

You've probably heard of Down Syndrome, Tourette Syndrome, and maybe even of Stockholm Syndrome. But have you heard of Turner Syndrome?

A chromosomal condition affecting one out of every two thousand girls, Turner Syndrome often goes undiagnosed until later in life, keeping the patient from receiving important medical treatments.

A conference held at Kean University by Turner Syndrome Foundation, Inc. last Saturday, entitled, Educating the Educators: Turner Syndrome in a School Setting, provided continuing education professionals, as well as families and patients, with in depth information about Turner Syndrome. This information will hopefully bring the diagnosing age to earlier in life, or even at birth, and bridge the gap between professionals and patients.

"Kean faculty and continuing education attendees equally expressed a newfound interest in Turner Syndrome across disciplines of nursing, education, and psychology, and had opportunity to interact directly with the patient community," said Laura Fasciano, director and founding president of Turner Syndrome Foundation, Inc., about the conference.

But why is it so important for professionals and patients to interact?

"This line of communication stands not only to inspire support but rather, to transform it altogether," says Fasciano.

"Turner Syndrome Foundation, Inc. has great ambitions for this education model, and is pleased to have Kean University standing as its guidepost," adds Fasciano.

Although I've lived with TS for twenty three years, the conference at Kean University, which was coined a Partnership in Caring, was the first one I've been to, so I was not quite sure what to expect. But after so long, you would think I would know absolutely everything about TS, right?

Wrong.

Dr. Paul Saenger, a pediatric endocrinologist who spoke at the conference, informed me, among other things, that TS patients have a life expectancy of only sixty-nine years, and getting pregnant can be potentially dangerous for us.

Steve Norton, founder of the Norton School of Lymphatic Therapy and certified lymphedema therapist, a common symptom found in TS girls, finally shed some light on why I have had cellulitis five times in my left ankle; it is a symptom of lymphedema. Now, thanks to Mr. Norton and the conference, I know where I can find a lymphedema treatment center to help me cure my issues with cellulitis.

A nutrition expert was also available to show us simple ways to prevent diabetes, which also often occurs in TS girls. With the right diet and at least one hour of exercise daily, the danger of diabetes drops immensely. I guess I better cut back on the lemonade.

I walked away more informed than I came, which makes Mrs. Fasciano's high hopes for this education model well founded.

Beyond learning more about what is happening inside me, I met a lot of great people. I felt immediately welcomed into the TSF community with open arms. I never felt judged, which often happens being the shortest person in a room. Furthermore, I met other girls with TS for the first time in my life. I finally didn't feel like I was alone. I could talk candidly with them about what I am going through and what I went through as a child. I've never felt comfortable doing that with my friends. Sure, I've told a few close friends what TS is and that I have it, but I've never went much further. As I said, I just never felt comfortable talking about something so personal.

After the speakers, my new friends and I enjoyed a great lunch and an amazing performance of William Shakespeare's *A Mid Summer Night's Dream*, a perfect ending to a great day.

"Dr. Suzanne Bousquet, Director of the School of Psychology at Kean University and dedicated Board of Trustee member of the Turner Syndrome Foundation, Inc, produced a well-organized and executed program. We cannot thank the Kean University faculty and volunteers for their time and support," said Fasciano.

I personally, agree with Mrs. Fasciano and hope to attend more conferences, like the one at Kean, that brings awareness and education to TS-It is the number one chromosomal condition in women, yet it is still known very little by Dr's, nurses, teachers and the general public- and continue to build relationships within the TS community. I am sure they will prove to be invaluable to me.

For more information on Turner Syndrome or to learn how you can help, visit the Turner Syndrome Foundation at www.tsfusa.org, email info@tsfusa.org, or call 800-594-4595