Turner Syndrome Awareness Month

Outreach Toolkit

Turner Syndrome Foundation

Turner Syndrome Foundation
www.TurnerSyndromeFoundation.org
(800) 594-4585

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 resurgence 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!

On the next page, 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!

Goals & Initiatives

Goal 1: My Story

Submit your story to help bring awareness to your experience and help others feel less alone. Complete this goal and you may be featured on the TSF website or social media!

Submit My Story

Goal 2: Petition

Sign the Petition for Turner Syndrome Patient Care, urging legislators to support policies to improve health care for the TS community. Help get their attention by signing our petition!

Sign the Petition

Goal 3: Social Media

Share a post on your social media to raise awareness of Turner syndrome, and be sure to tag us @TurnerSyndromeFoundation! Scroll to page [#] for post templates.

Goal 4: Fundraise

Set up your online fundraiser and invite your community to support you by donating to TSF. TSF is 100% run on donations, so your support helps keep our mission going!

Start a Fundraiser

Awareness Stories

Marissa's Story

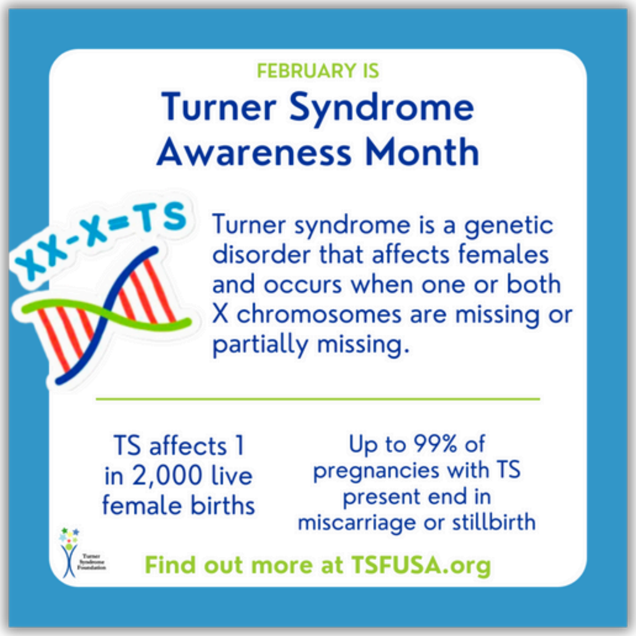
At 11 weeks, my doctor informed me over the phone that our baby had a chance of having Turner syndrome. One of the first options she gave me without even giving me time to process or look into TS was to terminate the pregnancy! Our daughter is now 7 months old. She has hit developmental milestones earlier 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 everyone she meets.

Marissa's Story

I am a physician immunologist, researcher, and mother. When my 12-year-old daughter to the pediatrician for an annual checkup, she 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. 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.

Graphics & Other Resources

Social Media Post Graphics



Turner syndrome is a genetic disorder that affects females and occurs when one or both X chromosomes are missing or partially missing.

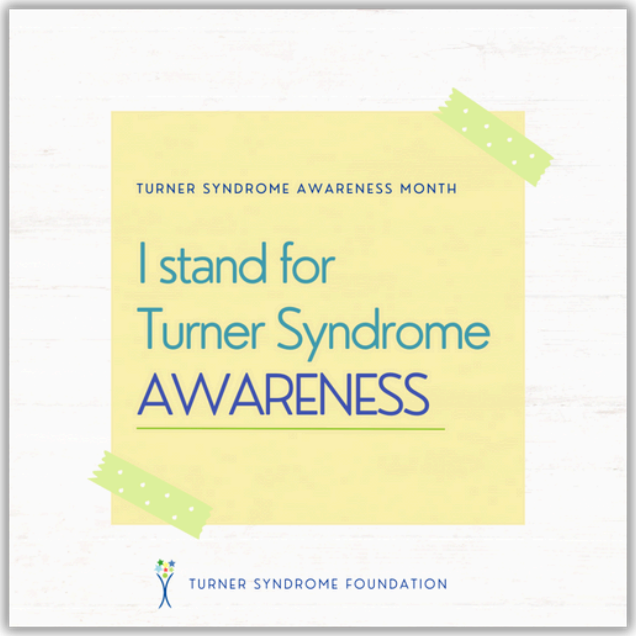
TS affects 1 in 2,000 live female births

Up to 99% of pregnancies with TS present end in miscarriage or stillbirth

Find out more at TSFUSA.org

(click to download)

(click to download)



(click to download)

(click to download)

Graphics & Other Resources

Social Media Post Captions

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

February is Turner Syndrome Awareness Month! Turner syndrome randomly affects 1 in 2000 live female births. Learn about Turner Syndrome and get to know the signs by visiting www.TurnerSyndromeFoundation.org.

Did you know that Turner syndrome can affect ANY female 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.

#TurnerSyndrome #TurnerSyndromeAwareness #TheXFactor

Be sure to tag us in your social media posts!

@TurnerSyndromeFoundation

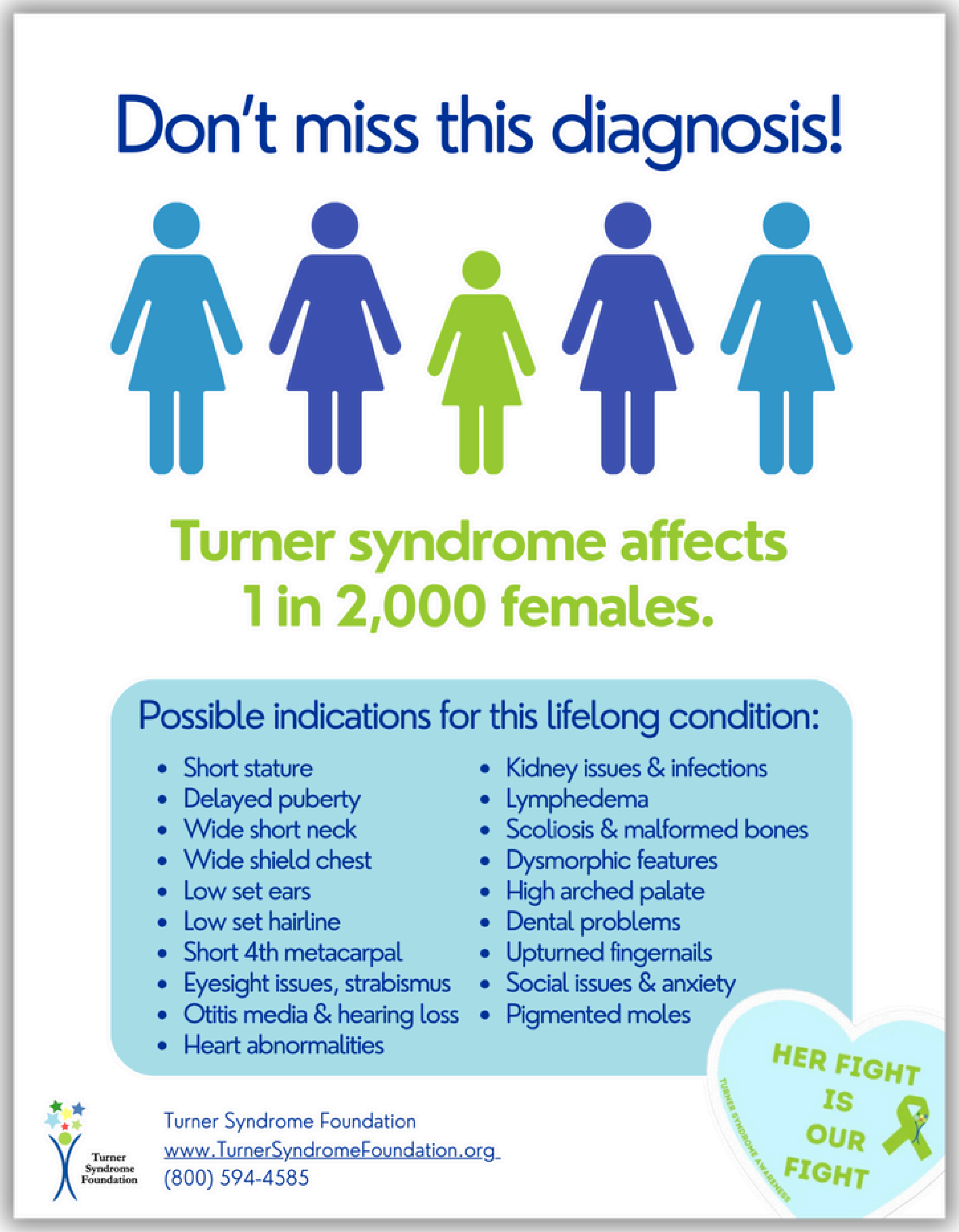
@TurnerSyndromeFoundation

@Turner-Syndrome-Foundation

@Turner-Syndrome-Foundation

Graphics & Other Resources

Printable Flyer - (click to download)



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
- Low set ears
- Low set hairline
- Short 4th metacarpal
- Eyesight issues, strabismus
- Otitis media & hearing loss
- Heart abnormalities
- Kidney issues & infections
- Lymphedema
- Scoliosis & malformed bones
- Dysmorphic features
- High arched palate
- Dental problems
- Upturned fingernails
- Social issues & anxiety
- Pigmented moles

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HER FIGHT IS OUR FIGHT

TURNER SYNDROME AWARENESS

Sample Press 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: 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.

Turner Syndrome Talking Points

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: 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 is 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.

Turner Syndrome Talking Points

Q: Are there any cognitive effects of 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!

Turner Syndrome Talking Points

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, this registry expanded to include the Turner Syndrome Research eXchange (TSRX), a patient centered registry focused on influencing TS research and advocacy. In addition, TSF's medical and advocacy committees regularly work to advance education and legislation relating to TS. Our vision of hope and possibility for the future of Turner Syndrome care permeates every program as we continue to improve and expand.

Turner Syndrome Talking Points

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 tax-exempt.

5. Take Action- Complete a Volunteer Application online at www.TurnerSyndromeFoundation.org.

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
for additional resources.