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Daughter with Turner's Syndrome inspires organization

By DANIELLE LYNCH, Staff Writer
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WEST VINCENT - When Steve and Kimberly Niggeman received the results of their 3-year-old daughter's diagnosis, they felt like they were scrambling to find information about it.

After several meetings with doctors of different disciplines, they were told their daughter, Cassidy, now 10, was diagnosed with Turner Syndrome, a chromosomal condition that affects about one in 2,000 live, female births worldwide. This condition results when one of the two X chromosomes normally found in females is missing or incomplete.

With the help of Steve's parents, Judy and Jack Niggeman of West Chester, the family took a proactive approach with Cassidy's diagnosis. In 2004, the Niggemans founded Chain of Love to support nonprofit medical research about Turner Syndrome and charitable activities. The Chain of Love Foundation for Turner Syndrome is a fund of the Chester County Community Foundation.

According to the Turner Syndrome Society of the United States, primary characteristics of this condition include short stature and premature ovarian failure. There are also several physical characteristics that can vary greatly from each individual, according to the national society. Health issues associated with the heart, kidney, thyroid and ears are common, too.

Cassidy has Mosaic Turner Syndrome, according to her parents. Along with a list of health problems, she has conceptual and processing issues, her parents said.

"She's a loving, pleasant, warm individual," Kimberly said of her daughter. "She's just a breath of fresh air."

When Cassidy's parents found out, they became actively involved with the national Turner Syndrome organization, and eventually Kimberly became the president of the tri-state chapter. Eventually, Steve said he and his wife decided to pull away from the national level and create a more direct foundation.

Judy Niggeman said she, too, found there was not a lot of information about the syndrome and wanted to help form the local Chain of Love.

"We felt it was the way to do it," she said.

Jack Niggeman said the idea of the foundation stemmed from the family's frustration of going to conventions and seeing a lack of awareness about the syndrome.

Chain of Love is looking to expand its board. And as part of the foundation's fundraising efforts, it recently held its third annual golf tournament in Elverson. Additionally, the family supports a large Turner Syndrome research project being done at Stanford University in California. And over the past three years, the foundation has provided scholarships to a Turner camp at Pepperdine University, also in California, for girls between the ages of 12 and 18.

For more information about the Chain of Love and Turner Syndrome, visit <http://www.turnerschainoflove.org/>.

For additional information about the national society and the syndrome, visit <http://www.turnersyndrome.org/>.

To contact staff writer Danielle Lynch, send an e-mail to dlynch@dailylocal.com.

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