



FOR IMMEDIATE RELEASE
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Chester County Couple Begin Foundation for Turner Syndrome
Golf tournament fundraising event for genetic disorder set for September

Chester Springs, PA – July 28, 2008 – A Chester County couple have started The Chain of Love Foundation for Turner Syndrome which focuses on public awareness, physician education and the support of medical research for the genetic condition.

Steve and Kimberly Niggeman, whose 10-year-old daughter was born with Turner Syndrome began the foundation as a means of helping families and parents of Turner Syndrome children.

In an effort to raise money for support and research into the causes and impact of Turner Syndrome, The Chain of Love is hosting a fundraising golf tournament at the French Creek Golf Club in Elverson, PA, on September 22nd. It will be the third golf tournament fundraiser hosted by the foundation. “The mission of the foundation is to help those afflicted with this condition and their families improve their quality of life through support, education and research,” says Kimberly.

Turner Syndrome is a chromosomal condition which results when one of the two X chromosomes normally found in females is missing or incomplete. It currently affects 60,000 girls and women in the United States. The disorder occurs in about 1 of 2,000 live female births worldwide. Each year, 800 new cases are diagnosed nationwide. Turner Syndrome can be diagnosed during pregnancy with amniocentesis. Nearly 98 percent of pregnancies with Turner Syndrome-afflicted fetuses spontaneously abort. Approximately 10% of fetuses from pregnancies that have spontaneously aborted have Turner Syndrome.

The syndrome represents a wide spectrum of clinical presentation. Symptoms can range from minor cosmetic issues to major heart defects. Some women may have many symptoms of Turner Syndrome, while other may have only a few. Almost all females with Turner Syndrome have short stature and loss of ovarian function. The condition can cause a multitude of other symptoms including abnormalities of the heart and blood vessels, kidneys, thyroid, immune system problems, hearing loss and neurological disturbances. Because it is part of one’s genetic

makeup, there is no cure.

The Chain of Love Foundation is currently funding a large research project at Stanford University, that will provide greater insight into the changes in brain structure and function in girls with Turner Syndrome.

Although they may have increased health risks and face some learning difficulties, with proper medical treatments and early intervention, all evidence suggests these girls can live full, healthy lives. Early diagnosis is critical for these girls to develop into their full potential.

For more information on The Chain of Love and the upcoming golf tournament fundraising event, contact Kimberly Niggeman at 610-827-9565.

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