chapter for local goals (over $37,000) and 20% was retained by the national office for national goals (over $9,200.) We’re grateful for each coordinator and their teams in which over 450 people participated in the walks, raising awareness and funds.

Heather DeRousse, Houston Chapter
Julie Leon, Minnesota Chapter
Lisa Smith, North Carolina Chapter
Tamara Douglas, Colorado Chapter

FABULOUS SOCIAL FUNDRAISERS OF 2015

A social fundraiser for TSSUS is someone who creates a digital fundraising page for any walk they participate in and who receives donations because they share their story with TS, asking for support of TS and TSSUS. We thank these 187 individuals, whose efforts, combined with the walk coordinators, resulted in over 1,000 donations to the walks in 2015. They truly are Fabulous Fundraisers!

Alison Boettcher
Amanda Holguin
Amanda Pennington
Amy Zambrano
Ashley Titus
Audrey Bider
Barbara Beck
Barbara Pannerl
Beth DeCamp
Brandy Greening
Bresanna Hoadley
Brittany Rayoum
Caley King
Cara Holguin

Carla Darnell
Carol Crawford
Cheri Svêgerko
Cheryl Foust
Christina Rogers
Cindy Kenward
Dana Elizabeth Tucker
Deanna Lail
Deb Norkus
Dedre and Kevin Lock
Dominick Russo
Donna Rice
Dorothy Beume
Elaine Fraizer

Elizabeth Bubelnik
Erica Bautista
Erica Haag
Erica Melman
Erica Scheuder
Ferrie Kitchin
Heather Anne Gooch
Heather DeRousse
Heather Matz
Jamie Gomez
Jamie Stowe
Jean Frischer
Jen Czarneczki
Jennifer Lynn Spencer

Jessica Budahn
Jolene Manternach
Joni Ensminger
Josefina Jimenez
Karyn Willie
Katherine
Vivanco-Risner
Kathy and Ed Boyle
Katie Crestlove
Kelley Valenzuela
Kim Graham
Kris Fulkerson
Kristy Holben

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My diagnosis of Turner syndrome hasn’t stopped me in my personal life, is educating and empowering peers and patients. I feel it is important to and a published author of both research and a children’s book. My passion became a Pediatric Allergist working at prestigious academic universities, late puberty and irregular periods, difficulty with physical procedures, etc. short stature, difficulty with geometry, challenges with social interactions, With her support and encouragement, I made an appointment with the fellow Pediatric Resident), who also happened to have Turner syndrome. I discussed my concern with a trusted friend and colleague (a knew something was off, as there was 0% chance I was pregnant. I also Then, out of the blue, came another defining moment. At 31 years of age 1st Annual TS Chasing Butterflies walk in Fredericksburg, VA: Walking for Awareness. CHASING BUTTERFLIES IN VIRGINIA 1st Annual TS Chasing Butterflies walk in Fredericksburg, VA: Walking for Awareness. The Nation’s Capital TS Resource Group, in collaboration with the Central Virginia TS Resource Group, hosted the 1st Virginia Chasing Butterflies Walk and Picnic on Sunday afternoon, September 27, 2015 at Old Mill Park in Fredericksburg, VA. Approximately 15 people, including 6 girls and women with TS, attended the event. Members were from cities as far as St. Mary’s County, MD and Richmond, VA. To make the walk fun, they posted handmade butterflies, which were made at their previous picnic, with awareness postcards along the route; participants spotted the butterflies and took photos. Other walkers could read about Turner syndrome as they walked by. After the walk, participants enjoyed mingling and eating our potluck picnic in the pavilion. •

PHOTOS Butterflies and their families from the Central Virginia TS Resource Group joined together this past September. They posted handmade butterflies and awareness postcards at each of the pathway’s mile markers.

ABOUT THE NATION’S CAPITAL RESOURCE GROUP
We are the Nation’s Capital Resource Group of the Turner Syndrome Society. It is our mission to assist TS women and girls, as well as their parents/guardians. Our group serves Northern Virginia, Maryland and the District of Columbia. We meet 3-4 times per year, in which we host educational meetings and social events, such as our Annual Potluck Picnic. In 2015, in collaboration with the Central VA Resource Group, we hosted our 1st Annual TS Chasing Butterflies walk in Fredericksburg, VA. •

WALKS AROUND THE COUNTRY

JOIN THE CHASE
Upcoming Walks in 2016

The Villages, FL ........2/06
Hollywood, FL ........2/20
Birmingham, AL .......2/20
Sacramento, CA ......2/20
Destin, FL ...............2/27
Land O’ Lakes, FL ......4/16
Ft. Wayne, IN ..........5/14
MAKING MILESTONES: HOW I CAME TO TERMS WITH MY INFERTILITY

- Bailey Lynch

My name is Bailey. I am a twenty year-old, Michigan-born girl living with Turner syndrome. My chromosome number is 45x47xxx, an extremely rare case. Being this rare is both a blessing and a curse. It is a blessing in the sense that I miss out on most of the health defects: I don’t have the webbing on my neck, my hands and feet aren’t puffy, and I’m pretty much a giraffe at 5’3”. It’s a curse because when I do have certain health problems, it takes awhile to figure out what is going on because it doesn’t happen with most girls with TS. And up until about a few months ago, I would have considered the infertility that comes along with TS a curse as well.

I am very much aware of the fact that nearly all women with Turner syndrome have ovarian failure, and as a result, cannot conceive naturally. An extremely small percentage of women with TS are granted the ability to have kids. I would consider this a miracle for how unusual it is. These statistics don’t change the fact that coping with this inability can be very difficult. It certainly was for me, for the longest time. As women, we are raised believing that one of the biggest things that we will do, if not the biggest thing, is to become pregnant and have children. As a kid, I often wondered about who my children would look like more—me, or my husband. This idea is essentially ingrained into our minds, simply because we are female. Because we are women, we are immediately expected to reproduce someday.

When something complicates this, it’s not hard to draw the conclusion that we aren’t “real” women. I remember the day when I first really understood the concept of infertility. I was thirteen years old. I was in a doctor’s appointment and my mother and I were in one of those back rooms, waiting for the doctor to come in and talk to us about the possibility of jaw surgery for me. There had been a lull in conversation, and I was once again contemplating my future kids and who they might resemble more. I put this thought into words, and that was when I learned the truth: I didn’t have any eggs left, and therefore could not be a biological mother. This hit me hard. I felt like someone had taken a cinder block and pressed it onto my chest, creating an unmeasurable amount of pain. One of my childhood dreams had been taken away from me. I’ve never liked crying, and I especially don’t like doing so in a public place where people might see me and hear me, but I couldn’t force down this overwhelming amount of grief. I burst into a mess of hot tears. My mother held me as I fought to regain composure in time, before the doctor arrived. I managed to calm down, but I was dismal during the entire appointment and only uttered a maximum of five words every time I talked. I depended on my mom to do the talking for me.

I struggled with this insecurity for a long time. Sometimes I would keep it to myself, suffering silently. Sometimes I would vent to my mom. This usually consisted of lots of tears and almost yelling from my end. My mom would offer me advice and remind me that there were other ways of being a mom, but I didn’t listen. I couldn’t listen. I was too focused on the fact that I couldn’t do what I’d most wanted to do: be a biological mother. I’d become ashamed of the fact that I could not be a mother the “natural” way, and I held on to any string of hope that I might be able to be a biological mother, even if it was the slimmest chance in the world. I’ve never been good at accepting the fact that there are things beyond our control.

A big part of the issue also stemmed from a fear of judgement. What if people judge me for not being able to have kids? What if they say I won’t be a “normal” mother? And here was the real zinger: What if my boyfriend/fiancé/husband leaves me because we can’t have a family the “natural” way? As irrational as it sounds, this was one of my biggest fears, and I still sometimes worry about it, to be honest. One day, though, everything finally clicked.

I was lying on my bed in my dorm room, scrolling through my Facebook feed, when I came across a political compare-and-contrast cartoon. It showed one couple that appeared fit to have a family and wanted to adopt, but yet they were denied by the agency because they were a same-sex couple. The other couple was a man and a woman, but the major difference was that the house was in poor condition, and that when the man wasn’t abusing the kids, the children were running around and causing ruckus because the mother cared more about her well-being than the kids’. Yet, they had a seal of approval from an adoption agency. I remember looking at this and thinking “Gosh, that is no way to treat a kid; I would be a much better parent to those children than those parents right there.”

Suddenly, it clicked. It didn’t matter how the child was related to the parent: biological, surrogate, or adopted. That child is a person, and deserves to be loved and have wonderful parents. One of the things that my mother always told me was that when you first see your child, it doesn’t matter how they’re related to you; the only thing you feel at that moment is how incredibly happy you are to not only be a parent, but to be that child’s parent. And it finally held true with me—I knew that I would love my kids unconditionally, no matter how they came to me, be it biologically, via a surrogate mother, or by adoption. I switched my mindset from “I can’t” to “I can.” I was emotionally drained and exhausted after years of seeing my infertility as a curse, when in reality, it’s a window of opportunity. A good friend of mine offered to be a surrogate mother for me when the time comes. There are plenty of wonderful children out there, waiting for someone to adopt them, and I am more than willing to be the parent for a few of them someday. My infertility does not make me any less of a woman, and adopting kids or having a surrogate does not make me any less of a “real mother.” The people who really love you will understand this and accept you as you are. My friends who know about my infertility, along with my family, have made it a point to remind me how much they love me by helping me deal with this insecurity.

This major switch in perspective has made me feel so much more comfortable in my own skin. I had a choice of attitude here, and I finally opened my eyes and chose the one that would benefit me more. Sometimes, you might not have control over the situation itself, but you can definitely choose how you react. I want to live a happy life, so I accepted the fact that I cannot change my infertility, and decided to look at it in a more positive light. I would be an awesome mom to some pretty special kids. There will be those who cannot see this, but I choose to not surround myself with these people. I have a wonderful, supportive group of people in my life who love me for me. I only have one life to live on this earth, so I’m going to make the best of it.
PERFECT JUST THE WAY YOU ARE  continued from page 5

Then, out of the blue, came another defining moment. At 31 years of age my periods just stopped. I waited 3 months, 4 months and... nothing. I knew something was off, as there was 0% chance I was pregnant. I also knew the most likely reason why; early ovarian failure and Turner syndrome. I discussed my concern with a trusted friend and colleague (a fellow Pediatric Resident), who also happened to have Turner syndrome. I knew the most likely reason why; early ovarian failure and Turner syndrome. I discussed my concern with a trusted friend and colleague (a fellow Pediatric Resident), who also happened to have Turner syndrome.

Go to page 5 to continue reading.

STAY FOCUSED

Stress. Don’t overwhelm yourself by setting too many goals at once. If you decide that in the next two weeks you are going to lose 20 pounds, start a new high-intensity exercise program, and give up your daily fast food run you may find yourself feeling overwhelmed. When we try to do too much all at once we can be setting ourselves up for failure. Reasonable expectations and a wellthought out plan will be the cornerstone to your success.

Be Kind To Yourself! A goal is a hoped for achievement. If you do not master your goal it is not because you have failed. It simply means that you were not able to get to where you thought you might. This mindset gives you the ability to be flexible with your goals. It’s not an all or nothing proposition.

Review. Remember to stop occasionally and look back at how far you’ve come. Change is a positive thing and you need to celebrate your successes. Review your plan and take a moment to acknowledge your achievements as you keep working towards your goals.

GOALS, NOT RESOLUTIONS

- Mira Dessy, The Ingredient Guru

The problem with resolutions is that we go about it the wrong way. We write down the results we are looking for not how we plan to get there. In order to be successful with your anticipated changes for the new year set goals instead of creating resolutions. Goals are a desired outcome as opposed to a resolution which is more finite. If we do not live up to our resolutions frequently we are left feeling discouraged and possibly have a loss of self-appreciation or self-confidence. With goals the end result is planned for but not mandated. Along the way there may be reasons that you did not achieve your goal which you can examine and reconsider. With goals we use qualifiers in order to think about how we will achieve our desired outcome. Be prepared to think all the way through the goal to increase awareness and mindfulness.

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My diagnosis of Turner syndrome hasn’t stopped me in my personal life, either. I have always had a loving family, and have developed several close and long-lasting friendships. And happily, a few years ago, I was blessed with meeting the most amazing and loving man, whom I married. My husband has helped me in so many ways to understand and accept myself for all that I am.

Ultimately, Turner syndrome is just one part of who I am. It doesn’t define me, or any other woman with Turner syndrome for that matter. It will also not keep me from continuing to live my life in service to others, or keep me from striving to chase the next dream.

I hope reading my story will encourage mothers of girls with Turner syndrome. To those mothers who are awaiting the birth of their daughter, who may fear for their daughter’s future, I hope my story helps you see that women with TS can and do lead full, happy, and productive lives. To those mothers who are parenting a child with TS, I hope that you, too, can see that we women with TS can accomplish whatever we set our minds to with love and support! I also hope my sisters with Turner syndrome will find my story gives them hope and courage that they too can continue to reach for, and expect to fulfill, their dreams. You, my sisters, are perfect just the way you are!
WE HONOR & REMEMBER
TSSUS proudly thanks everyone whose gifts make awareness, research and support happen.

In Honor of:
Abbey Kartak
Abby Blech
Abby Lemieux
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Deanna Lail
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SOCIAL COMMUNICATION continued from page 4

desire to communicate. Thinking about your own and others body language will help determine what messages you are sending and receiving in a variety of situations.

Step 3: Use your eyes to think about people as you relate to them.

Our eyes are the 'window to our thoughts' and are the most powerful nonverbal clue that indicates our desire to communicate. Even if our physical presence sends the message that we want to communicate, others are still not sure until we connect with our eyes. For example, if we want to join a group conversation, we must slowly walk up to the group and listen with our eyes to the conversation by 'bouncing' our eyes from person to person while following the comments of those speaking in the group. Next, we 'lock our eyes' on someone while listening to them so they know our desire to enter the conversation. Once they see our eyes, the person will usually pause and ask a question or just wait until we interject with a question or a comment.

Conversely, too much eye contact can leave the wrong message with people. If we consistently stare at someone from across the room without approaching them, it may make them feel like we are stalking them, however directed and constant eye gaze at work communicates a sense of urgency and is totally acceptable when an important message needs to be communicated, whether a person is standing alone or walking with others.

Step 4: Use your words to relate to people when you talk to them.

Once we read the thoughts and intentions of others around us, use our body language and our eyes to connect with others, our language helps us make connections with others around us. We use language in lots of different ways to connect with others and build relationships with them, however some people have significant difficulty figuring out what to talk about with others. One strategy in social language involves showing interest in others, even when they are not very interesting. People don’t always remember what you say, but they always remember how you made them feel, so when you ask on topic questions and/or comment on what they are talking about, you will leave a positive impression with your new acquaintances.

Here are a few suggested topics for starting a conversation with others:
1. Seasonal topics: holidays, vacations, annual events (i.e. Super Bowl), etc.
2. Current Events: News events, sporting events, school related events, etc.
3. Commenting on what we observe going on around us: People walking by, buildings or shopping centers going up, weather events, traffic patterns, etc.
4. Common interests or shared memories: This requires having a little knowledge or past experience with a person but if you don’t know someone well, asking questions to learn more about a person’s interests is a good place to start.

Social communication can be tricky for many of us, but the 4 Steps of Communication provide helpful strategies for becoming a more effective social communicator across a variety of settings and situations.

If you would like to learn more about the 4 Steps of Communication, you may find more in depth information in the following books:


Social Thinking At Work; Why Should I Care? A Guildebook for Understanding and Navigating the Social Complexities of the Workplace, 2011. Written by Michelle Garcia Winner.

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