

Young and On a Mission: Girl Scouts Creating Awareness of Turner Syndrome

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Victoria Carolan and her troop of Cadet Girl Scouts, Troop 60478, are girls on a mission—to increase awareness of Turner Syndrome in New Jersey. What led them to choose Turner Syndrome awareness as their mission? One girl in the troop has Turner Syndrome and her story inspired the rest of the troop to want to change the way Turner Syndrome is perceived in New Jersey.

Victoria was diagnosed with Turner Syndrome at birth and has been under treatments and care for her condition since birth. She may have Turner Syndrome but it does not define her life. She moved to Basking Ridge a few years ago and tried to find friends and ways to impact the community through a local Girl Scout Club. A troop was formed with three other girls, Jenna, Radhika, and Maya.

The girls have been very active in the community ever since and have participated in activities such as a fall cleanup at an arboretum, a food drive and cooking for Samaritan Homeless Interim Program, wrapping gifts for children in need, and reaching out to senior citizens and veterans in the community. They truly enjoyed making an impact in their community but wanted to have an impact on the world.

This was how the troop came up with the idea to go for their Silver Award, the highest national award that a Girl Scout can receive. Girl Scouts who try to go for a Silver Award must engage in a project that has a sustainable impact outside of their immediate community and must spend a minimum of 50 hours on the project. The troop decided to make their project Turner Syndrome awareness as Turner Syndrome affects 1 in 2000 females in the United States and is a condition that is common but often misunderstood.

The girls in the troop watched online testimonies by other girls and women with Turner Syndrome and tried to educate themselves on the topic. After they brainstormed amongst themselves they decided to put their project into action. Since February is national Turner Syndrome Awareness Month, they began sending information about Turner Syndrome to local schools, doctors' offices, libraries, churches, and women's crisis pregnancy centers. They also were able to talk to school nurses in local schools about Turner Syndrome and the importance of early diagnosis.

Turner Syndrome is a condition that is often diagnosed at a late age because not all girls exhibit classic indications of Turner Syndrome including a webbed neck, low set ears and hairline, heart abnormalities, and a broad shield chest. This late diagnosis impacts their ability to receive the necessary treatments to develop normally as a female including estrogen replacement therapy and human growth hormone injections. Early diagnosis will not only benefit them physically but also academically as well since many girls with Turner Syndrome have a nonverbal learning disability.

Increasing awareness of the condition will allow the condition to become more understood by members of the general public and allow individuals with Turner Syndrome to be more accepted by their communities. One major awareness event coming up is the New Jersey Marathon where the Turner Syndrome Foundation will be serving as an official charity and beneficiary of the marathon for the fourth year. This is their largest fundraising event and allows individuals with Turner Syndrome and their families to meet others with Turner Syndrome, share their stories, and participate in events in a fun and exciting atmosphere.

Victoria and her mother, Kimberly, ran the New Jersey Marathon ½ Marathon for Team TSF to raise awareness not only for the foundation but for Turner Syndrome in general. At the event there was a Turner Syndrome Treats and Sweets bake sale and members of Victoria's troop baked goods for the bake sale.

Another event that the Girl Scout troop will be participating in is at the Basking Ridge Charter Day on May 18. The girls will have a booth offering face painting and henna and will be distributing pamphlets about Turner Syndrome. These girls are working hard to make a difference in the lives of

individuals with this condition and can truly change the way Turner Syndrome is perceived in communities not only in New Jersey but around the country as well.

