

A Race for Her Daughter

Caitlin L. Gong



Kathy Caron of Gorham, Maine, is a mother on a mission. She is participating with the Turner Syndrome Foundation running the full 26.2 mile NJ Marathon going from Oceanport to Long Branch on May 5 in honor of her daughter, Brooke, who has a random genetic mutation called Turner Syndrome. This is her first time coming to New Jersey so this is a great opportunity to experience life at the Jersey Shore. The Turner Syndrome Foundation through its participation in the marathon and its goal to spread awareness of Turner Syndrome is contributing to the economy by having participants stay in local hotels, eat at restaurants, shop in local stores, and visit local attractions. By coming to the region supporters are adding to the rebound and rebuilding of the beautiful Jersey Shore.

Joe Gigas, the race director for the NJ Marathon said,

“Some of you may not have thought of your participation in our event as helping to Restore the Shore; however the millions of dollars of economic impact which our event will produce for these communities and charities is very much needed, and much

appreciated. If you'd like to do even more, here's how: Spend an extra night in a local hotel, have a great meal at a local restaurant, shop in the local shops, etc. That's part of "Run, Rebuild, Restore", our plan to continue to help this part of the Shore!"

An article by Joshua Burd in *NJ BIZ* about the Jersey Shore returning back to business described the proceedings that occurred at March 8's annual NJBIZ Real Estate Symposium. The keynote speaker, Michele Brown of the Economic Development Authority, said the state is launching a \$25 million federally funded marketing campaign to promote shore tourism. Brown said,

"It's not going to be any more complicated than "We are open, please come."

She comes all the way from Maine for this event so the question that remains to be asked is—what made her travel so far to run for Team TSF?

This is her first time running for Team TSF and she decided to do this because there was a lack of support in Maine and throughout New England about Turner Syndrome. She said,

"For six years, I have tried reaching out and found nothing."

She decided to take Brooke and her family down to New Jersey to participate in the marathon because she had seen the work that the Turner Syndrome Foundation was doing in the community and around the country to advocate and create awareness of Turner Syndrome. This would also give Brooke a chance to meet other girls with Turner Syndrome and their families.

Brooke was diagnosed with Turner Syndrome when she was ten after she went for her annual checkup and they found that she had not grown yet. She did an online search about short stature and found out about Turner Syndrome. Realizing that Brooke had all of the symptoms of Turner Syndrome, she asked to have a karyotype test done which led to her diagnosis with Turner Syndrome.

Affecting one in 2,000 females, the condition occurs when one of the two X chromosomes normally found in females is missing or incomplete. Although the exact cause of Turner syndrome is unknown, it appears to occur as a result of a random error during the division of sex cells.

Babies born with Turner Syndrome are considered miracles, because typically, their life ends in spontaneous abortion. There are a host of possible physical and medical characteristics: short stature, lack of secondary sexual development at puberty, infertility, a short webbed neck, heart defects, kidney abnormalities, and other malformations. There is also a heightened incidence of osteoporosis, type II diabetes,

hypothyroidism, learning strengths and weaknesses, and social challenges.

Since her husband was 6'4" and because of her daughter's age upon diagnosis it was decided that Brooke would not have growth hormone shots. Brooke even said,

"God made me this way. I will grow the way He wants me to grow."

Her biggest health issue was her ears which were left damaged after going through too many tubes and scar tissue but had a major ear surgery done at Boston Children's Hospital by an ear, nose, and throat doctor that Kathy called "one of the greatest ENTs I have ever met." She hasn't had any heart and kidney issues but has regular checkups to assess her heart and kidney functions. Her doctors are very well informed on Turner Syndrome which she calls a blessing. Most doctors aren't familiar with the condition, and therefore, diagnosis arrives later in adolescence, keeping patients from obtaining critical screenings, early interventions and medical treatments. Kathy does however wish that someday doctors could find a way to keep healthy eggs frozen and wants others to become more educated on nonverbal issues that many girls and women with Turner Syndrome have.

Brooke is now a sophomore in high school who was described as vibrant and beautiful. She is very active and Kathy said,

"She is in her high school band and plays the flute, was part of the cheerleading team this winter, plays lacrosse, is in honors classes, was recently invited to participate in the Youth Leadership Forum on Medicine in Boston this summer, and will be studying and shadowing at Harvard and Tufts."

Kathy said that the marathon has great personal significance to her and her family because she said,

"For six years we have been searching for support, someone we could talk to regarding all the changes and what to expect. It wasn't until recently that we met a family who had just found out their daughter had Turner Syndrome. After speaking to Brooke's doctors, we continue to learn that there are patients out there and girls and ladies who have also gone undiagnosed. It is important because we not only want Brooke to see she is not alone, but to raise awareness here in Maine and New England. Being part of this team has already caught the attention of many and is about to reach so many more!"

This marathon would also help her fulfill a promise she made to her father who was left paralyzed after a stroke. He asked if she believed he could run an Ironman and while at the time she was overweight she promised she would take him there. He died after Brooke was diagnosed with Turner Syndrome and since his death she has

participated in a few sprint triathlons, two half Ironmans, a number of 5Ks, and still has the full Ironman promise to keep.

Kathy has gone through a health ordeal of her own as she is a cancer survivor and has been a part of the cancer survivor triathlon training groups in Maine. It was exciting when she found out that the foundation had a team and hopes to have a Team TSF team in Maine as well someday.

She is training for the marathon through a running schedule and program she found online which is 16 weeks long and is cross training with P90X while interning to become a personal trainer and health coach in Maine. The treadmill and snowshoeing have been a major part of her exercise routine.

Brooke's story is an inspiration to others with Turner Syndrome. She is a girl with many strengths and accomplishments and has a great support system behind her. Kathy said,

“As a parent you read so much about the obstacles girls with Turner Syndrome need to potentially overcome or whatever their weakness may be, but really, they have so many strengths and so much to offer the world.”

You can find out more about the Turner Syndrome Foundation at www.tsfusa.org, contacting (800) 594-4585, or emailing info@tsfusa.org.



**Turner
Syndrome
Foundation**