



Short and Sweet An Advocates Guide Talking Points

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 how you are working to help the TS community be recognized, be confident.
4. Speak slowly and make eye contact.
5. Be mindful of their 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.

Here are some talking points that may be useful:

- **Are you familiar with Turner Syndrome?**

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 diagnosis story.)*

If, No. I understand. Most people are unfamiliar with the condition. That is why I volunteer my time to the Turner Syndrome Foundation to share information about TS. Did you know that TS is the leading chromosomal abnormality that affects women? It is a random mutation of genes affecting the secondary X with it being fully or partially deleted resulting in a complex endocrine disorder. 1 in 2000 females are born with TS, but sadly most fetuses will die before birth resulting in accounting for upwards of 10% of all miscarriages. Only 3% of fetuses affected by TS survive, my daughter is a survivor and a true miracle.

- **So what is Turner Syndrome?** In non-clinical basic terms, Turner Syndrome is an endocrine disorder. Girls will need hormones to grow, estrogen therapy to feminize at puberty and throughout much of their lifetime, and the majority of women will be infertile. Some girls are born with clinical features or congenital defects. There is a host of co-morbidities affecting organs including the heart, kidneys, and bladder and will affect thyroid function, blood pressure, diabetes, bone health and so much more.



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- **Is TS hard to diagnose?** No. During prenatal screening, doctors may perform an amniocentesis or perhaps display certain features through a sonogram. At birth if girls exhibit indications for TS she will be identified through a simple blood test called a karyotype.
- **What is a karyotype?** (kār'ē-ə-tīp') An organized visual profile of the chromosomes in the nucleus of a body cell of an organism. Karyotypes are prepared using cells in the metaphase stage of cell division, when chromosomal strands have coiled together and duplicated, rendering them easily visible under a microscope after staining. Photomicrographs of the stained chromosomes are then arranged in a standard format according to size, the relative position of the centromere, and other criteria. The normal human karyotype consists of 46 chromosomes. Females are 46xx.
- **What is the average age of diagnosis?** The average age of diagnosis is 15 1/2, arriving too late for life-altering treatments, early interventions and most importantly health screenings for a potentially fatal heart defect.
- **If the test is simple, why is diagnosis overlooked for so long?** 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 health story, that being Turner Syndrome.
- **What are the life-altering treatments?** Human growth hormone is the medication to increase growth velocity. The final height of women that miss the window for treatment due to advanced age of diagnosis is 4'8" on average. The other life-altering treatment is estrogen therapy to initiate gradual feminization for pubertal development and overall women's health throughout a lifetime.
- **Are there any cognitive affects in Turner Syndrome?** Yes, there is a psycho-social affect and virtually all girls have what is sometimes referred to as a nonverbal learning disability. They will present with a set of strengths and weaknesses to some varying degree. Fortunately, most girls will have average to above average intelligence and many will depend upon supportive services in an academic environment.



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What are some social implications for women with TS? While the social implications are a burden to share, they are factual. Our goal is to change these statistics:

1. Girls with TS are not being diagnosed early in life to benefit from interventions.
 2. Children spend most of their young life in a classroom. Educators must be educated about Turner Syndrome in a classroom setting.
 3. Transition from pediatric care is a concern. Recent studies show that only 3% of adult women receive the recommended care as outlined in the NIH Clinical Guidelines.
 4. 70% of adult women are unmarried and reliant upon extended family or other systems for support.
 5. TS is the most prevalent genetic defect in females affecting 1 in 2000 women – and many professionals have never heard of it!
- **What does the Turner Syndrome Foundation do?** The Turner Syndrome Foundation has assumed a leadership role in the United States to advance communications through the facilitation of education program, advocacy, outreach, and supporting research initiatives.
 - **How does the Turner Syndrome Foundation advance communications?**
 1. Facilitating education programs for professional audiences
 2. National athletic campaign: Team TSF
 3. National bake sale: Treats and Sweets for Turner Syndrome
 4. Host quarterly workshops for education- information -support
 5. Cross agency collaborations
 6. Provide free access to web resources
 7. Publish a monthly e-Newsletter
 8. Toll-free hotline offering peer-to-peer mentoring
 9. Online blog and social networking
 - **How does the Turner Syndrome Foundation fund these programs?**
 1. As a 501c3 charitable nonprofit organization, TSF relies primarily on public support.
 2. Participates in National Athletic Events
 3. Treats and Sweets for TS National Bake Sale
 4. Annual Holiday Party to Benefit TSF
 5. Special Events
 6. Foundation grants
 7. Travel for TSF
 8. Corporate match program
 9. Gift in-kind
 10. Gift tribute
 11. Gift memorial
 12. Onecause.com
 13. Ebay Mission Fish
 14. Volunteers!



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- **Why should you care about Turner Syndrome?** Turner Syndrome is a random mutation of genes, 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 TS! Know the indications – early diagnosis is critical!
- **What can you do to help?**
Volunteer! Like you, I am interested in women's health. I want to help young girls become identified at an earlier age. I want the researchers, providers and educators to understand the unmet needs of this community. By increasing advocacy efforts, I want to call attention to these issues and make a difference. This all takes tremendous effort and funding. The foundation is growing and needs our help.

What you can do now:

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. Check mailed to Turner Syndrome Foundation, PO Box 726, Holmdel, NJ 07733
4. **Donate-** Write a check. Donations without the exchange of goods or services may be considered a tax-exemption. Consult with your financial advisor.
5. **Act now-** Complete a Volunteer Application and agreement online at tsfusa.org.