



Turner Syndrome Talking Points

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One of the biggest challenges in advocacy is starting the conversation!

1. Phone ahead to make an appointment whenever possible.
2. People connect to personal stories... share yours.
3. Think about how you are working to help the TS community be recognized, be confident!
4. Speak slowly and make eye contact.
5. Be mindful of other's time. People are busy – keep it “short and sweet.”
6. Leave them with a piece of literature to have on hand for future reference.
7. Always thank them for their time.
8. Enter their contact information into the tsfusa.org website (newsletter) with a note including you as contact and any action items that may be needed.

Understanding Turner Syndrome

Q: Are you familiar with Turner Syndrome?

A: If Yes: Are you, or someone you know, personally affected by TS? I ask this because most people I encounter are unfamiliar with the syndrome, as was I until ... (Share your personal story.)

If No: Unfortunately, most people are unfamiliar with the condition. That is why I volunteer my time to the Turner Syndrome Foundation to help raise awareness. In short, Turner Syndrome is an endocrine disorder and the leading chromosomal abnormality among women. It is a random mutation of genes, in which the secondary X-chromosome is fully or partially deleted. Every 1 in 2000 females are born with TS. However, the impact is even greater when considering those that do not survive. Only 3% of the fetuses affected by TS survive, accounting for 10% of all miscarriages.

Q: What are the implications of Turner Syndrome?

A: Every girl affected by Turner Syndrome will experience health problems and medical complications because Turner Syndrome impacts every organ system in the body. The most common health issues are heart defects, infertility, frequent ear infections, diabetes, and osteoporosis. Short physical stature also occurs in at least 95% of girls unless addressed early on with growth hormone.

Q: How is TS treated?

A: Individuals affected by the disorder 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 starting at birth, though early diagnosis occurs less frequently than preferred. Human growth hormone is a daily injection used to increase growth velocity. The final height of women that miss the window for treatment due to a late diagnosis is 4'8" on average. The second common treatment is estrogen therapy to

initiate feminization for pubertal development and overall women's health throughout a lifetime.

Q: What is the average age of diagnosis?

A: The average age of diagnosis is 15½ - too late for life-altering treatments, early interventions and, most importantly, health screenings for potentially fatal heart defects.

Q: How is TS diagnosed?

A: During prenatal screening, doctors may perform an amniocentesis or display certain features through a sonogram. At birth, if a girl exhibits indications of TS, she will be identified through a simple blood test called a karyotype. A karyotype is a laboratory technique that produces an image of an individual's chromosomes. It is used to look for abnormal numbers or structures of chromosomes. [Source: National Human Genome Research Institute]

Q: Why is a late diagnosis so common?

A: TS not part of the newborn screening panel. Only newborns that exhibit indications for TS will be screened; however, many infants with TS will appear normal at birth and are considered healthy. Many providers will treat each health issue (vision, hearing, growth, behavior, development, etc.) as separate conditions without piecing these symptoms together as one condition.

Q: Are there any cognitive affects in Turner Syndrome?

A: To some degree, 99% of those with TS will have a nonverbal learning disability (NLD) and many will depend upon support services in school. Those with NLD may have trouble with math, particularly geometry. Challenges may also involve using visual maps to navigate. Fortunately, most girls will have average to above average intelligence and many are verbally gifted.

Q: What are some social implications for women with TS?

A: Some of the psycho-social implications of NLD include difficulties adapting to new situations, which could lead to inappropriate behavior in these situations, issues with social skills and making new friends, difficulty gauging how to act in a social environment, and anxiety and depression that may develop. Shyness, social anxiety, and reduced self-esteem are also common and generally relate to the premature ovarian failure and fertility issues.

Q: Why should everyone care about Turner Syndrome?

A: Turner Syndrome is a random mutation that occurs at the time of conception, and everyone is potentially at risk. If not you, it can be a daughter, granddaughter, sister or friend that could potentially be the 1 in 2000 females affected by Turner Syndrome! Know the indications – early diagnosis is critical!

[About Turner Syndrome Foundation](#)

Q: What does the Turner Syndrome Foundation do?

A: The Turner Syndrome Foundation has assumed a leadership role in the United States to advance communications through the facilitation of education programs, advocacy, outreach, and support of research initiatives.

TSF is unique because all of these programs are offered without charging dues to anyone. TSF believes all information should be open-access in order to reach the greatest number of patients. In addition, our resources are a collaborative effort, with contributions from the people who know TS best: professionals and TS girls, women, and caregivers.

Q: How does TSF fund these programs?

A: As a nonprofit organization, TSF relies primarily on generous donations from our supporters. Other funds are generated through Team TSF athletic events, special events, foundation and corporate grants, memorial gifts, vehicle donations, and affinity programs.

Q: What are some of TSF's accomplishments?

A: Since 2009, Turner Syndrome Foundation has seen tremendous successes as a result of its programs. TSF introduced a Patient Registry to better understand the patient population and their needs. In 2018, we are happy to report that this registry has expanded to include the Turner Syndrome Research eXchange (TSRX), a patient-centered registry focused on influencing TS research and advocacy. In addition, TSF has partnered with countless medical centers and universities to increase TS education, such as Kean University, Emory University, Princeton University, Rutgers University, University of South Carolina, Montefiore Medical Center, Jersey Shore University Medical Center, and more. Finally, the Team TSF awareness campaign has grown from local races to prestigious national events. Our vision of hope and possibility for the future of Turner Syndrome care permeates every program as we continue to improve and expand.

Q: What are the opportunities to get involved?

1. Lead- Have professional experience? Are you an industry insider? Do you possess a passion for helping others? If so, then take your passion forward and lead a committee.
2. Participate- Exhibit, attend a meeting, join a committee, host a talk, rally support, run-walk-skip to keep the momentum going!
3. Fundraise- Host a fundraising event. Donations will benefit TSF. Checks can be mailed to Turner Syndrome Foundation, PO Box 726, Holmdel, NJ 07733
4. Donate- Donations without the exchange of goods or services may be considered a tax-exempt.
5. Take Action- Complete a Volunteer Application online at www.TurnerSyndromeFoundation.org.