

Going Green for Turner Syndrome Awareness

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The Turner Syndrome Foundation is an official charity and beneficiary of the NJ Marathon again for the fourth year. The NJ Marathon Festival at the Shore is approaching quickly with only two months left before the event begins on May 4 and 5.

Donna Villavicencio has been involved with the NJ Marathon since 2010 when she decided to run the half marathon and raise funds for the Turner Syndrome Foundation because her then-fifteen month old daughter, Ava, had Turner Syndrome and it was a cause dear to her heart. She went to the website of the marathon and saw that there was a charity program. She then contacted Laura Fasciano, the founder and president of the Turner Syndrome Foundation, who was very enthusiastic about the foundation becoming an official charity of the marathon.

Laura said, "Team TSF is our national awareness campaign in motion where individuals and families bond together to create a community of awareness and compassionate support. Many transcend from this to become stronger self-advocates to find support for themselves and to help others."

After many phone calls and emails and paperwork to fill out, the foundation became an official charity of the NJ Marathon.

Donna is motivated to run because it is a great way to raise awareness of Turner Syndrome and raise funds for the foundation all in a fun and exciting atmosphere. It also allows those with Turner Syndrome to meet others with the condition whom they may not have met before and to learn from their experiences. Their stories are inspiring to her because she says, "It gives me hope that Ava will live to her fullest potential."

Her daughter, Ava, was diagnosed while in utero when Donna was 19 weeks pregnant. Her doctors noticed a lot of abnormalities in the ultrasound scan particularly heart and kidney issues, a cystic hygroma (a pocket of fluid on the neck), and hydrops (swelling and excess fluid in the organs). They advised her to terminate the pregnancy but she went ahead with the amniocentesis which showed her and her husband that Ava had Turner Syndrome. They prayed for Ava and on October 17, 2008 Ava was born.

Ava was born with many issues including several heart defects which will require surgery someday. She has a horseshoe-shaped kidney and difficulty on the left side and has had numerous surgeries and procedures to help with her chronic urinary tract infections. Earlier this year she had several surgeries, kidney stones, and infections but is now doing well.

She is enrolled in the local public school which goes from pre-K to 3rd grade and receives occupational and speech therapy there. Ava also takes gymnastics and swim lessons. Donna said, “She is an amazing, funny, loving little girl who brings us joy in every way. She is perfect just the way she is and we tell her everyday how wonderful she is and that she can do anything. “

Donna is the lead organizer of Team TSF events for the foundation and helped organize a team and ran for the foundation in Phoenix. Currently, the foundation has Team TSF events planned in Nashville on April 27; Seattle on June 22; and Brooklyn on October 12.

It is a major effort to organize these events as she has to recruit volunteers and runners, order T-shirts for the participants, and order other supplies as needed. How does she do all of this and still have time for her family?

She said, “Well, I just do the best I can do. Obviously Ava's care and caring for her younger sister, Lila, is my first priority. But the support from TSF and others in the Turner Syndrome community makes our lives so much easier than it would have been had we not found such a great group of people. It feels good to give back what you can and know that you are helping others who live in the same world as your little girl.”

This year Donna is being helped in her organization of Team TSF events by Joan DeVito, a grandmother of a 6 ½ year old girl with Turner Syndrome. Joan has previously participated with Team TSF with her family in the Saturday events with a few family members running in the marathon in 2011. She said that she didn't realize how much it took to organize the marathon until she herself became involved in organizing the event.

She chose to participate with Team TSF because she said, “Until my granddaughter, Ava, was diagnosed with Turner Syndrome, I had never even heard of Turner Syndrome. I think it is so important for everyone to become aware of the condition and understand exactly what it is. As with any condition, awareness leads to knowledge, understanding, and acceptance.”

Joan described Ava as a happy and healthy little girl who loves life. She knows that Ava has some challenges ahead but they will be met as they come. She agrees with Donna that the marathon is a great way to promote awareness of Turner Syndrome. When Joan's daughter received Ava's diagnosis of Turner Syndrome they immediately began searching for information. Joan said,

“Much of the information was frightening and we didn't have anyone to talk to or learn from anyone's personal experiences. When my daughter found the Turner Syndrome Foundation, she was so happy to connect with others going through the same experiences that she was. We have learned so much and met so many wonderful people.”

Laura added, “The foundation is organized in New Jersey and services the needs of the community throughout the United States. We're hoping to grow a nice team of support this year at the New Jersey Marathon.”

Joan chose to volunteer with the foundation because she lost her job and went into retirement earlier than she had planned to. She babysat her youngest granddaughter and volunteered in a few areas before deciding to volunteer with the Turner Syndrome Foundation after her granddaughter went into school full-time. She said,

“Since Turner Syndrome is a cause that is near and dear to my heart, I felt that was the best area to see if I could be of some assistance.”

One change that she would like to influence through volunteering with the foundation is to see Turner Syndrome become a condition that people are more familiar with so that girls and women with the condition feel more understood and accepted.

If you want to register to volunteer or run for the Turner Syndrome Foundation, please visit <https://tsf.myetap.org/fundraiser/NJMarathon2013/> or call (800) 594-4585. This will provide with you the full schedule of events, fundraising requirements, and forms that you must submit by fax to (800) 594-3862, mail to PO Box 726 in Holmdel, and by email to coach@tsfusa.org. Runners for Team TSF will receive a Team TSF T-shirt and wristband and volunteers will receive a NJM T-shirt, a volunteer certificate with their hours, and a wristband.

