MAKING A DIFFERENCE
...for every female living with Turner Syndrome
Turner Syndrome Foundation (TSF) is a humanitarian organization dedicated to the welfare of the women and girls affected by Turner Syndrome (TS). Since 2008, TSF has been working to reduce the age at which diagnosis is made, improve access to care, promote research, and offer essential systems of support.

We see a delay in the diagnosis of TS babies who require care beginning at birth. We see a void in the transition from pediatric to adult care. We see girls and women of all ages without knowledgeable care providers or support groups. We see families ravaged by the loss of their precious baby girl. We see families who struggle to find the words to share a diagnosis.

With our vision, we also see a world where TS women are proud to be members of our community. We see ongoing research to increase understanding of this common, but uncommonly known, disorder. We see support groups and care centers in every corner of the nation. We see caregivers with important resources at every step of their journey. And we see the smiling faces of TS girls and women who are receiving the care and attention they deserve.

Join us and make our vision a reality.
Babies born with TS are considered miracles because typically, their life ends in spontaneous miscarriage. Turner Syndrome is a random disorder affecting only women. It occurs when cells are missing all or part of an X chromosome. Every girl affected by Turner Syndrome will experience health problems and medical complications. Individuals affected by TS experience different symptoms at various levels of severity. A regimen of medical care is needed to monitor and treat the effects of the disorder throughout the lifespan of the individual starting at birth, though this early diagnosis occurs less frequently than preferred.

Clinical Features
- Short stature and stunted development (95%, average height 4’8” if untreated)
- Unique skeletal and physical features
- Delayed puberty (70-80%)
- Ovarian and reproductive failure (98%)
- Constriction in heart blood vessels (10%)
- Heart valve problems (30%)
- High blood pressure (30-50%)
- Kidney malformations (33%)
- Osteoporosis (50%)
- Type II diabetes (twice the risk of the general population)
- Thyroid disorder (33%)
- Issues with visual-spatial coordination tasks
- Social issues and anxiety
- Hearing loss and frequent ear infections (up to 90%)
- Dental and palate issues

"I have been trying to get my daughter involved with the Turner Syndrome Foundation. She has not been on this journey long, as she didn't find out until she was 17. Nobody we know understands Turner Syndrome, thus it's been hard to discuss questions and concerns with anyone. Thank you again for reaching out. It means a very lot to me."
Turner Syndrome affects every 1 in 2,000 females. That’s more than two million women and girls worldwide! This number actually may be even higher since many go undiagnosed or are diagnosed late in life. The average diagnosis age remains at 15.5 years old. This is an issue because, depending on the case, care can begin as early as birth. Fewer than 30% are diagnosed before puberty, meaning 70% are diagnosed too late for timely medical interventions and effective treatments. Unfortunately, this inadequate care continues. In adolescence there are minimal resources available to her about the necessary steps to take as she transitions into adult care. As adults, Turners women are not managing their condition effectively. Only 3% of adult women with TS are adhering to the clinical care guidelines outlined by the National Institute of Health. Similarly, these women are unable to find local support groups or caregivers specializing in TS care.

**Turner Timeline**

Highlighting Interventions that Produce the Best Outcomes for Turner Syndrome Patients

- Growth Hormone Therapy as early as 9 months
- Celiac Disease Screening at age 4
- Cardiac MRI by age 9
- Estrogen Replacement Therapy at age 12
- Vision Screening by 18 months
- Orthodontic Evaluation at age 7
- Pubertal Evaluation by age 10
- Average Diagnosis Age: 15 years old

The average diagnosis age for Turner Syndrome is 15 years old - too late for patients to receive vital medical interventions, including many more not listed on the timeline.

We need your help in raising awareness, generating research, and lowering the diagnosis age of Turner Syndrome!
THE SOLUTION

This is where Turner Syndrome Foundation comes in. We partner with hospitals, universities, researchers, physicians, specialists, educators, legislators, patients, caregivers, and more to raise awareness of Turner Syndrome, promote research, encourage advocacy, and provide education to garner a greater understanding of this condition.

Our Strategy
Turner Syndrome Foundation has four main program areas: awareness, advocacy, research, and education.

AWARENESS
When physicians, educators, legislators and the general public are aware of Turner Syndrome and the devastating effects it causes, real change can and will happen.

ADVOCACY
Advocacy is the path to obtaining support, services, empowerment, and success.

RESEARCH
In order to reduce diagnosis age and improve treatment options, scientists and physicians must have a comprehensive understanding of Turner Syndrome.

EDUCATION
Education is key to helping caregivers cope with a diagnosis and showing patients how to manage their condition.
OUR MAIN PROGRAMS

Professional Education
Programs have focused primarily on professional development for medical providers and teachers. Activities include conferences in affiliation with universities, *continuing medical education* (CME) programs in conjunction with local hospitals, and numerous exhibits throughout the Mid-Atlantic. Participants range from endocrinologists and geneticists to school social workers and professors. TSF generated the premier CME program focused on Turner Syndrome, which reached tens of thousands of allied health professionals.

Patient Resources
TSF hosts patient education workshops to provide information and support to patients and caregivers by experienced, knowledgable providers. Over the past five years, the Foundation has served over 1,000 individual patients and caregivers at these events. In addition, the TSF website, www.TurnerSyndromeFoundation.org, has become a reliable, welcoming resource to those affected by Turner Syndrome. We believe in breaking down barriers and giving everyone access to vital information, so our resources and website never require memberships.

National Council of State Leaders
TSF’s National Council of State Leaders (NCSL) is devoted to improving the lives of patients affected by Turner Syndrome. The objectives of this program are
to communicate and deliver initiatives at the local and state level, provide resources for state residents, provide activities such as workshops, grand rounds, and large-scale awareness events, and collaborate with medical professionals to create meaningful, transformative programs for women nationwide.

**Awareness Events**

"I think I may know someone who has TS." This is a common response from people who see TSF’s green shirts and signs at awareness events and ask, “What is Turner Syndrome?” These events are excellent opportunities to educate the general public about TS while creating an energetic community of support. Team TSF, our national awareness movement of athletic events, has been included in events in New Jersey, Arizona, Florida, Tennessee, New York, Texas, and Washington. New events are being added to our calendar every year! Team TSF is a movement that connects patients, doctors, volunteers, supporters, and the general public to forge a system of awareness.

**Research Initiatives**

The TSF Research Committee works with universities to target and develop opportunities for innovative TS research. TSF recognizes that research is a team effort and encourages patients and caregivers to become part of the solution by participating in research studies. We continue to expand our relationships with universities and government agencies to make an impact in TS care. TSF has had major research successes, including a white paper published in the *Journal of Pediatric and Adolescent Gynecology* and a **patient and caregiver registry** project launched in 2009.
Turner Syndrome Foundation, a 501(c)3 organization, was founded to create a community and increase education, awareness, and advocacy for families affected by Turner Syndrome. An executive board, committees, and a prestigious medical advisory board were assembled to fulfill the foundation’s mission. Since 2009, TSF continues to see growth in all areas. Below are some examples of TSF’s most recent growth, including the average gift donated to TSF and the number of professional and patient contacts registered with us.

The average gift to Turner Syndrome Foundation has increased by 130% since 2015, showing our constituents’ growing faith in our abilities as a direct result of our programs and successes.

Since 2013, Turner Syndrome Foundation has seen tremendous growth in the number of people signing up through the online registry. This shows an increase in interest, website traffic, social media traffic, and dedication to research.
Turner Syndrome Foundation is recognized as a world leader for its contributions to a host of issues related to TSF programs. The greatest accomplishments of the organization to date would be the education and advocacy resources developed that reach thousands of allied health professionals, teachers, policy makers, patients and caregivers. We have been successful in raising awareness with professionals and families, but we must forge stronger collaborations with hospital networks and professional medical societies to translate information to actionable support networks. Our goal is to align our mission with that of women's health care centers, hospitals, and community clinics to provide access to helpful information and support where and when it is needed most. With over 80,000 women living with TS in the United States, our mission will not be fulfilled until the average diagnosis age is reduced and lifelong care is easily accessible.

**Priorities**

With greater philanthropic support for this cause, TSF can a) increase professional communities' awareness of the void in transitional care from childhood to adulthood, and b) increase access to specialists and care centers that are equipped to care for this specialized population. This project is important because Turner Syndrome has classically been categorized as a pediatric condition. However, proper care and management must transcend a lifetime. Our goal is to be the solution with transparent, inclusive, and accessible information and support. This is possible with you as our partner in caring.

“As I worked with these girls, I came to know that they were intelligent, hard workers who were fun and funny, nice and caring and hoping to be like the other girls of their age. I also understood that the earlier the diagnosis, the better the care and progress was. The Turner Syndrome Foundation offers assistance for patients, families, providers and educators. Few organizations accomplish that. What a great organization in that everyone can help these girls and women! It’s one you want to support and be involved with!” -Rosemary
Hi, everyone! My name is Sarah. I am a 27-year-old who was diagnosed with Turner Syndrome before birth. Geneticists speculated that if I survived birth I would have medical and educational challenges, and I would likely end up in an institution. Throughout my life I have had 13 surgeries and spent a lot of my childhood in and out of hospitals and doctors’ offices. I went to high school as scheduled for my age, but was a continuing participant in the Special Education System. I applied myself academically and was mainstreamed, going on to attend college. In 2011, I graduated with my Bachelors Degree in Human Services. For the past 5 years I’ve worked in a variety of positions for agencies that provide services for adults with disabilities. I am planning to go back to school for a Master’s Degree so that I may continue helping children and students! As I advance my career, I would love to one day have the privilege to work for an organization like TSF that does such amazing work creating better futures for all girls and woman affected by TS and are at the forefront of advocacy and research.

Since joining TSF as a volunteer, Sarah has hosted a Denim Day fundraiser raising over $1,500, ran a 5K with Team TSF, and was a featured volunteer in the TSF newsletter. Sarah said it best: "Turner Syndrome may be a part of who I am, but it does not define me.” Sarah did not let her diagnosis limit her; she chose to rise up as a TS advocate. The potential of TS girls and women is limitless, if they are diagnosed early in life and provided the proper care and resources. Together, we can make that happen.
Turner Syndrome is a completely random disorder. Any daughter, sister, aunt, or friend could potentially receive a diagnosis. TS does not discriminate against race, ethnicity, socioeconomic status, or geographic location. Take a look at the map below. Did you know that many women and girls were living with Turner Syndrome in your area? This number may actually be even higher due to the lack of timely diagnoses.

For Turner Syndrome Foundation, these are not just numbers on a map but the lives, stories, and needs that fill our mission with purpose. Together, we can educate providers to lower diagnosis age, advocate for those without a voice to offer empowerment, promote research to improve care options, and raise awareness to inspire real change. We encourage involvement in our mission to influence the future of women's health. For more information, contact philanthropy@tsfusa.org.
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