Turner Syndrome Awareness Month

Outreach Toolkit
February is Turner Syndrome Awareness Month, a special opportunity to join forces, shed light on this condition, and show the world that Turner’s girls may be unique, but they are just like us. Imagine what an insurgence of Turner Syndrome awareness would mean – more support for endocrinology clinics, an increase in researchers interested in TS, and improved care for everyone affected.

Even today, many girls are diagnosed later in life when treatment options are less effective. Through education and awareness, girls and women with Turner Syndrome can be diagnosed sooner to ensure they receive proper medical interventions. Join us in our efforts to spread awareness and allow every Turner Syndrome girl the chance at a fulfilling life.

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Goals & Initiatives

“Never question the power of one. Throughout history it has been the actions of only one person who inspired the movement of change.”

What if one person (in this case, YOU!) chose to take one simple action to raise awareness for Turner Syndrome? The impact would be incredible! One more doctor educated about Turner Syndrome, one more legislator ready to join our efforts. Now imagine the impact if we all chose to take one action together. The outcome could be legislation protecting members of the TS community on a national scale, improved support for TS clinics in your area, and a community of women and girls connecting over shared experience. Don’t wait for change – make it happen today!

Below we’ve outlined goals that we believe will make the greatest impact by connecting with every individual that influences the TS community – physicians, legislators, and your own group of friends, family, neighbors, colleagues, and more!

**Goal 1**
Be the image of Turner Syndrome awareness! Submit your photo and we’ll create your own awareness poster. Complete this goal and you’ll be featured on the TSF website! Submit your photo at [https://www.getfeedback.com/r/yfBCYu8p/](https://www.getfeedback.com/r/yfBCYu8p/) to receive your poster by email.

**Goal 2**
Sign the TSF Awareness Month Petition. Legislators hold the power to getting insurance help, securing that all babies be screened for TS, and more. Let’s get their attention first by signing the TS Awareness Month petition, urging them to help us declare Awareness Month on a national scale! Find the petition at [turnersyndromefoundation.org/volunteer-3/awareness/turner-syndrome-petition/](https://turnersyndromefoundation.org/volunteer-3/awareness/turner-syndrome-petition/)

**Goal 3**
Share at least one post on your social media platforms. Visit @TurnerSyndromeFoundation on Facebook and share the pinned post titled “February is Turner Syndrome Awareness Month” to your newsfeed. Educating your followers about Turner Syndrome will help raise tremendous awareness!

**Goal 4**
Set up your online fundraiser and raise $250 or more. While you’re checking off goals 1-3, invite your community to support you by donating to TSF. TSF is 100% run on donations, so in order to continue these actions all year long on your behalf we need your help! Set up your fundraiser at [https://turnersyndromefoundation.org/online-fundraising/](https://turnersyndromefoundation.org/online-fundraising/)

One lucky person who completes all of these goals will win free entrance to the Autumn Retreat, a weekend of connection, friendship, and learning for women and girls affected by TS!
Awareness Stories

The following stories demonstrate the need for a greater Turner Syndrome awareness to prevent loss, lower diagnosis age, and improve care. Share these stories – and your own – throughout Awareness Month to demonstrate the need for support!

Marissa’s Story
At 11 weeks, my doctor informed me over the phone that our baby had a chance of having Turner Syndrome. One of the first options she gave me without even giving me time to process or look into TS was to terminate the pregnancy! Our daughter is now 7 months old. She has hit developmental milestones earlier than most and is a happy, healthy girl. The endocrinologist will be meeting with us again in 6 months to discuss the possibility of growth hormones. Avery is constantly on the go and brings a smile to nearly everyone she meets.

Isabella’s Story
I never thought I would have the opportunity to write about my personal Turner Syndrome story as a physician-immunologist, researcher and mother. I took my 12-year-old daughter to the pediatrician for an annual checkup, who ordered a karyotype test because she was worried about growth stopping. The diagnosis was Turner Syndrome. Feelings of guilt crowded my heart and I started blaming myself for not realizing it sooner. My mother, also a physician and pediatrician, was the first endocrinologist to initiate growth hormone in girls with Turner syndrome in her hometown of Maracaibo-Zulia, Venezuela. Today, my daughter attends a school of good academic standing, is a brilliant student and is doing the elective subjects that she is passionate about.

Josey’s Story
I am sure not many of you know this, but women with Turners Syndrome can easily develop anxiety. I definitely have had anxiety for as long as I can remember. After years of dealing with it, I finally went to get help. I was a junior in college looking for an internship for the summer when my anxiety got so bad it was almost crippling. I was lashing out at everyone because I was putting stress on myself. Talking about it with my counselor helped me process why I was having anxiety, which helped. Knowing why can help prepare you for triggers. I tried my best to handle my anxiety about the unknown and impending adulthood I was about to face, but like most I had good days and bad days.
February is Turner Syndrome Awareness Month

Know the signs.

www.TurnerSyndromeFoundation.org

February is TURNER SYNDROME AWARENESS MONTH

Know the signs. Change a life.

www.TurnerSyndromeFoundation.org
Sample Social Media Posts:

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

**Facebook**
February is Turner Syndrome Awareness Month! Learn about Turner Syndrome and get to know the signs by visiting www.TurnerSyndromeFoundation.org. There you’ll learn about this female only condition that randomly affects 1 in 2000.

Did you know that over 80,000 women and girls in the United States are living with Turner Syndrome? Did you know that some of them have not yet been diagnosed? Learn the signs of Turner Syndrome and help change a life.

Did you know that Turner Syndrome can affect ANYONE of any race, age, or location? Take action this Awareness Month – learn more about Turner Syndrome and what you can do to raise awareness at www.turnersyndromefoundation.org

**Twitter**
February is #TurnerSyndromeAwarenessMonth. Learn more and take action at www.turnersyndromefoundation.org

This February take action for #TurnerSyndromeAwarenessMonth. Learn how you can help at www.turnersyndromefoundation.org

Many with Turner Syndrome are diagnosed late. Know the signs and change a life. #TurnerSyndromeAwarenessMonth
Don't miss this diagnosis!

Turner Syndrome affects 1 in 2,000 females.

Possible indications for this lifelong condition:

- Short stature
- Delayed puberty
- Wide short neck
- Wide shield chest with wide spaced nipples
- Low set ears
- Low set hairline
- Short 4th metacarpal
- Eye sight issues, strabismus
- Otitis media & hearing loss
- Heart abnormalities
- Kidney issues & infections
- Lymphedema
- Scoliosis & malformed bones
- Dysmorphic features
- High arched palate
- Dental problems
- Upturned fingernails
- Academic strengths & weaknesses
- Social issues & anxiety
- Weight gain & associated risks
- Pigmented moles & dry skin

February & Everyday Awareness
February is Turner Syndrome Awareness Month, but raising awareness for this common but uncommonly known condition must continue all year. Do any of your patients have one or more of the indications mentioned above? Consider testing them for a Turner Syndrome diagnosis. Visit www.TurnerSyndromeFoundation.org for more patient and professional resources.

www.TurnerSyndromeFoundation.org
(800) 594-4585
info@tsfusa.org
Sample Announcement

[YOUR ORG NAME] is joining the Turner Syndrome Foundation to Celebrate Turner Syndrome Awareness Month!

[CITY OF YOUR ORG] – [YOUR ORG NAME] is proud to stand with the Turner Syndrome Foundation this February to raise Turner Syndrome awareness! Turner Syndrome is a leading genetic disorder in females and affects every 1 in 2,000 randomly. Though Turner Syndrome is a lifelong condition, health outcomes can be improved through early diagnosis and comprehensive treatments.

[OPTIONAL PARAGRAPH WHY YOUR ORG SUPPORTS AWARENESS MONTH]

This month and throughout the year, [YOUR ORG] and the Turner Syndrome Foundation encourage you to play a role in raising Turner Syndrome awareness in your community. Educate yourself on the signs and symptoms of Turner Syndrome. Then share that knowledge widely. “February is a special opportunity to support the women and girls affected by Turner Syndrome. We must have everyone’s participation to make the greatest impact for this women’s health initiative,” [YOUR SPOKESPERSON’S NAME & TITLE].

[ADD ANY DETAILS ABOUT LOCAL AWARENESS MONTH ACTIVITIES]

While Turner Syndrome awareness is especially celebrated throughout the month of February, support for TS women and girls must continue all year long. To find more ways to get involved, please visit the Turner Syndrome Foundation website at www.TurnerSyndromeFoundation.org.

[BRIEF PARAGRAPH DESCRIBING YOUR ORG]

The Turner Syndrome Foundation supports research initiatives and facilitates education programs that increase awareness and enhance medical care of those affected by Turner syndrome. Turner Syndrome Foundation collaborates with patients, physicians, educators, legislators, and researchers to fulfill our mission through our four program areas of awareness, advocacy, education, and research. TSF serves more than 20,000 individuals through our patient and professional education workshops, national awareness athletic events, research registry, and open-access education resources. To learn more, visit www.TurnerSyndromeFoundation.org
Turner Syndrome Talking Points

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.
FAQs

Who can participate?
Anyone! Everyone is invited to join us in spreading awareness this February. Those under the age of 18 must have parental consent to participate. If you are not an individual directly impacted by TS, you may donate your grand prize to a TS girl or woman.

How long do I have to complete each goal?
The competition will run through the month of February (Awareness Month), ending on Friday, March 15. Goals do not need to be completed in order and can be completed simultaneously.

If I am participating for my daughter, who wins the grand prize?
Parents completing the challenge for or with their daughter are eligible to win the grand prize for their daughter as well. Please keep in mind that anyone age 16 and below must be accompanied by an adult, so you will be required to purchase your own entry to the Retreat.

Assistance

Email Support
When you sign up to receive your personalized poster (goal #1), we'll add you to the Awareness Month email list. Be on the lookout because we'll be sending you tips and tricks to your inbox all month long to help you raise awareness!

Live Videos
We'll be hosting live videos to answer your questions throughout the month of February. The schedule of these events will be shared with you closer to the event date, so make sure you open your emails from us during February!

Need additional support? Contact us; we're here to help!
Email: info@tsfusa.org
Phone: (800) 594-4585 10AM-6PM EST
Visit our website at https://turnersyndromefoundation.org/volunteer-3/awareness/ for additional resources.