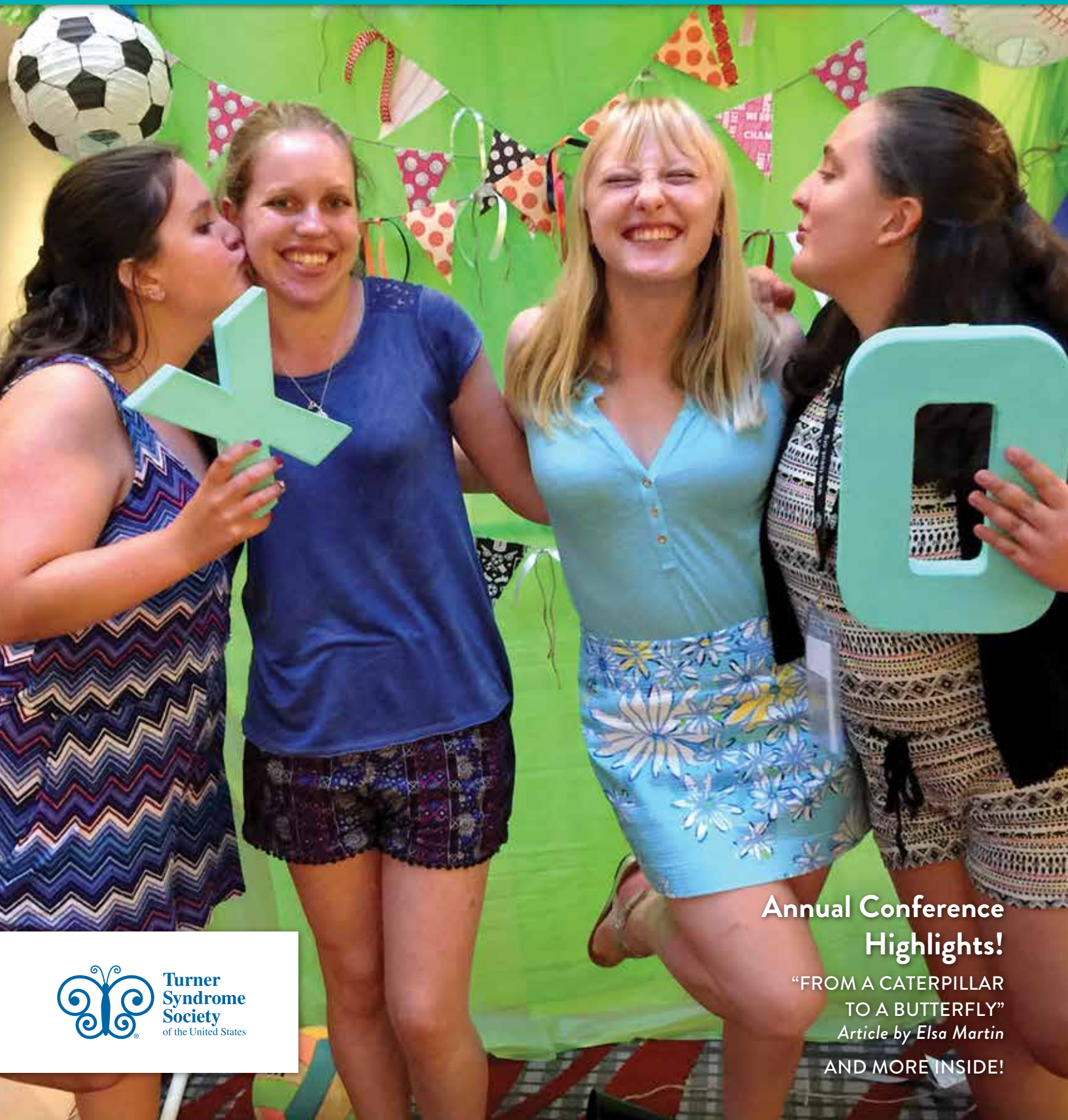


TSS CONNECT

FALL 2016



Annual Conference Highlights!

“FROM A CATERPILLAR
TO A BUTTERFLY”

Article by Elsa Martin

AND MORE INSIDE!



Turner
Syndrome
Society
of the United States



Creating awareness, promoting research and providing support for all persons touched by Turner syndrome.

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TSS CONNECT Fall 2016

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TSSUS RESOURCES FALLING INTO PLACE

We reflect on our accomplishments as we approach the end of 2016.



As the leaves begin to fall, the hard work of TSSUS staff, board members, and volunteers is falling into place. I'm so excited to announce that in 2017 our members and the TS community will reap the benefits of greatly anticipated, necessary, and tangible resources. TSSUS is empowering women and girls with TS and their families by giving them tools to help with TS-related needs. A successful TS journey is dependent on the helpful resources one has available to them.

My daughter's diagnosis story is similar to so many of yours. You think you have life all figured out, but then the unexpected happens. Nineteen years ago, my mom gave me a popular essay titled "Welcome to Holland." It talked about perceiving

the unexpected and its silver lining. As I read the article, I thought my eyes would burn holes right through the paper. I shook my head and thought, "This is not my story. I feel like my plane was hijacked, I can't breathe, I don't know if Brooke is going to live, I don't know what country we're in yet, and I'm too exhausted to understand!"

If only I had been able to go online and print factual patient guides, written by women with TS, parents, and doctors, that told me exactly what I needed to know. If only I could have talked on the phone or met with someone in my community who had experience with TS. If only I could have sat at my personal computer and asked questions to others and read what they had experienced through message boards. If I could have done any of these things, I would have known we would be okay.

I truly believe that 2017 will be the year that the TS community will have the best collective information ever available. The new Turner Topic Guides will merge the TS health recommendations, advice from the TS community, resources, and more, in easy-to-read, printable documents. The TSSUS strategic planning is not final so I cannot "let the cats out of the bag" and tell you all of the exciting plans we have for the next few years, but stay tuned until January!

Please check out the exciting accomplishments that we made in 2016 on the website, under "About Us."

Sincerely,

Cindy Scurlock

TSSUS Executive Director



LEFT PHOTO

Dr. Michael Silberbach on stage talking with Cindy and the rest of the attendees at the 2016 Annual TS Conference.

COVER PHOTO

Young adults posing in front of the Team Turner backdrop at the 2016 Annual TS Conference!

TSSUS 2016 ANNUAL CONFERENCE SNAPSHOTS

Lots of fun and engaging times at the Annual Conference - so many great photos!



FROM A CATERPILLAR TO A BUTTERFLY

Reflections on the 2016 Annual TSSUS Conference, By Elsa Martin

The dance party was probably the highlight of the weekend, but this story doesn't start there; it started when I was born. Before I was even born, I was diagnosed with Turner syndrome (TS), a genetic disorder affecting the second X chromosome. Up until this summer I had only met one or two other girls with Turner syndrome, and I never kept in contact.

Every year, the Turner Syndrome Society of the United States (TSSUS) holds a national conference, and this year the conference was in Cincinnati, Ohio. My mom and I flew to Cincinnati for a long weekend; I was super excited because this was my very first conference. When I arrived at the conference, it was weird to see so many women and girls who also had Turner syndrome. It was not super hard to tell which girls had Turners, because the most common trait of TS is short stature; it was basically a hotel full of women and girls under five feet tall.

During the programmed parts of the conference, I was placed in a group of girls similar in age. We talked about and had speakers come in to discuss topics related to living with Turner syndrome. We also did some fun team building activities in hope of getting to know each other.

I gained a new sense of pride and confidence about being a girl with Turner syndrome.

On Saturday night, there was a dance party for all of the girls at the conference. I walked into the room that was lit only by blue, green and red disco lights. Pop music was blasting from the portable speakers and turntable set. We had been told to bring a banquet dress, so it was fun to see all of the girls in anything from a sun dress, like me, to the girls wearing what clearly was their prom or formal dress. Normally at any dancey-type situation I'm extremely self conscious, and just bob along to the beat of whatever song is playing, but this was totally different.

I entered the dance party with two girls around my age who I just met at dinner, and I don't know why, but for some reason I felt one hundred percent comfortable dancing with them to the various pop remixes that were now echoing through the hotel. By far the best part of the dance party was how it was in what was really just an ordinary hotel conference room, but for that one night 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.

After a while, towards the end of the night, the DJ announced he would start playing our requests. "We should totally ask him to play



'Livin on a Prayer'!" Danica, one of the girls I was hanging out with, shrieked.

"Yeah!" Hannah and I agreed.

We raced up to the DJ and gave him our ingenious request. A couple songs later, we heard the classic bass intro and bolted to the center of the room.

"...we've gotta hold on to what we got/ It doesn't make a difference if we make it or not/ We've got each other and that's a lot for love/ We'll give it a shot/ WOH OH WE'RE HALFWAY THERE/ WOH OH LIVIN ON A PRAYER/ Take my hand and we'll make it I swear/ WOH OH LIVIN ON A PRAYER..." Danica, Hannah, and I belted out the lyrics along with pretty much everyone in the room.

Only after the DJ played the last song did I realize how sweaty and tired I was, but that didn't stop me from giving Danica and Hannah one last hug before we went to our hotel rooms. "This was so much fun!" I said mid-hug.

"Yeah! We should totally sit next to each other tomorrow," Hannah agreed.

"Definitely, Hannah and I will save you a spot," Danica stated as our parents showed up.

I gave my mom a tired, sweaty, and happy hug as I told her about how amazing it was to meet all of these girls. "Thanks for forcing me to talk to Danica and Hannah at dinner," I said bashfully.

Meeting, talking to and getting to know other women and girls with Turner syndrome at the conference was fun, but it was so much more than that. I think I am a different, more confident, and pride-filled person now than I ever was before I attended the conference. ♦



SAVE THE DATE

Start making plans **NOW** to join us for the
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Aqua Net, because we're heading back to the 80s!**

It will be held at the stellar Denver Marriott Tech Center.



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

Find more information on our website | www.tssus.org

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PHOTO
One of our little butterflies during
craft-time at the 2016 Conference.

MY TWO JOURNEYS

- Kim Lumpkin



First, some background on my first journey, which began when I was born. At just six weeks old, my parents had to endure having their infant daughter operated on due to pylorostenosis, which was blocking my stomach and preventing me from holding down any food. Later, when I was six years old, I had spinal meningitis. My parents had no idea that those two health crises might be related by a complex genetic condition.

As a child, teen, or adult, I never minded being short. I did mind the ear infections, but I had no idea there was a connection. When I hit my preteen years, I started to wonder about the changes I saw and heard about other girls going through, and while part of me worried about when it would happen to me, a part of me was also relieved that it hadn't yet. But when nothing happened by the time I turned 16, my pediatrician had me tested to find out what was going on. The next thing I knew, I was in a hospital, where I spent at least two days. My memories of that time are hazy, but I do remember watching Princess Diana's wedding (and struggling with the volume control that was blaring loud enough to wake the person next to me.) I also remember having full body pictures taken, which leads me to believe my testing was also part of some kind of research. Alas, I can find no evidence of that, and while the testing proved I have TS, neither I nor my parents thought to save the relevant details, like the karyotype, so I don't know if I am classic or mosaic (something I've been trying to find out this year.)



After the testing, and finally finding out a name for what I had, I took growth hormones for awhile which gave me a couple more inches before my bone plates sealed. Knowing I could be a bit taller if I had started taking them sooner didn't bother me. I don't know if it bothered my parents, but I hope not. After that, I didn't think about TS for years until a doctor told me I needed to take hormones because I was in danger of getting osteoporosis and needed the estrogen. Even then, it was just something I had to do, and I didn't really think of TS beyond that.



It wasn't until a friend of mine told me about seeing a segment on television about a mother who was told her unborn child had TS that I became more curious about my own case, and my second journey, a journey to find a community of other girls and women like me, truly began. The Internet had come far enough that I was able to find out more information fairly easily, and I was surprised to discover how many of the health issues I'd faced as a child could be traced to TS.

Eventually, I found my way to the Turner Syndrome Society of the US website, still in its early days, and learned they had yearly conferences. As much as I wanted to attend one, I didn't think it would be possible due to time and money constraints. Then I got an email from Darlene Hay, a mother of a girl with TS who was starting a much-needed South Florida organization to raise awareness. She invited me to one of her first events. She has incredible energy and passion and has organized some excellent fun and educational events in the area. We in South Florida are so lucky to have her. This year, she helped make it possible for me, at the ripe young age of 51, to attend my first TS conference in Cincinnati, Ohio. I was, and still am, humbled by the hard work and generosity that made my trip possible, but I have learned that it is a trait of TS women and those who care about them to support and advocate for each other in any way possible.



I arrived on the Friday afternoon of conference weekend, so sessions were already going on and I jumped right in. Since I was late, I had to sit in the back of a session and missed out on a lot due to my poor hearing. I vowed to sit in the front, like a good student, from then on! The warm, welcoming vibe helped me feel right at home. The poutine and gin I had in the hotel pub didn't hurt, either! The icing on the cake was meeting my hotel roommate and hitting it off immediately; she's also a teacher with hearing loss, and as we discussed our challenges, I lost track of the times I said, "Me, too!"

Saturday was kicked off by the general meeting. The Team Turner sports team helped charge the

continued on page 9

THE TRAVELING TURNER TOWN PROJECT

The Turner Town has traveled to TSSUS Annual Conferences and other public events!

Created in 2005, the Turner Town Project is a self-teaching awareness campaign for Turner Syndrome and Nonverbal Learning Disabilities. Turner Town is a large collection of doll houses where each building/scene and accompanying storyboard illustrates a symptom or characteristic of TS or NLD. These characteristics are shown through the life of a young woman named Joy, a fictional character with both TS and NLD.

Since 2010, all or parts of Turner Town have been displayed at the annual TSSUS conventions. In addition, this innovative, interactive exhibit has been on display for over ten years in various other public venues as well.

Over the July 4, 2010 weekend, the Beach House debuted (with the entire Town) at the Indianapolis TS convention. A Fourth of July theme was chosen for this house to complement the conference decorations and holiday. The Beach House dealt with the main character's fear of fireworks, probably caused by a simultaneous multi-sensory overload.

Turner Town School came to the 2011 Buffalo TS convention along with an Education Station consisting of a demonstration classroom, "academic accommodations" poster and quick "Flip-Tips" for dealing with NLD.

The Sweet Petite Boutique (along with a red-carpeted Petite Princess Fashion Show) reinforced the princess theme of the 2012 TS Garden Grove convention. Accompanying activities included "Fashion Flip-Tips" (to look taller) and paper doll handouts to cut, color and customize.

At the Dallas conference in 2013, the Little Stars Theatre and the Butterfly Sisters Society (a girls' club,) focused on TS speech patterns and self-esteem issues respectively. The TSSUS uses the butterfly symbolism in much of their material—thus the theme for these two houses. Educational placards and a "Flip-Tips" display offered advice for building self-esteem.

The Grandmother's/Storybook House and the Turner Town Tree House were displayed at the 2014 TSSUS Jacksonville, Florida convention. These two settings spotlighted Joy's excellent rote memory skills as well as certain social difficulties. The standing storybook, "Joy's Story," was introduced.

In 2015, The Big House was set up at the Kansas City, Missouri conference and illustrated potential problems dealing with an environment change for a person with NLD. The informational placards contained ideas for easing a move to a new home, school and/or place of employment.

The Thanksgiving House (*more information on page 8*), presented at the 2016 TS Cincinnati conference, illuminated assets rather than deficits of those affected by NLD.

Each of these scenes is a snapshot of possible issues faced by those living with TS and/or NLD. In addition to the stand-alone buildings, the rest of Joy's story is portrayed in photos, a standing storybook and/or other books specifically written about this project. Suggestions or solutions presented in the storyboards, Parents' Guides, related activities, and "Education Stations" are meant to be thought-provoking and are packaged in quick and easy formats so that visitors/viewers have access to "instant" information on the topics showcased. ♦



COUNTING BLESSINGS AT THE 2016 CONFERENCE

- Jennifer Wakenell, Turner Town Director



You may have seen it at the 2016 TSSUS Conference: a doll house, decorated in a Thanksgiving theme. This doll house, called “Counting Blessings,” is the latest addition to Turner Town, an educational traveling exhibit created to raise awareness about Turner Syndrome and Nonverbal Learning Disabilities.

Turner Town focuses on a young woman named Joy, who has Turner Syndrome and Nonverbal Learning Disabilities. This unique exhibit follows Joy’s experiences from birth to young adulthood, showing how TS and NLD impact her life, her strengths, challenges, and her wonderful and encouraging support system.

The Thanksgiving story in this new house finds Joy celebrating the holiday with her family. The storyline illustrates some of the assets of those affected by NLD, such as good rote memory skills, auditory learning, and an excellent vocabulary.

To watch videos or learn more about The Turner Town Project, please check out my campaign’s website at: www.jwakenellts.wix.com/theturnertownproject. “Virtual visitors” to the Town are *always* welcome!

Joy’s tale has been inspired by events in my own life, and ones other girls and women with TS have told me at camps and conferences. Joy’s new adventures are continuously being added to Turner Town, so if you would like to share your story, you can email me at jwakenellts@g-mail.com for consideration.

Please help spread the message of this important awareness campaign and become an honorary Turner Town ambassador! ♦



PHOTOS ABOVE

Girls exploring Turner Town excited to learn through fun dolls and pretty doll houses at the 2016 Annual TS Conference.



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HAPPY VETERANS DAY

- Lisa Mawson



Growing up I had always wanted to join the Army like my father. I was healthy and a pretty normal kid except for my size and wasn't diagnosed with TS till 17 years old. At 20, I tried to join the Air Force but was too short (you have to be 5 feet tall) so I joined the Army instead (I barely made it at 4'10"). I passed the physical with the only deficiency being hearing. Turner Syndrome was listed in my records, but in 1983, I don't think the Army doctors knew enough to question my ability to serve. I made it through basic training and medic school and was sent to Germany. That is where I met my husband Bill.

Serving four years in the Army was the hardest thing I've ever done, and the most rewarding. I am humbled to have honorably served the country that is truly the greatest on earth. It gave me opportunities I would not have gotten anywhere else.

I know at least three other Butterflies who have served in the military. We are a special group! Today, I have two boys in the Army who have served in Afghanistan. Happy Veteran's day to all who served! ♦



DID YOU KNOW?

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

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

To learn more about how YOU can make a difference through Social Fundraising, contacts:
shawn@turnersyndrome.org or
deborah@turnersyndrome.org



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

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

MY TWO JOURNEYS

continued from page 6

atmosphere full of positivity and excitement. Then we all went to different conference rooms, and looking at the program, I was once again surprised by the sheer variety of topics of interest for women and girls with TS and their families. From diet to driving (both potentially big challenges for women with TS), organization to foot care, there was something for everyone there. Speakers were all experts in their fields, offering their contact information in case we had questions beyond the sessions' time limit. We also could partake in the educational or social activities that interested us (although at times it was hard to choose which session to go to!)

That day, I also learned about and became part of the Turner Syndrome Research Registry which has been set up as a way for women with TS and families of girls with TS to create a storehouse of information to help further knowledge and understanding about TS. If you haven't already, please go to <http://www.turnersyndrome.org/#!ts-registry-love/cpe6> and fill it out. It isn't long, but it is so important for everyone to offer what information they can to help all girls and women with TS and their loved ones.

Sunday was the closing session, then a final series of sessions; I chose to go to the one about financial planning – who doesn't need help with that these days? Finally, there was a special treat – a cruise down the Ohio River. All too soon the conference was over, but my roommate and I spent one more night there, and I learned about some potentially helpful technology to help with my hearing issues.

Through the careful planning and festive spirit, the conference was a truly joyful and educational event that both fostered mutual support and teamwork and honored our individual paths. I hope my story has helped inform those who read it who are unsure about participating in local events or going to a conference. It is so worth it. I was, indeed, hooked, and hope I will be able to get my fix again in the future. ♦

FAVORITE FALL FEASTS

Try some delicious gluten-free fall recipes!

As the seasons are changing and the weather is getting colder, it's time to start breaking out some of your favorite autumn recipes! But if you, or your daughter, have to stick to a gluten-free diet, sometimes it can be hard to find versions of the foods you love that are safe and easy to make. Here are two recipes for autumn classics—a warm, filling potato soup, and a crumb-topped pumpkin cake—that will warm you up and won't break the bank! Thank you to Keaghan Wier for the recipes compilation. We hope you enjoy them! ♦



SLOW COOKER POTATO SOUP

Makes 8-10 generous servings.

Ingredients

- 3-4 cups of chicken or vegetable broth
- 2 pounds of potatoes
- 1 medium yellow or white onion
- 4 tablespoons bacon grease or butter
- 1/3 cup gluten-free all-purpose flour
- 1 (12 ounce) can of evaporated milk
- 1 cup shredded cheddar cheese
- 1/2 cup plain yogurt or sour cream
- 6 slices of cooked bacon
- 1 teaspoon salt, or more to taste
- 1/2 teaspoon black pepper
- Optional toppings: green onions or chives, extra shredded cheese, extra bacon, sour cream—anything you'd put on a baked potato!

TIPS & NOTES

- The best potatoes for this recipe are Yukon gold potatoes or normal baking potatoes. Either one will work, it's just up to you!
- If you do not have evaporated milk, regular milk will work as well. Just make sure it is at room temperature before you add it to the grease and flour.
- You can also make this recipe vegetarian by using vegetable broth, not adding bacon, and adjusting the seasoning to give it more flavor.
- If you want the soup thicker, you can add a couple spoons of instant potato flakes!

YOU WILL ALSO NEED

- Large slow cooker
- Vegetable peeler
- Cutting board(s)
- Knives
- Frying pan for the bacon
- Whisk

Instructions

1. PREPARE

- Wash, peel, and dice potatoes. The pieces don't need to be even or tiny, just chop it into chunks.
- Peel and dice the onion.

2. COMBINE & COOK

- Add three cups of the chicken (or vegetable) broth, potatoes, and onions to the slow cooker. Stir so that the vegetables are covered by the broth.
- Cook on low for 6-8 hours or on high for 3-4 hours. The soup is ready for the next step when the potatoes are completely tender and cooked. You can test them by poking them with a fork—they should almost fall apart when you do, and it should be easy to poke them. When the potatoes are cooked, move on to the next step.
- Dice your bacon into chunks. Fry it and set aside. Keep 4 tablespoons of grease in the pan.

NOTE: You can also drain the bacon fat out of the pan and use butter instead.

- If you are using butter, melt it in the pan. If not, give the bacon grease a few minutes to cool down by turning off the heat and letting it sit. This will keep your flour from scorching in the next step.
- Add the flour to your grease or butter and cook it over medium heat until it is completely combined.
- Slowly add in your milk while whisking to make sure that it is smooth.
- After adding the milk, let it cook for a few minutes. Keep stirring it and let it come up to a simmer. The sauce should start to thicken. Wait until it is really thick.
- Pour the milk mixture into the slow cooker with the potatoes and other ingredients. Stir until it is all combined.
- Add in the cheddar cheese, yogurt (or sour cream), salt, pepper, and bacon. Stir it until combined.

TIP: If you would like your soup to be thicker, you can take a potato masher or large spoon and mash up about half of the potatoes so that it gets thicker. If you would like it thinner, add another 1 cup of broth. Add more salt and pepper if you want.

3. ENJOY

Serve warm, and topped with your favorite, desired toppings.

TIP: This soup does not freeze well, but it can be kept in the fridge for up to 3 days.

This recipe adapted from Slow Cooker Potato Soup originally posted on www.gimmesomeoven.com on December 14, 2015.

If you have celiac disease, it is very important that you adhere to a strict gluten-free diet.



PUMPKIN CRUMB CAKE

Makes two 8" round cakes, one 8" round and one loaf, or one 8" square cake.

Ingredients

FOR THE TOPPING

- ¼ cup unsalted butter (½ of a stick, or 4 tablespoons)
- ½ cup brown sugar
- 1 teaspoon vanilla extract
- ¼ teaspoon salt
- ¾ cup gluten-free all-purpose flour or regular all-purpose flour *See Tips*

FOR THE CAKE

- 2 cups gluten-free all-purpose flour *See Tips & Notes*
- 1 cup brown sugar
- 1 ½ teaspoons baking powder
- 1 ½ teaspoons baking soda
- 1 ½ teaspoons pumpkin pie spice *See Tips & Notes*
- ½ teaspoon salt
- 1 cup canned pumpkin puree *See Tips & Notes*
- 3 large eggs
- ¾ cup vegetable oil
- ½ cup sour cream or plain yogurt
- 1 teaspoon vanilla extract *See Tips & Notes*

FOR THE ICING

- 1 cup powdered sugar
- 2 tablespoons milk or cream

TIPS & NOTES

- You can use any gluten-free all-purpose flour blend for this: King Arthur Flour, Pillsbury, and other companies have very good ones. Just make sure you are using a blend, not just rice flour.
- If you don't have pumpkin pie spice, you can make your own! Mix together 1 teaspoon cinnamon, ¼ teaspoon nutmeg, ¼ teaspoon ginger, and ¼ teaspoon cloves. Then measure out 1 ½ teaspoons to use in the recipe!
- Make sure when you buy pumpkin puree that you buy the can that says 100% Pumpkin, not pumpkin pie filling.
- This recipe also tastes delicious with almond extract instead of vanilla!

YOU WILL ALSO NEED

- Baking pan: either a round pan, square pan, or loaf.
- Small pot or a microwave-safe bowl
- Large & medium mixing bowl
- Whisk
- Spoon
- Spatula to scrape down the bowl
- Toothpick or cake tester to make sure the cake is done
- Wire cooling rack

Instructions

1. PREHEAT YOUR OVEN to 350°F. Spray your baking pan with non-stick spray on both the bottom and sides. Set the pan aside.

2. MAKE YOUR TOPPING

- Melt your butter, either on the stove over medium heat (in the pot) or in the microwave (in a bowl,) until it is completely melted but not boiling.
- Add the brown sugar, vanilla extract, and salt. Stir until it is smooth.
- If you are using the stove, remove the pot from the heat. If you are using the microwave, skip this step.
- Add the flour and stir. The mixture will be thick and almost clumpy, but still very shiny from the butter.
- Let the topping cool completely while you make your cake batter.

3. MAKE YOUR CAKE

- Combine the flour, brown sugar, baking powder, baking soda, pumpkin pie spice, and salt in your large mixing bowl. Whisk the ingredients. Make sure there are no clumps and everything is mixed well.
- Combine the pumpkin puree, eggs, vegetable oil, sour cream (or plain yogurt) and vanilla in your medium mixing bowl. Whisk it to combine the ingredients. Make sure everything is well mixed.

TIP: It's easier to get the eggs to mix into the rest of the ingredients if you poke the yolks with a fork before trying to whisk the ingredients together!

- Pour the liquid ingredients into your dry ingredients and whisk them together. Mix it until it's just smooth—don't mix for too long, since this will make the cake tougher.

- Pour your batter into the prepared cake pan(s). You only want your pan to be about half to two-thirds of the way full. This cake will be fluffy and will rise a lot while in the oven!

- Take your topping mixture and crumble it into pieces on top of the cake batter, and put your cake pans into the oven. Try to put it as close to the middle of the oven as possible—on the center rack, in the middle.

4. BAKE

- Bake for 30-40 minutes, or until a toothpick put into the middle of the cake comes out clean.

TIP: It's better to set your timer for less time and check it than to bake it for too long! Set your timer for as little as 25 or 30 minutes and check the cake, then bake it for a few more minutes at a time if it isn't ready yet.

- Remove your cake from the oven. Set up a wire rack and put your pans on top of the rack so that the air can move around the pans. Let the cakes cool completely.

5. MAKE YOUR ICING

When your cakes are cool, you can make your icing!

- Whisk together the powdered sugar and milk in a small bowl until it is smooth.
- Drizzle the icing over the cooled cake.

6. ENJOY

Cut your cake into pieces and serve!

TIP: If you want to save some of your cake, or you know you won't eat it in the next couple of days, don't put the icing on the cake. This cake works well if you slice it, wrap each slice in plastic wrap, put the slices in a bag, and freeze it. You can also save leftovers in the fridge.

This recipe adapted from Pumpkin Crumb Cake originally posted on www.iwashyoudry.com on September 28, 2015.

If you have celiac disease, it is very important that you adhere to a strict gluten-free diet.

GLUTEN-FREE TIPS

Some helpful tips and lunch ideas, by Keaghan Wier



Starting a gluten-free diet can be daunting. First, there's the complication of realizing that gluten can be in anything—from seasoning blends to salad dressings, from any baked good to sauces and convenience food. Even things that at first glance you would think were safe turn out to be havens for wheat flour.

But once you've settled into the gluten-free life and have figured out some ways to deal with the new restrictions, one of the biggest challenges can be figuring out how to eat gluten-free, or for some, feed a family, while keeping your grocery bill from skyrocketing. Gluten-free flours and packaged food can be twice as expensive as the "normal" versions. This can add up quickly, and leave you wondering if you'd be better off just eating carrots and rice for the rest of your life.

Don't give up hope! There are ways to eat gluten-free on a budget! It can take some creativity and a bit of trial-and-error, but you will eat well and you will eat affordably!

Here are a few tips for finding your gluten-free diet that suits your needs and your pocketbook:

- Make your own gluten-free flour blend in bulk instead of buying overpriced blends at the grocery store. Check out www.glutenfreeonashoestring.com for some great recipes. It might be a bit pricey upfront to buy all of the individual flours, but when you compare the cost to the \$6 you could easily pay for a few cups of good gluten-free flour blend, it is worth it.
- Figure out some recipes that are naturally gluten-free. Rice, quinoa, beans, corn products, and potatoes are great options for naturally gluten-free carbs that you can use as sides instead of bread or pasta.
- Buy naturally-gluten free snacks, like cheese, nuts, peanut butter, etc. Do NOT fall for the gimmicks of overpriced gluten-free crackers, cookies, and snack bars. To make up for the lack of gluten, most have significantly more fat than the "normal" version, and they are usually smaller portions. Use these as a treat, not a regular purchase.
- Vegetables, fruits, meat, and beans are great bases for your meals. Try to steer away from flour-based meals and find new alternatives. For example, swap out the tortillas in a taco night for taco salad, gluten-free corn chips, or gluten-free corn tortillas. (Most corn tortillas and chips are gluten-free, but always check the ingredients to be sure. There's always the risk of cross-contamination if something isn't marked as certified gluten-free.)
- Read the ingredients labels. Even if you think something is probably gluten-free, read the label! If it is not marked as certified gluten-free, there is a risk for hidden gluten in things like "wheat byproduct" and "natural flavorings." Depending on how strict your diet is, be careful!

But what about heading off to school or work in the morning, and you need to throw together a quick lunch to pack? Those go-to wraps and sandwiches aren't always an option anymore, so what can you do? Here are a few ideas:

- Pack a healthy lunch of cheese cubes, fruit, nuts, crackers or pretzels, vegetables, hummus, and hardboiled eggs. This lunch is protein-packed and filling. You can also include a piece of chocolate for a sweet treat!
- Cheerios (brand-name only) are now certified gluten-free! These make a great snack, or combine it with a cup of yogurt and fruit for a good lunch.
- Make cheese roll-ups with corn tortillas. Pack a side of sour cream, guacamole, or salsa – whatever your favorite toppings are. Include some fruit or vegetables to round out the meal.
- Chicken or tuna salad with carrots or bell pepper strips, especially if you swap out mayonnaise for plain Greek yogurt or add a chopped up boiled egg, makes another great protein-filled lunch.
- Veggie tacos are another fun meal to make. Black beans, roasted sweet potato chunks, and sautéed onions topped with your favorite taco fixings – make the filling ahead of time, then pack it in a bag and a few corn tortillas on the side to assemble at lunchtime!

Hopefully these tips and ideas have jump-started your brain and will give you a fresh outlook on what it means to eat gluten-free. Now you can tackle those school and workday lunches with confidence! ♦

Keaghan Wier is a freelance writer, community theatre owner/director, and a "foodie" who lives a gluten-free lifestyle. She is the sister-in-law of a TS Butterfly, and lives in Northern Virginia.

RECORD-BREAKING WALK ATTENDANCE

Congratulations to the TSS Texas Gulf Coast Chapter!

On October 1st, 170 people gathered as they hosted their annual TS Walk for Awareness and dedicated it in memory of Audrey Groover.

Audrey was the chair of their first Houston Walk three years ago, and passed away this year. Be on the lookout for a video of the balloon release on the TSSUS Facebook page! ♦



TULSA WALK

The Northeast Oklahoma TS Resource Group had their 2016 Chasing Butterflies Walk for Turner Syndrome on Saturday October the 8th. They created

awareness and raised \$550 while having fun at the Whiteside Park in Tulsa, Oklahoma! ♦



Walking for Turner syndrome is a great way to raise TS awareness and funds for TSSUS!

And our staff is here to help you all the way.



Visit turnersyndrome.org and click on **Take Action.**

Enter to Win a

FREE
Conference Registration!

Host a walk between

JAN 1st - JUN 1st

and be entered in a drawing for a
COMPLIMENTARY

**2017 CONFERENCE
REGISTRATION!**

1ST ANNUAL TS PATIENT EDUCATION DAY

A wonderful turnout in Los Angeles, CA!



What a wonderful turnout the Northern California Turner Syndrome Resource Group had at their 1st Annual Turner Syndrome Patient Education Day in Los Angeles, CA.

Over 65 adults, children, and family members gathered to receive the latest TS news. The event was hosted by the Children's Hospital of Los Angeles and included several doctors who discussed topics on Cardiology Pathology, Turner syndrome & Mathematics, The Genetics of Turner syndrome, Nonverbal Learning

Disability, and many others. Attendees left the sessions well-informed and were able to make long-lasting connections. ♦

INTERNING WITH DR. ANGELA LIN

Congratulations Caitlyn Sullivan!



ABOVE
Caitlyn and her mom, Sarah (TSSUS
Treasurer), at the 2016 Annual Conference.

Following my freshman year at St. Anselm's College in Manchester, N.H., I wanted to spend time learning more about healthcare. I knew healthcare "from the inside," but I was eager to experience new things. I'm lucky to have picked a career path that excites me – as a nursing student, my hope is to teach others, but also to learn from my patients.

Over the summer, I had the incredible opportunity to intern with Dr. Angela Lin, a medical geneticist at the Massachusetts General Hospital for Children. Dr. Lin is also a co-director at the MGH Turner Syndrome Clinic. I was pleased to have this opportunity to be myself while helping others understand that Turner syndrome is more than what they might learn from a book. She reminded all of us about patient confidentiality, which I know from firsthand experience is very important.

Working with Dr. Lin and her terrific research assistant, Erin McNamara, I learned the basics of genetics, much of which I had learned in my nursing courses. They compiled topics for me to review. The main project they assigned me was to be a guest editor for the MGH Turner Syndrome Clinic newsletter. Erin and Dr. Lin thought it would be a nice change of pace to have a special issue about the TSSUS Annual Conference in Cincinnati and the BITSS (Boston International Turner Syndrome Summit).

I was given the title of "reporter" and asked to come up with a series of questions to ask people while attending the TSSUS Conference (a big thank you to everyone who participated.) I enjoyed developing the list of questions and listening to what people had to say about the conference and their experience with

Turner syndrome. I also worked with a good friend from Boston who also has Turner syndrome, and who reported on the BITSS. It was a very successful "summer in the city" experience. The newsletter was published on schedule, I'm happy to say! It has been shared among women, families, and the professionals who work with Turner syndrome at MGH.

I also had the pleasure of meeting with patients and families in the Turner Syndrome Clinic and the hospital, as well as doing rounds with Dr. Lin. Since I am a nursing major, it was eye opening to see how the topics discussed in my nursing classes apply in a real-life setting. The MGH staff nurses, as well as the families and patients in the clinic, encouraged me and welcomed me with open arms. I am so thankful for everything I learned from them.

Turner syndrome is more than what [you] might learn from a book.

I didn't realize that I would be teaching as much as learning, and I loved it. One of my favorite opportunities was presenting a talk about living with Turner syndrome. I love creating slide shows, and this was good practice teaching. I spoke to the students, interns, and other staff. On another occasion, I presented to other "summer students." One of the other students wanted to go to medical school, and another was applying to be a genetics counselor.

A special moment occurred when I introduced myself to the mother of a young girl with Turner syndrome as someone also living with Turner syndrome. I could imagine how they felt, just like my mom and me many years ago, sitting in a clinic room. When I explained I was like her daughter, the mother's face lit up with a big smile. Life is filled with amazing coincidences, and she told me she had graduated from my college's nursing program. Another wonderful opportunity to spread Turner syndrome awareness!

It was an incredible experience, and I would not trade a single minute of it! Thank you again, Dr. Lin! ♦

ONLINE TS COMMUNITY

A great way to connect with others!

Check out our Message Board at www.turnersyndrome.org

 **Follow Us on Facebook**

Do you have an article suggestion, content request or want your group highlighted?



Please send any inquiries to
newsletter@turnersyndrome.org

TURNER SYNDROME RESEARCH REGISTRY

Have you signed up for the Turner Syndrome Research Registry yet?

We need your help, and hope you will decide to be one of the first to participate in this exciting new research. The Turner Syndrome Research Registry (TSRR) is a registry dedicated to Turner syndrome research and is the only registry that allows research teams to share the stored information for years to come.

The TSRR encourages researcher collaboration and is a private and secure system for collecting TS related health care information. You will be able to participate in multiple research projects, and only have to fill out your personal information once!



Look for a new Step-by-Step guide on the TSRR page for help filling out the registry! It should only take 15 to 20 minutes to fill out. ♦

Please call us at 1-800-365-9944 if you have any questions or need help with the survey!

HOW TO REGISTER

1. Go to www.turnersyndrome.org homepage; double click on the blue button "Learn more" underneath the Turner Syndrome Research Registry picture.
2. Look for a New Step-by-Step guide on the TSRR page for help filling out the registry!
3. After you register, a code will be sent to your email address so you will need your email password. If you need a free email account, you may go to gmail.com and set one up.
4. A parent may register for an adult daughter with her permission.
5. After you begin answering the survey, you may stop and return as needed.
6. The TSRR is one of many registries that use the PEER system, so during registration, you may notice that some of the selections are not specific to the TS Community.

DALLAS-FORT WORTH GROUP TEACHES

Great opportunity to educate future endocrinology doctors!



DFW area group of TSSUS was invited to participate in an information fair for budding endocrinologists studying at UT Southwestern in Dallas. Students had the opportunity to learn more about Turner syndrome by speaking directly to those affected by TS.

The students asked good questions and seemed very interested the effects of Turner syndrome. This was the first event of its kind, and hopefully the first of many to come. ♦

Participating in the TSRR empowers you to make a difference.

For science and treatments to expand and the causes of the problems be understood, people need to share their information, so researchers have enough information to ask questions and potentially get answers.



Barbara Flink, former TSSUS President, asks you, "Please be a part of this registry so we can all help each other."

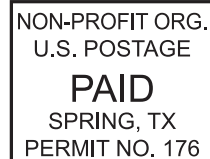
Please consider participating in this valuable and exciting opportunity if you have TS, are the parent of a daughter with TS, or have authority to register on behalf of someone with TS (or deceased).

The more people that participate in the registry, the more potential there is to understand health issues related to TS. ♦





11250 West Road, Suite G
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2016 Annual
Fundraising Campaign:
It's personal.

"Words cannot convey our experience that weekend.
We met so many wonderful people at our very first chasing butterflies walk
that changed our lives and *the puzzle pieces began to fall into place.*"

"I felt like a *whole new world* opened up for me
when I was awarded the hearing aid scholarship.
For the first time in my life,
I did not have to turn my head to my good side,
in order to try and comprehend what someone was saying.
I felt after many, many years,
I finally stopped having to compensate for my severe loss of hearing."

With your help, we've committed to meeting the many needs of the TS community for the past 29 years.