Turner Syndrome awareness begins with YOU!

Awareness is a team effort. If we want to see real change, we have to work together. By signing up to receive this toolkit, you’ve taken the first step to something great. Don’t stop now!

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 are unstoppable! But we can’t stop there! It’s important to continue raising awareness all year long. Imagine what a movement of Turner Syndrome awareness would mean – more support for endocrinology clinics, an increase in researchers interested in TS, and improved care for everyone affected.

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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? One more doctor educated about Turner Syndrome, one more legislator ready to join our efforts...

Now imagine if our community took action together. The outcome would 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!

Our goal is to save lives, reduce diagnosis age, and improve care standards. This is made possible only by the support of generous donors and volunteers like you who recognize the importance of contributing to this cause.

Unfortunately, Turner Syndrome remains unknown to the general public. We need the voices of everyone affected by TS to speak louder if we are going to be heard! Will YOU join in?

Easy Ways to Take Action NOW

1. Sign the TSF Awareness 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 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/

2. Share on your social media platforms. Find graphics and more in the pages of this toolkit to share to your newsfeed. Educating your followers about Turner Syndrome will help raise tremendous awareness!

3. Set up your online fundraiser. 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/

4. Print and share the awareness poster on page 8 of this toolkit. Leave a handful at your local library, on your community’s message board, or in your office. You never know whose life will be changed when they find a poster because of YOU!
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 – 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 almostcrippling. 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.
Graphics & Other Resources

I stand for Turner Syndrome Awareness

Join me to support 1 in 2000 women and girls.

www.TurnerSyndromeFoundation.org

One of these is not like the others.

Know the signs. Change a life.

Learn more at www.TurnerSyndromeFoundation.org

© 2019 Turner Syndrome Foundation
I support Turner Syndrome awareness so all children will be diagnosed early.

www.TurnerSyndromeFoundation.org

I support Turner Syndrome awareness to improve access to specialized care.

www.TurnerSyndromeFoundation.org
Sample Social Media Posts:

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

**TSF Social Media Platforms**
Facebook: @turnersyndromefoundation
Instagram: @turnersyndromefoundation
Twitter: @TeamTSF
YouTube: @TheTSFUSA

**Hashtags**
#TurnerSyndromeAwareness
#TurnerSyndromeFoundation
#TurnerSyndrome
#TurnerGirlsCan

**Facebook**
February is Turner Syndrome Awareness Month, but it’s important to raise awareness all year long! 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 – learn more about Turner Syndrome and what you can do to raise awareness at www.turnersyndromefoundation.org

**Twitter**
How are YOU supporting #TurnerSyndromeAwareness? Learn more and take action at www.turnersyndromefoundation.org

I stand for #TurnerSyndromeAwareness. Will you join me? Learn how you can help at www.turnersyndromefoundation.org

Many with Turner Syndrome are diagnosed late. Know the signs and change a life. #TurnerSyndromeAwareness
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.
Sample Announcement

[YOUR ORG NAME] is joining the Turner Syndrome Foundation to Take Action
Turner Syndrome Awareness!

[CITY OF YOUR ORG] – [YOUR ORG NAME] is proud to stand with the Turner
Syndrome Foundation 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]

[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. “We are proud
to stand with 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 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

[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.

Need additional support? Contact us; we’re here to help!
Email: info@tsfusa.org
Phone: (800) 594-4585 10AM-5PM EST
Visit our website at https://turnersyndromefoundation.org/volunteer-3/awareness/ for additional resources.