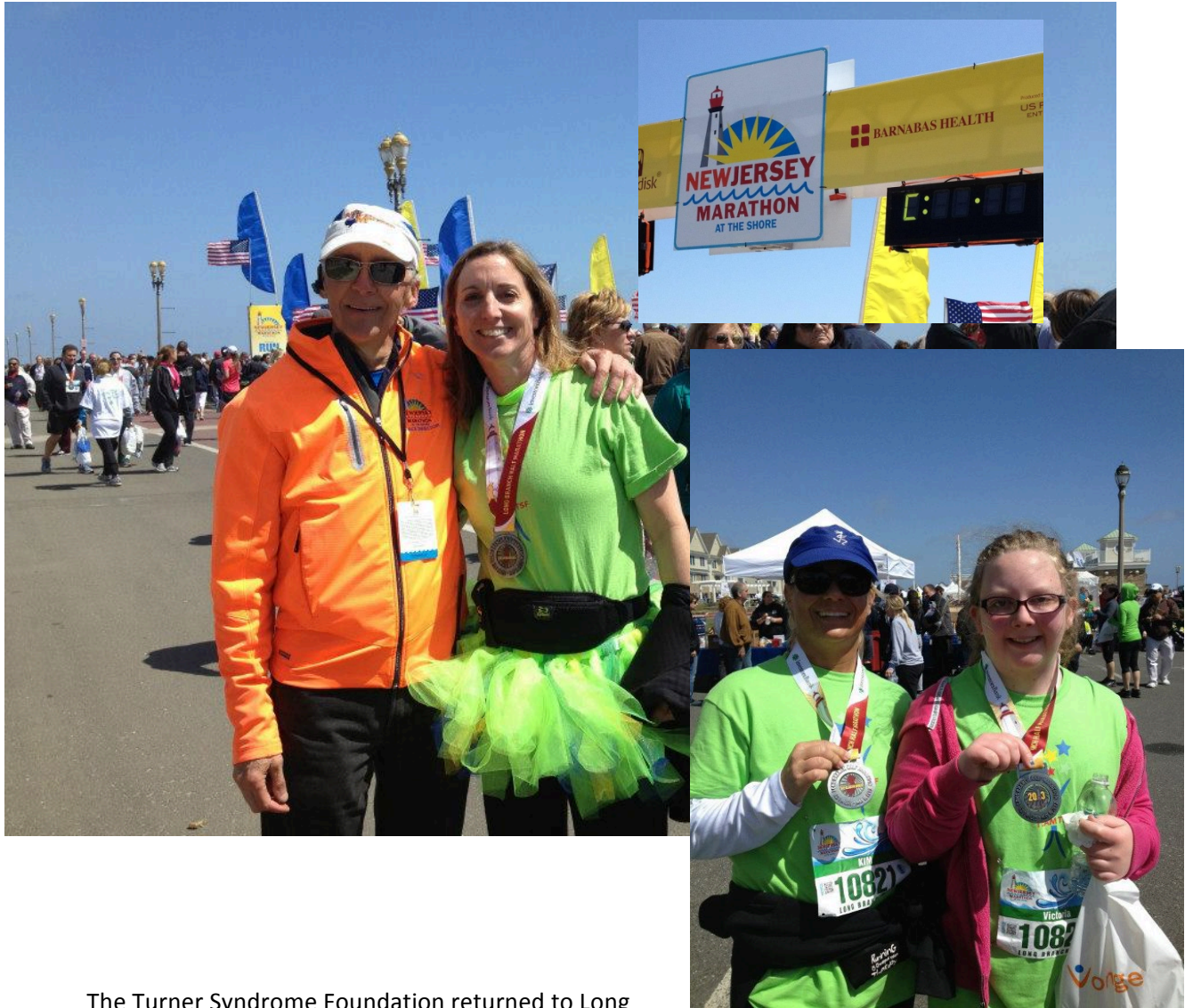


Team TSF Has Successful Fourth Year at New Jersey Marathon

Caitlin L. Gong



The Turner Syndrome Foundation returned to Long Branch for another year at the New Jersey Marathon raising over \$11,000 for the foundation. This will help the foundation in its mission to increase awareness and help advocate for girls and women with Turner Syndrome, a chromosomal abnormality that affects 1 in 2000 females in the United States. The marathon is one of several awareness events that the foundation participates in during the year as it has events currently in Arizona, Florida, New York, Tennessee, Texas, and Washington but continues to expand to other states.

Preparing for the marathon is a months-long process as the foundation is an official charity and beneficiary of the event. Laura Fasciano, founding president of the foundation said,

“We are so very grateful to the families who lead a team to raise awareness and support for the advocacy efforts of the Turner Syndrome Foundation. As I always tout, together we can make a difference! As we have seen in Arizona, Florida, Texas, Washington, New York, Tennessee and of course in New Jersey, families enjoy the community that is shared in this endeavor. The smiles and grins on the girls’ faces are priceless and for many, lifelong friendships are established.”

The Turner Syndrome Foundation’s presence at the New Jersey Marathon was not possible without the many volunteers, bakers, and participants. Volunteers helped the New Jersey Marathon facilitate the activities on Saturday and Sunday and helped the foundation in the charity tent by helping participants register and distributing their T-shirts. They also assisted with the bake sale that the foundation held on the day of the marathon. Anyone was able to donate baked goods to the bake sale and the Mackey family, Fasciano family, DeVito family, and Kym Hall baked goods for the bake sale. The foundation’s two Team TSF organizers, Joan DeVito and Donna Villavicencio, were vital to ensuring the success of this event.

Donna has a four year old daughter, Ava, who has Turner Syndrome and related health issues and participated in the NJ Marathon ½ marathon relay with her friend, Kristin Grazevich. Donna loves the community that she finds at the marathon and said, “It gives me hope that Ava will live to her fullest potential.”

Joan is the grandmother of a 6 ½ year old girl, Ava, who also has Turner Syndrome, and would love to have greater awareness of the condition. She and her husband registered to participate in the 5K fun run/walk along with several others supporting the foundation. Other members of her family participated in the events at the marathon including her daughter, Dawn Fox, who ran the ½ marathon and her granddaughter, Sara, participated in the 5K and kids’ races for ages 2-12.

One team of participants returned again this year, Team Sox, which included Jenny Ryan, Kyle Mirena, and Elyse Heine. Jenny is a writer for the foundation and has Turner Syndrome. She ran this year in support of the city of Boston and explained just how significant awareness events such as this are when she said,

“This event definitely did enough to raise awareness of Turner Syndrome. If one person sees our bright green shirts and asks about Turner Syndrome or stops at the TSF booth while registering, that is worth it. Two years ago, my mom and I went into a shop near the boardwalk where the event was being held in our TSF shirts and the store clerk asked us what our shirts meant! The fact that Turner Syndrome can happen to anyone and having more people know about it and recognize the symptoms, the better. Maybe the store clerk has a niece or sister who is tiny with droopy eyes but she has not been diagnosed with anything. Because of our shirts, the clerk might convince the girl’s doctor to test for Turner Syndrome. I saw a lot of TSF shirts last weekend and that means a lot of awareness. You cannot miss our bright green shirts!”

She is already planning to participate in next year’s 5K on April 26 with a big group of people and said, “Turner Syndrome is very personal to me, so anything I can do to raise funds and awareness to help fellow Turner Syndrome patients I will.”

This year there were new participants supporting the foundation including the Blake family, Kathy Caron, and the Rakowski family. The Blake family has a two year old daughter, Olivia, who was diagnosed with Turner Syndrome two years ago. They came with members of Stacy's family who participated in the 5K. They connected with the foundation in the end of April and signed up immediately for the marathon. Their team exceeded their fundraising goal and the foundation hopes that they will consider coming back for next year's marathon which will be held on the weekend of April 26 and 27.

The Rakowski family was featured in an article in the *Star Ledger* about their participation with the foundation in the New Jersey Marathon. Eileen and Andrew Rakowski are parents of an 11 year old daughter, Elizabeth, who has Turner Syndrome, and Mary, a 9 year old. Elizabeth was only diagnosed with Turner Syndrome last year and Eileen hopes that girls can be diagnosed with Turner Syndrome at an earlier age. What has changed since her diagnosis is that Elizabeth now does her own growth hormone shots at night and has been taking thyroid medication.

In the article, Eileen and her family discussed why they chose to run for the foundation. Eileen said, "This is for the Turner Syndrome Foundation. We wanted to raise awareness."

Elizabeth and Andrew ran the 5K on Saturday morning and Andrew ran the half marathon on Sunday. Andrew and Eileen instilled a love of running in Elizabeth and Mary and Eileen was the first one to begin running. She said, "I started first, it was part of the corporate challenge so I started training. It just became something we liked to do."

Kathy Caron and her family came from Maine to support her participation in the New Jersey Marathon for Team TSF. Her participation in this event inspired her to begin creating a team in Maine and she said, "We came to New Jersey to learn about the Turner Syndrome Foundation and meet your staff, to learn how to bring awareness back to Maine, and to create a team up here. All of this information was provided and then some! We learned how much work is being done in an effort to really educate providers. This is crucial and I look forward to doing the same in Maine."

She wasn't able to finish her first marathon as she dropped out at mile 19 but her husband, daughter, and son let her know about the information provided about Turner Syndrome at the foundation's Treats and Sweets bake sale at the finish line tent area. She said, "To me, that speaks volumes. It clearly is catching the eye of people. I know as I raised money here in Maine, many, many people now are being made aware of what Turner Syndrome is. The website is eye catching as is the Facebook, two great avenues."

Kathy greatly enjoyed participating in the marathon for the foundation and said, "Donna is a phenomenal coach who really cared and truly has a passion as does Laura. I loved meeting them both and would love to do another event with them someday soon."

Everyone who was involved with Team TSF at the New Jersey Marathon this year had their own reasons for supporting the foundation. Some may have friends with Turner Syndrome. Others

have family members and relatives with the condition. No matter what their reason was, they were all there to support the cause. With over 40 registered participants and a large number of volunteers this year—some of whom volunteered for the foundation for the first time—it only served to prove that there are many who support Turner Syndrome awareness.

It is not too early to register to participate with the foundation in next year's New Jersey Marathon events so visit <https://tsf.myetap.org/njm2013/> and click "register now".

