Press Release for MEDIA COVERAGE
For Immediate release

• **ANNOUNCEMENT**
  Turner Syndrome Foundation Announces TSRX

Turner Syndrome Foundation announces the Turner Syndrome Research eXchange (TSRX), leveraging Invitae’s Patient Insights Network (PIN) to amplify patients’ voices and accelerate research of Turner Syndrome. We encourage all professionals to invite Turner Syndrome patients to provide medical information to the PIN to help the global community – patients, families, researchers, clinicians, and pharmaceutical companies – learn more about Turner Syndrome. The goal is improved diagnosis and medical care, as well as empowerment of patients and families through knowledge, connections, and support.

The PIN is different from traditional patient registries because it allows patients to update their medical data in real-time, connecting patients to clinical trials and information that best matches their responses. Patients hold the key to advancing science and medicine. TSRX offers an outlet for patients to share their data and clinicians to see the results in the form of statistics, graphs, and more.

Storing data in one place has many benefits across all sectors. Joining the TSRX can help patients understand their own health by exploring de-identified data submitted by others. Physicians and clinicians are able to connect with larger target patient populations to drive research growth. In addition, PINs help pharmaceutical companies find better treatments faster and help advocacy organizations, like TSF, better understand the needs of the community they serve.

Why Invitae? Invitae has a current database of more than 75,000 patients representing more than 400 diseases. They are also working with more than 100 advocacy organizations, established national researchers, clinicians, and more. Invitae understands the importance of connecting all of these groups in order to accelerate the understanding of conditions like Turner Syndrome, with the patient at the center of it all.

Allied healthcare professionals are invited to share this opportunity with their patients. We can all benefit from full participation of TSRX and together, we can reach more patients and family members. Stand together for the future of Turner Syndrome research and care. TSRX can be accessed at: [TSRX.us](http://www.TurnerSyndromeFoundation.org)
ABOUT TURNER SYNDROME FOUNDATION, INC.

Tag Line:
Turner Syndrome affects 1 in 2000 females. We can help.

TSF mission statement:
The goal of the Turner Syndrome Foundation (TSF) is to support research and develop programs, which will increase professional awareness and enhance medical care of those affected by Turner Syndrome. Early diagnosis and comprehensive treatments over the lifespan may lead to a brighter and healthier future for all young girls and women with Turner Syndrome. TSF is a registered 501 (c) 3 organization incorporated in New Jersey.

First a baby, soon a growing child, and finally a woman, our efforts must transcend the Turner syndrome life span.

Understanding Turner Syndrome:
Turner syndrome 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. This chromosomal disorder occurs in 1 out of 2000 live female births. 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 possible malformations. There is also a heightened incidence of osteoporosis, type II diabetes, hypothyroidism, learning strengths and weaknesses, and social challenges. With Turner Syndrome, there appears to be a great variability in the degree to which each person is affected by any or all of these manifestations.

Our history:
In August 2008, the Turner Syndrome NJ Chapter was formed to create community, education, awareness and advocacy. In December 2009, the chapter was reorganized as an independent 501(c)(3) organization with a national focus on advocacy. An Executive Board of Trustees, Committees, and a prestigious Medical Advisory Board have been assembled to fulfill the mission statement.