

Can you believe we are only about 6 weeks away from the New Jersey Marathon Festival at the Shore?

As an official charity of the event, taking place May 5 – 6, 2012 in Long Branch, NJ, Turner Syndrome Foundation, Inc. would like to introduce you to one of the participants and share their inspiring story.

Nick Russo's daughter, Cece, was diagnosed with Turner Syndrome, a random chromosomal condition found in girls, when she was 3 years old. TS affects 1 in 2000 girls and occurs when one of the female X chromosomes is completely or partially missing. Unfortunately, TS is not very well known, even with doctors and nurses, and is often not diagnosed until the patient is around 14 years old. In fact, it took a second endocrinologist to diagnose Cece with TS.

"She had been diagnosed with 'failure to thrive' twice and we had started seeing an endocrinologist every 6 months. About a year into seeing the endo doc we missed an appointment and ended up with another endo doc who literally said she showed no outward indications but the short stature so he thought it was worth testing her for Turner Syndrome. She is mosaic [only partially missing an X chromosome]," says Russo.

These late diagnoses keep the patients from important medical treatment and therapies, such as growth hormone shots to improve height, until it is too late. Fortunately, Cece was diagnosed at a point when treatments and therapies were still beneficial and now, about 4 years after the diagnosis, she is doing great!

"Her heart and kidneys are fine, thank God. She does daily growth hormone shots, which she has never adjusted to--she hates them and it is a struggle after more than 3 years but we feel it is worth it. She has had some random isolated issues that have resolved. She has had one hospital stay since her diagnosis that was hormone related and anomalous, but is generally well and healthy and quite a character:). We see some indications of nonverbal and spatial learning issues but at 7 years old in first grade it is early to say too much about how it may shake out," says Russo.

Shortly after Cece's diagnosis, Russo started searching for a TS support group, or others who are effected by the condition, and found Turner Syndrome Foundation, Inc., a non-profit organization that raises support and awareness for TS.

" [TSF] is such a fantastic group of committed people who want to make a difference in the lives of girls and women with Turner Syndrome. We were desperate to find support and a network when Cece was first diagnosed and I had to search very hard to find local families dealing with Turner Syndrome. We have since developed a small group of local contacts, but TSF has been an impressive high-functioning group that truly makes active efforts to educate and inform," says Russo.

Now, in support of their daughter, Nick and his wife have decided to join Team TSF

and participate in some of the events at the New Jersey Marathon and Festival at the Shore and help raise awareness for TS.

“My wife and I were high school runners and have continued running for fitness for the past 25 years or so. I have done some half marathons but never felt the drive to do a full marathon until this cause was a sponsored cause--because I have a personal connection. My wife, Mary Catherine, decided to join me in the fundraising, too and is training for the half marathon... We felt it was a way to make a difference and challenge ourselves in the process... It was something we wanted to do together for others in Cece's name,” says Russo.

Don't worry; you don't have to be an experienced runner like Nick to participate. There are events on Saturday, May 5, 2012 perfect for families and individuals of any athletic ability, with the marathon and half marathon taking place on Sunday May 6, 2012. If you can't find an event of your liking, you can volunteer, donate or come and cheer on the participants, while enjoying beautiful ocean views.

The more people we have spreading the word about TS, the better. Remember, the sooner patients are diagnosed and start treatments, the better. And it all starts with awareness and education.

For more information on Turner Syndrome, Turner Syndrome Foundation, Inc., or to register with Team TSF, volunteer or donate, visit the Foundation's website: [www.tsfusa.org](http://www.tsfusa.org)

For more information about the New Jersey Marathon Festival at the Shore, visit the official event website: [www.njmarathon.org](http://www.njmarathon.org). To benefit TSF you must register with TSF.

