

MAKING A DIFFERENCE

...for every female living with Turner syndrome



Turner Syndrome Foundation Annual Report
2023-2025





“This fiscal year has been transformative for TSF. We welcomed thousands of new visitors and nurtured our global support network. Through peer mentorship, our groundbreaking Turner syndrome research registry, and national awareness efforts, we’ve strengthened our community’s voice and reach. Thank you for standing with us—for the girls and women whose lives we touch every day.”

-Laura Fasciano,
Executive Director

-Elena, age 17

What is Turner Syndrome?

Turner syndrome (TS) is a genetic condition that affects approximately 1 in every 2,000 live female births. While many pregnancies with TS sadly end in miscarriage, the babies who are born are truly miracles, and their lives are filled with strength, resilience, and possibility.

TS is a random condition that only affects females, caused by a missing or incomplete X chromosome. While it can lead to certain health challenges—such as heart conditions, infertility, frequent ear infections, and short stature—early diagnosis and ongoing care can make a meaningful difference.

Each individual with TS is unique. Some may experience only a few symptoms, while others face more complex health needs. With proper medical care and support, individuals with TS can lead full and empowered lives.

An early diagnosis opens the door to early intervention, personalized care, and greater awareness, starting at birth and continuing throughout life.



Clinical Features

- Short stature (average height 4'8" if untreated)
- Unique skeletal and physical features
- Delayed puberty (70-80%)
- Ovarian and reproductive failure (98%)
- Constriction in heart blood vessels (10%)
- Heart valve problems (30%)
- High blood pressure (30-50%)
- Kidney malformations (33%)
- Osteoporosis (50%)
- Type II diabetes
- Thyroid disorder (33%)
- Issues with visual-spatial coordination tasks
- Social issues and anxiety
- Hearing loss and frequent ear infections (up to 90%)

About Turner Syndrome Foundation



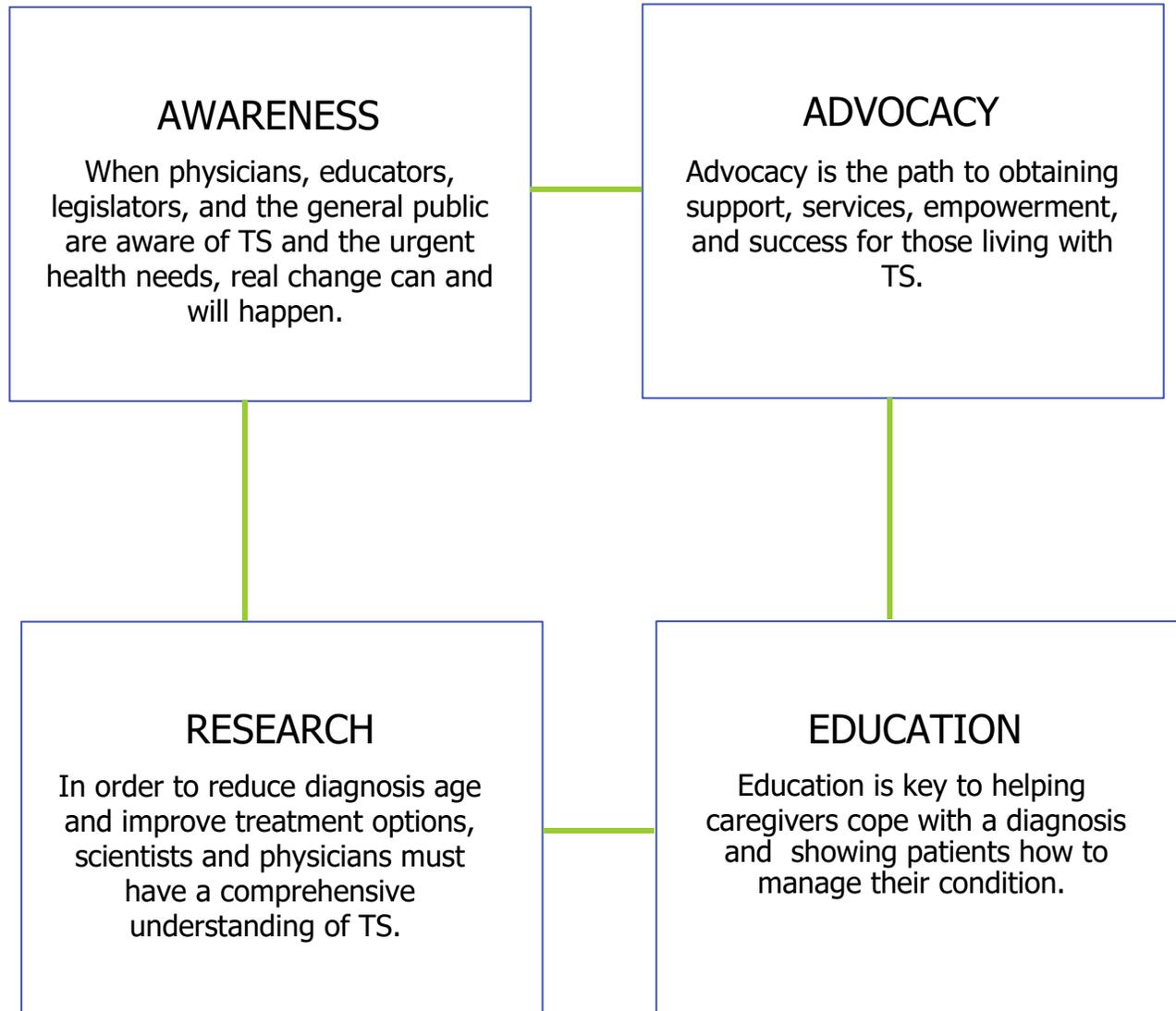
The Turner Syndrome Foundation (TSF) is a national nonprofit dedicated to improving the lives of individuals with Turner syndrome (TS). Despite affecting 1 in 2,000 females, awareness remains low, and most girls aren't diagnosed until an average age of 15.5, missing critical opportunities for early care. Many face lifelong gaps in guidance and support, and for adults, access to proper care remains limited, with only 3% adhering to clinical guidelines.

TSF exists to change that. Our work spans four key areas: awareness, advocacy, research, and education. We collaborate with hospitals, healthcare providers, researchers, educators, policymakers, and families to increase early diagnosis, promote evidence-based care, and provide vital resources. From educational tools to community events, TSF empowers individuals with TS and their caregivers to navigate the condition at every stage of life.

By offering trusted information, peer support, and a strong advocacy voice, TSF is helping build a world where everyone with TS receives the care, understanding, and respect they deserve.

"I am the proud mother of an 18-year-old daughter who was diagnosed with Turner syndrome while I was still pregnant. The Turner Syndrome Foundation has been an incredible source of support and guidance throughout our journey. Over the past 18 years, they have equipped me, my family, and especially my daughter to face each milestone and challenge with confidence. I will always be grateful to Laura and the entire team at the Turner Syndrome Foundation for the knowledge and support they have given us."

Our Mission



Key Programs:



WE Learn Webinars

Offering information to patients and their caregivers from experienced and knowledgeable providers.



Awareness Events

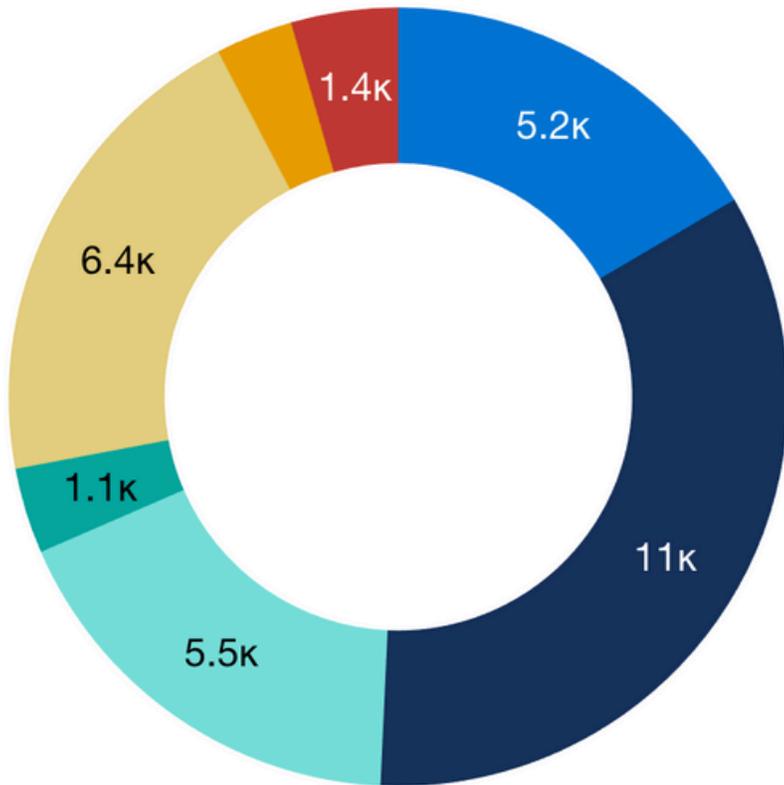
Events that bring the TS community together and amplify our mission to a broader audience.



TSRX Research Pin

An international patient registry to support clinical research initiatives to advance the understanding of TS.

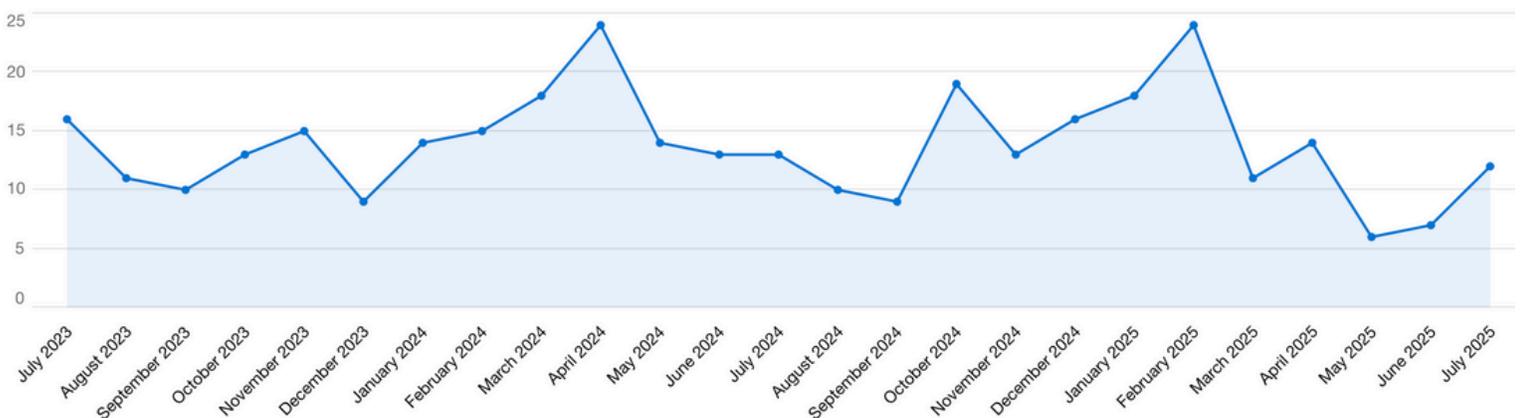
Who We Serve



- TS Patient
- Family Member
- Supporter
- Administrative Contact
- Medical Professional
- General Public
- Others (Combined)

Our database currently includes over 5,000 individuals with TS and 11,000 family members. In addition, we have contacts for over 6,000 medical professionals.

New Patients Per Month:



In any month, we receive between 5-25 New Patient Registries. Patients are consistently coming to TSF looking for information, resources, and support.

Turner Syndrome Stories



"Aurora began having issues with vomiting and a lack of weight gain at around 3 months old...she underwent extensive testing with no answers, and at 6 months, she was diagnosed with failure to thrive. After that, I transferred her care to another hospital that found a heart defect within two days and diagnosed her with Turner syndrome.

Turners has impacted almost every aspect of my daughter's life...she spent almost 3 months of her first 6 living in a hospital, underwent heart surgery at 7 months, and her development was severely delayed. She is still very small and has been having thyroid and gastrointestinal issues.

For those seeking care, keep advocating for yourself, your children, and anyone needing help. It is so hard, but sometimes you need a second opinion or a new set of eyes. If it doesn't feel right, keep asking questions!" -Kimberly

"I had been tiny, and in and out of hospitals my whole life with no real idea why. When I was 14, I still hadn't grown or developed much, and my doctor referred me to an endocrinologist to have testing done. I then found out I had Turner syndrome. I had never heard of TS before, so I was terrified of the future. My endocrinologist explained everything to me and made me feel so much better and reassured me that I could still live a fulfilling life.

Turner syndrome has affected me in many ways. I had trouble fitting in and making friends in school. I felt so disconnected from everyone my age. I still struggle with this sometimes, along with understanding social cues. I've since been able to make long-term friends and continue to work on my social skills. I sometimes struggle in school due to learning complications and have been able to get school accommodations to help.

My doctors have been very helpful in my TS journey and have helped lessen my anxiety around my health. Make sure you advocate for yourself. You know yourself the best, so communicate and do what's best for you!"
-Tayla



Events

Fairbanks Strikeouts for Turner Syndrome with the Tampa Bay Rays

Fairbanks Strikeouts for Turner Syndrome, created by Pete and Lydia Fairbanks in memory of their daughter Ellis, has elevated national visibility for TS, brought together families from across the country, and sparked conversations that continue to educate and inspire. This campaign, supported by the Tampa Bay Rays Baseball Foundation for two years in a row, mobilized thousands through game day events, exclusive merchandise, and an online auction to support the Turner Syndrome Foundation's mission.



"The entire experience was unbelievable and so heartwarming for us. We're new to the Turner syndrome community, and even though our story is a heartbreaking one, it brought us so much joy to meet other members of the community. It truly was a weekend that helped our family continue to heal after the loss of Cassidy.

We loved getting to connect with some of the girls who live with TS and hear their stories as well. To see some of the amazing things they're accomplishing was incredibly inspiring. We can only hope to continue helping support them in Cassidy's honor. Lydia, Pete, and the Rays are doing amazing work and we can't be more appreciative of their efforts."

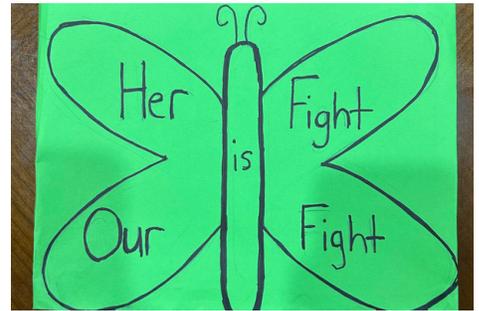
— Marvin, father of TS angel, Cassidy

Events

February Turner Syndrome Awareness Month

Turner Syndrome Awareness Month is a powerful opportunity to bring visibility to TS and facilitate new connections in the community. In 2025, we reached over **575,000** people on social media and featured more than **50** personal stories.

From student presentations and heartfelt fundraisers to meetups and media coverage, the community came together in meaningful ways. The 2025 theme of "Her Fight is Our Fight" encouraged individuals to submit photos for our social media campaign. In addition, the annual Card Auction garnered support from an international audience.



LSU Women's Basketball Game

LSU Women's Basketball hosts an annual Turner syndrome awareness game in memory of Scout Marie Fuller, Coach Kim Mulkey's granddaughter, who was stillborn. The game raises awareness and honors survivors of Turner syndrome.

TS Community Picnic & BlueClaws Games in NJ

TSF hosts several in-person events in New Jersey, where our office is located. Gatherings like the Community Picnic and Community Days at BlueClaws games offer meaningful opportunities for local families to connect, share experiences, and build lasting relationships within the Turner syndrome community.



Program Highlights

WE Learn Webinars

TSF's free, virtual webinars brought critical information and education to Turner syndrome patients, caregivers, and healthcare providers. Highlights include "Review: Clinical Guidelines for Management of Turner Syndrome," "Dental Issues Seen in Turner Syndrome," and "Considerations for Driving Readiness."

Expanding the Network of Care

With the help of dedicated volunteers, TSF has reached out to healthcare providers across the United States to expand our database of professionals knowledgeable in the care and management of Turner syndrome.

Blog Articles

TSF has maintained a consistent online presence through our blog, thanks to the support of volunteer writers and editors. Covering topics such as health, education, and personal stories, the blog offers timely, accurate information and a much-needed positive perspective on Turner syndrome, ensuring that those searching online can find support and understanding.

Petition for TS Patient Care

With nearly **2,000** signatures to date, the Turner Syndrome petition demonstrates strong national support for improved care, earlier diagnosis, and greater awareness. Each signature represents a collective call for change, strengthening TSF's advocacy efforts and amplifying the voices of those affected by Turner Syndrome.

Research Initiatives

TSF supports vital research initiatives to advance understanding and care for Turner syndrome. Through the Turner Syndrome Research eXchange (TSRX), a Patient Insights Network in collaboration with Invitae, individuals with TS can securely share health data to support improved diagnosis, treatment, and patient empowerment. Participants control their information and can access de-identified data and research opportunities. In addition, TSF encourages blood and tissue donations to the NIGMS Human Genetic Cell Repository at the Coriell Institute, building a valuable resource for scientists studying the genetic basis of Turner syndrome and accelerating future breakthroughs.

Volunteers

At the heart of the Turner Syndrome Foundation is a deeply committed network of volunteers whose compassion and dedication make our mission possible. As a primarily volunteer-led organization, TSF relies on the generous contributions of time, talent, and energy from individuals across the country. Whether they're supporting us virtually or working alongside our staff in person, these volunteers are the foundation of our growth.

Many volunteers support TSF on a long-term basis, offering consistency, insight, and care that extend far beyond the scope of a single project. We are especially grateful to those who help manage day-to-day operations by answering phones in our office and responding to the needs of the TS community with warmth and professionalism. Others contribute their voices to our blog, crafting accessible, informative articles that empower readers with knowledge, understanding, and connection. Their storytelling helps to elevate Turner syndrome awareness and bring visibility to the challenges and triumphs of those living with this condition.

TSF volunteers also lend their expertise to several key committees.



The Advocacy Committee leads national efforts such as the Petition for TS Patient Care, along with legislative outreach campaigns that push for policy changes and increased awareness among lawmakers.



The Awareness Committee plays a vital role in organizing both Turner Syndrome Awareness Month in February and year-round activities that spotlight the condition in everyday spaces.



The TS Women in Medicine group, comprised of healthcare professionals, meets quarterly to identify unmet needs in patient care and collaborate on ways to better support individuals with TS throughout their lives.



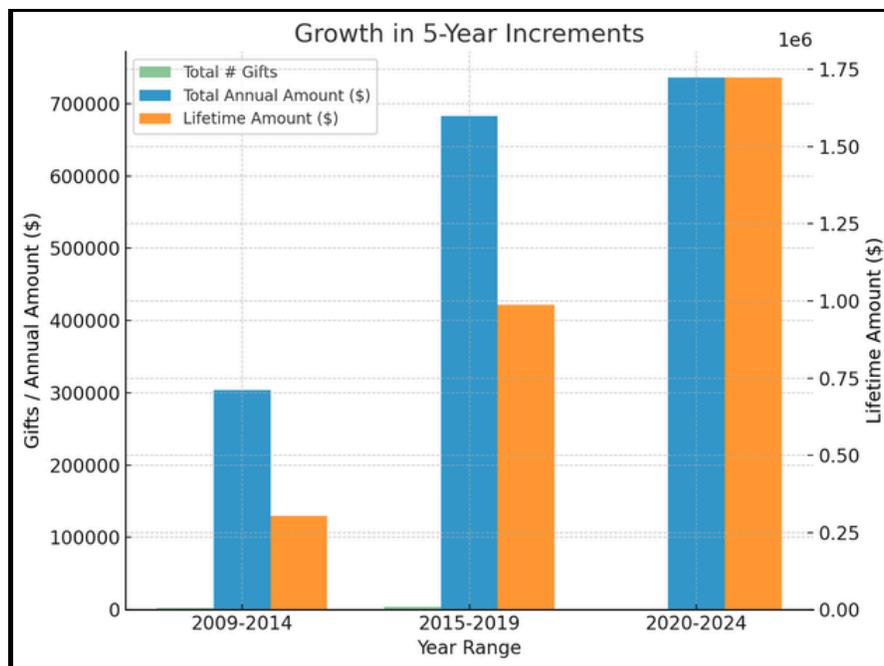
The Education Working Group is dedicated to addressing the academic and developmental needs of students with TS, advocating for inclusive education practices and increased school-based awareness.

Every volunteer, from those who contribute a few hours a month to those who stay involved year after year, is an essential part of the TSF community. Their impact is far-reaching, and we are endlessly grateful.

Financials

We are deeply grateful for the generous and creative ways our community supports our mission, from car and stock donations to workplace giving programs, and more. Each unique gift plays a vital role in helping us advance research, raise awareness, and support those living with Turner syndrome.

In our effort to keep up with the times and expand access, we're now accepting cryptocurrency donations, offering a modern way for supporters to give in a way that suits them best.



To truly grow our impact, TSF needs widespread, sustained support. As we work to scale our infrastructure and build lasting change, monthly giving is one of the most powerful ways you can help.

Join the **1938 Giving Club**, named in honor of the year TS was first identified, and become a monthly donor fueling long-term progress and hope.

Fiscal Year:
July 1 - June 30



Leadership

Executive Officers:

Laura Fasciano
Director and Founding
President & Board Trustee
Executive Director

Lorraine Kobular
Vice President & Board Trustee
Fundraising & Events

Doreen Sullivan
Treasurer & Board Trustee
Fundraising & Events

Suzanne Bousquet, Ph.D.
Secretary & Board Trustee
Director of Education and
Professional Development

Janis H. Elwell
Board Trustee
Client Services

Kayla M. Ganger, PA-C
Board Trustee
Health Initiatives & Professional
Membership

Michael McDowell
Board Trustee
Corporate Partnerships

Danielle Moore, Ph.D.
Director of Scientific Affairs
Board Trustee

Dawn Petr, Eng.M.
Director of Information
Technology & Board Trustee

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Kesha Amin

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Thank you to our community partners!

LexisNexis

Enterprise Mobility Foundation

America's Charities

Benevity

Rays Baseball Foundation

JPMorganChase Foundation

YourCause



-Sydney, age 20

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