

A Spark of Lightning: How a Late Diagnosis Sparked a Need for a Community

Caitlin L. Gong

Jennifer Kraweic is a burst of energy. From the moment you first meet her you are swept away by her enthusiasm and passion for raising awareness of Turner Syndrome. She even recently attended the annual conference of the American Academy of Pediatrics NJ Chapter and was able to share her story with medical professionals who were unaware of the condition. However, she is 28 and did not meet anyone with Turner Syndrome for 14 years.

She was diagnosed at the late age of 14 after she didn't go through puberty. Her mother was concerned not only because of this but because she was far behind on the growth chart at less than 4 feet. They went to see a pediatric endocrinologist at the Joslin Center for Diabetes and Endocrinology in Livingston, New Jersey who after conducting a bone test and blood tests determined that she had Turner Syndrome. Jennifer expanded on her story when she said, "To be diagnosed with Turner Syndrome so late was very difficult. I was 14 years old and went into depression.

After being depressed for about 6 years, I motivated myself and said that Turner Syndrome is not a life sentence. I am a regular person and can do anything. So I finished high school and finally let people know that yes, I have Turner Syndrome. I started to hang with friends and came out of my shell. I graduated from Kean with a BA in Psychology and want to continue to my PhD in child psychology."

A major goal of hers right now though is to have a social group created for women with Turner Syndrome. You never want to feel like you are alone in having your condition and when she was first diagnosed she didn't have anyone like her to talk to about her condition. She proposed the idea of having social programs for others with the condition after participating in a research study in midtown Manhattan where she for the first time met other young women with the condition. How does she feel that this will benefit others like her? She said, "I believe the social group will benefit girls with Turners because since there isn't enough information out there, families and women with Turners don't know where to turn to. There is a great need to share resources about finding knowledgeable doctors, enrichments, and having the opportunity to speak with others who truly understand. Just to have that kind of support is amazing. Everyone can say I understand, even a psychologist can say they understand, but in reality they have no idea of your feelings. I felt so alone that it would have been nice to talk to someone with Turners so they can help me and guide me. I don't want any girl to have to feel all that I felt and go through depression. This is why this support group is amazing so girls have a friend that is exactly like them and can help them understand that it's going to be okay."

The social group launches with its first meeting on Friday, July 12, at 7:30 p.m. in the Turner Syndrome Foundation's new office at 1 Bethany Road, Building 1, Suite 5, Hazlet, NJ, 07730. It will be a pizza and movie night and all teens and young adults with Turner Syndrome are welcome to come. To learn more about the social group, call 732-847-3385 or email cgong@tsfusa.org. To register for the free pizza and movie night visit:

<https://app.etapestry.com/cart/TurnerSyndromeFoundation/default/item.php?ref=3829.0.515914795>.