Coley's Story

Living With Turner Syndrome
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Photographs courtesy of
Natalie & Steve Bonfig
Hi! My name is Coley. I am four years old and I have Turner Syndrome (TS). Only girls can have TS, and it can be discovered at any time. When I was three, my mommy and daddy found out that I am a "Turner Girl" because I wasn’t growing.

There are some common TS features, but not all "Turner Girls" look alike. For example, see my chin? It’s kind of small. Some girls even have changes in their neck, chest, eyes and ears.
Some girls with Turner Syndrome have heart or kidney problems. I have a heart defect called Aortic Stenosis. This is very common in "Turner Girls." When I was a tiny baby, I had open heart surgery. Now, Dr. Tom checks out my heart just once a year.

After finding out that I had TS, I had some tests done by Dr. Joe and a couple of other doctors. Dr. Joe checked me over, took some blood and put a cuff on my arm to take my blood pressure. It didn't hurt; it felt like a hug!
Dr. Kent makes sure my ears, nose and throat are healthy. I’ve had ear tubes put in my ears twice, which is pretty common for “Turner Girls”. Soon, my tonsils and adenoids will have to be taken out. This is also common for us “Turner Girls”.

Now I see Dr. Joe every three months. He weighs me, measures how tall I am and asks my mommy a lot of questions. Sometimes I have to have more tests done.
I just started going to the dentist. Dr. Jill checks my teeth and mouth. I will probably need braces someday because my high palate and small jaw may crowd my big girl teeth.

To help me grow, my mommy and daddy give me a shot every day. It kind of hurts at first, but I am getting used to it because we have a special routine that we follow.
Here's what we do: First, I sit in my special chair. Next my sister, Emily, holds my hand and I get my shot.

Then Emily or my brother, Max, put on the bandage. My shot usually doesn't bleed, but I still like the bandages, especially the blue ones! After my shot is done, I get to have one of my favorite candy bars...yummy!
What is really great about my shots is that they have helped me grow almost five inches in one year. I am happy because I get to wear new and bigger clothes!

Having Turner Syndrome doesn’t stop me from having fun. I can play, swim, fish and do all of the things other kids do. That makes me happy!