



2022

ANNUAL REPORT



Turner
Syndrome
Foundation

Letter from the Executive Director



The Turner Syndrome Foundation has been a big part of our journey with TS, and my daughter is the inspiration. It is remarkable to be surrounded by the many wonderful people who have come into our lives to challenge and inspire hope and possibilities for the future of TS. I've learned over the years that it is in community and sharing where we find our greatest strength and peace in knowing that we are not alone.

The Turner Syndrome Foundation attends to everyday challenges by sharing the stories and meeting the needs of the people we serve. Over the past 13 years, it has been an upward climb on a new frontier establishing a mission to improve and save lives.

At this very moment, someone is being told they or their child have Turner syndrome, a condition that is not widely recognized. They will turn to TSF to find compassionate support that will include information, education, and enriching initiatives. With the ongoing support of our many donors and volunteers, we are here for them today, and we will be here for them throughout their lifelong journey.

Our greatest victory is when individuals and families come in their time of need and eventually express a desire to pay it forward through their activism for this mission. Each of us is a steward of this mission by giving money and providing service to a cause that truly impacts the lives of baby girls and the women they will become.

Thank you for entrusting Turner Syndrome Foundation with your most generous support. May you and yours remain safe, sound, and in good health!

Laura Fasciano, Director and Founding President

OUR REACH

3,000+
TS Women & Girls

Through educational programs, events, webinars, one-on-one meetings, events & more



8,100+
Family Members

Through events, social media, webinars, one-on-one meetings, events & more



5,900+ Medical Professionals

Incl. Healthcare providers, specialists, nurses, clinicians, & researchers



Nationwide Presence

With concentrations in New Jersey, New York, Arizona, California, Texas, Pennsylvania, and Florida



2,900+ Donors & Volunteers

Ongoing partnerships for events, awareness initiatives, research, sponsorship and more



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LEADERSHIP

Board of Directors & Medical Advisory

TSF is primarily a volunteer-led organization, meaning every dollar goes towards our mission. It is because of the experts in the field who devote their time and talent to this cause that we may advance Turner syndrome care. Individuals interested in serving in a leadership role with TSF may nominate themselves for Board or Committee service or Professional Membership.

Welcome

Kayla M. Ganger, BS, MHS, PA-C Physicians Assistant TSF Board Member and Professional Member Chair Health Initiatives Chair Working Group, TS Women In Medicine



Kayla Ganger is a physician's assistant who was diagnosed with Turner syndrome at the age of 2. Kayla has contributed to several initiatives in partnership with TSF to advance patient care through advocacy and physician outreach.

Professional Members - A Growing Network of Care

Mary Gwyn Roper, MD | Kayla M. Ganger, PA-C | Zvi Marans, MD | Kutluk Oktay, MD | Siddharth K. Prakash, MD, PhD | Dean Mooney, PhD | Henry Anhalt, DO | Michelle Schweiger, DO, MPH | Joanne Foodim, MD | Doris O. Fadoju, MD | Wendy Brickman, MD | Catherina Pinnaro, MD, MS | Eirene Alexandrou, MD | Alexis Capozzoli, MD | Peter G. McGovern, MD | Paul Saenger, MD | Ebru Gultekin, MD

Gratitude

To the many experts who dedicate their lives' work to the improvement of the health and well-being of Turner syndrome patients, thank you!

We shall change the future of Turner syndrome by bonding and working together.

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PIVOTAL PROGRAMS IN 2022

You spoke, and we listened. 2022 may have been different in many ways, but the needs of the Turner Syndrome community have not changed. This year, thanks to our supporters, we have been able to launch several new programs to address these needs.

24/7 Caregivers

An online support group for caregivers of individuals with TS who require 24/7, lifelong care. This group will offer a safe space for caregivers to express themselves, ask questions, and seek support as they navigate providing care to a loved one with unique needs.



My name is Lori Kobular, and this is my 34-year-old daughter with TS, Julie. Julie is diagnosed as having multiple disabilities, and it has taken me a long time to come around to opening up about Julie and what our life was like. But I have come to realize that there are other families out there like mine struggling with similar issues, and 24/7 Caregivers is a group in which we can help and support each other. ~ Lori Kobular



Growth Hormone Program

In collaboration with Pfizer, TSF organized a patient-oriented webinar about Growth Hormone and resources for those who lack adequate insurance. Growth Hormone is a mainstay of treatments for individuals with TS, and access to the treatment has lifelong benefits. Now more than ever, financial barriers limit access to this treatment. The webinar aimed to inform caregivers about the financial resources available to them and how to navigate insurance challenges.

Star Sisters

Star Sisters is a private, online support group for all individuals with Turner syndrome. In 2020, we introduced virtual meetups, which provide a unique opportunity to form deeper connections. Star Sisters membership more than doubled in 2022!

WE Learn Webinars

Our webinar program is a cornerstone program. Individuals seeking information about various aspects of life with Turner syndrome rely on this virtual platform to learn and ask questions. The Foundation recorded a 300% increase in participants from 2019 to 2022. All webinar recordings are available to view on-demand for free on our website.

EXPERT SPEAKERS

- Gwendolyn Quinn, PhD
- Ilyse O'Desky, PsyD
- Kutluk Oktay, MD, PhD, FACOG
- Mary Gwyn Roper, MD
- Michelle Schweiger, DO, MPH
- Brittany McLarney, MS, CGC
- Peter McGovern, MD
- Henry Anhalt, DO
- Helen Rhoads, MS



**Paula Glashausser, LCSW, ACM, Medical Social Worker
Cedars Sinai Medical Center, Los Angeles**

It was a pleasure working with your team. I think the TSF site has excellent information to help educate and support families. I provide the Foundation's information as a resource to families.



Dr. Megan Edwards Collins, Ph.D, OTR/L, CAPS, Associate Professor, Winston-Salem State University

As a woman with Turner syndrome, I have greatly enjoyed engaging with the Turner Syndrome Foundation. They provide wonderful learning opportunities and activities for people impacted by Turner syndrome individuals who have Turner syndrome, parents and family members who have a loved one with Turner syndrome, and those interested in learning more, to name a few. The information provided is at an appropriate level and helps to provide needed support and encouragement. This includes helping people establish connections with others. I look forward to my continued involvement with the Turner Syndrome Foundation!



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Highest Ranked by GuideStar & Great NonProfits

13+

Years Of Experience

100+

Free Awareness & Education Resources

2000+

One-on-one Support Offerings

20+

Research & Medical Advisory Team

3

PROFESSIONAL INITIATIVES

Strategies for Improving Cardiovascular Care

The Council on Cardiology (COC) is an initiative dedicated to improving cardiac care outcomes that can save lives. It is formed of representatives from the professional, medical, scientific, and educational communities. The COC addresses key challenges in the field by using knowledge gained from current research findings to create and distribute an educational module that will benefit cardiologists nationwide.

GOALS INCLUDE:

1. To promote the importance of early diagnosis and best possible care of congenital and acquired cardiovascular disease in patients with Turner syndrome.
2. To raise clinical awareness of cardiac care guidelines for Turner syndrome patients throughout their lives.
3. To emphasize preventive cardiac care in an at-risk population.
4. To develop a crisis plan to recognize, diagnose, and treat an emergent cardiac event in patients with Turner syndrome.

Research

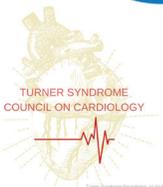
TSRX

The TSRX PIN, in collaboration with Invitae, is a global patient registry that collects data from individuals diagnosed with Turner syndrome to make accessible to researchers worldwide. In 2022, the registry expanded to include organ systems and common conditions associated with TS.

COVID IMPACT STUDY

The COVID-19 study has had a profound impact on all communities worldwide, but the extent of the impact on individuals with rare diseases was unknown. TSF was proud to partner with researchers at the National Institutes of Health to engage Turner syndrome patients and caregivers in participating in a study to assess the impact of COVID on our community.

COLLABORATIONS WITH RESEARCHERS AT FACILITIES INCLUDING:



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TURNER SYNDROME STRONG IN 2023

Always looking to the future, the Foundation has several top priorities for patient-centered programs in 2023...

- **RESEARCH**

- Expansion of the TSRX.us, a global patient registry for Turner syndrome.
- Collaborative research initiatives with government & universities.

- **PATIENT & CAREGIVER RESOURCES**

- Welcoming & supporting patients & caregivers along the TS journey.
- Producing webinars & providing educational resources, including a new guide for expectant parents, for best care outcomes.

- **ADVOCACY**

- Petitioning for legislative advocacy to achieve goals through federal policy.
- Strengthening activism through coordinated volunteer recruitment and engagement.
- Advocacy is the key to change for the Turner syndrome community.

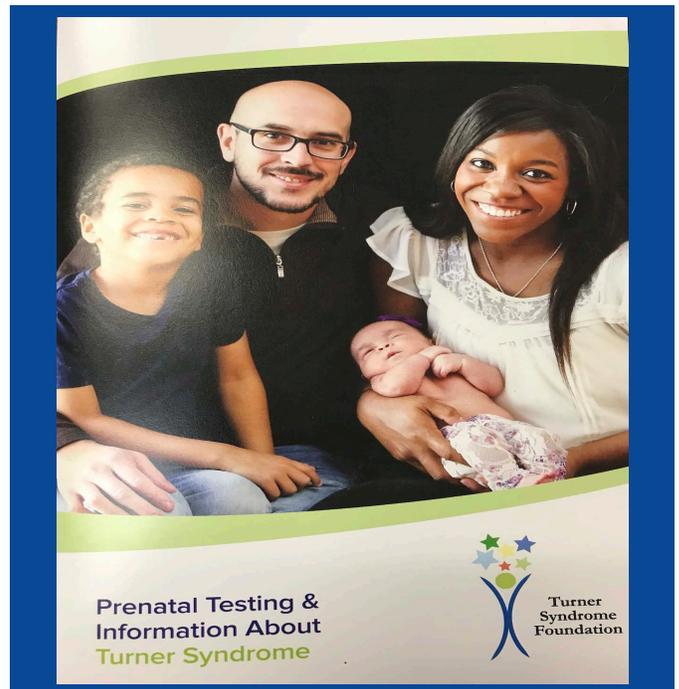
- **PHYSICIAN OUTREACH**

- Providing resources to professionals, in an effort to address the challenges and opportunities of applying new knowledge from evidence-based research into practice.
- Educating physicians about TS to decrease the age of diagnosis.
- Developing a guide for pediatricians.
- Offering professional membership to specialized care providers.

TURNER SYNDROME FOUNDATION IMPACT

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*The Prenatal Testing & Information About Turner Syndrome booklet has been requested by many genetic counselors to provide this resource to their patients. We are thankful to Alan Fisher, MD and others for their contributions to this important resource. View for free or order a printed copy at:
<https://turnersyndrome.foundation.org/living/life-stages/expecting-baby-turner-syndrome/>*



#TURNERSYNDROMESTRONG

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*My daughter was diagnosed with Turner syndrome in utero, and we have been exposed to a lot of misinformation about this genetic disorder from our first genetic counseling session and from various providers who don't know enough about TS to provide really good guidance when dealing with their medical care and individual situations. The Turner Syndrome Foundation has been a tremendous support system for not only my daughter, but for parents of girls with Turner syndrome. ~
Susan, parent of a woman with TS*

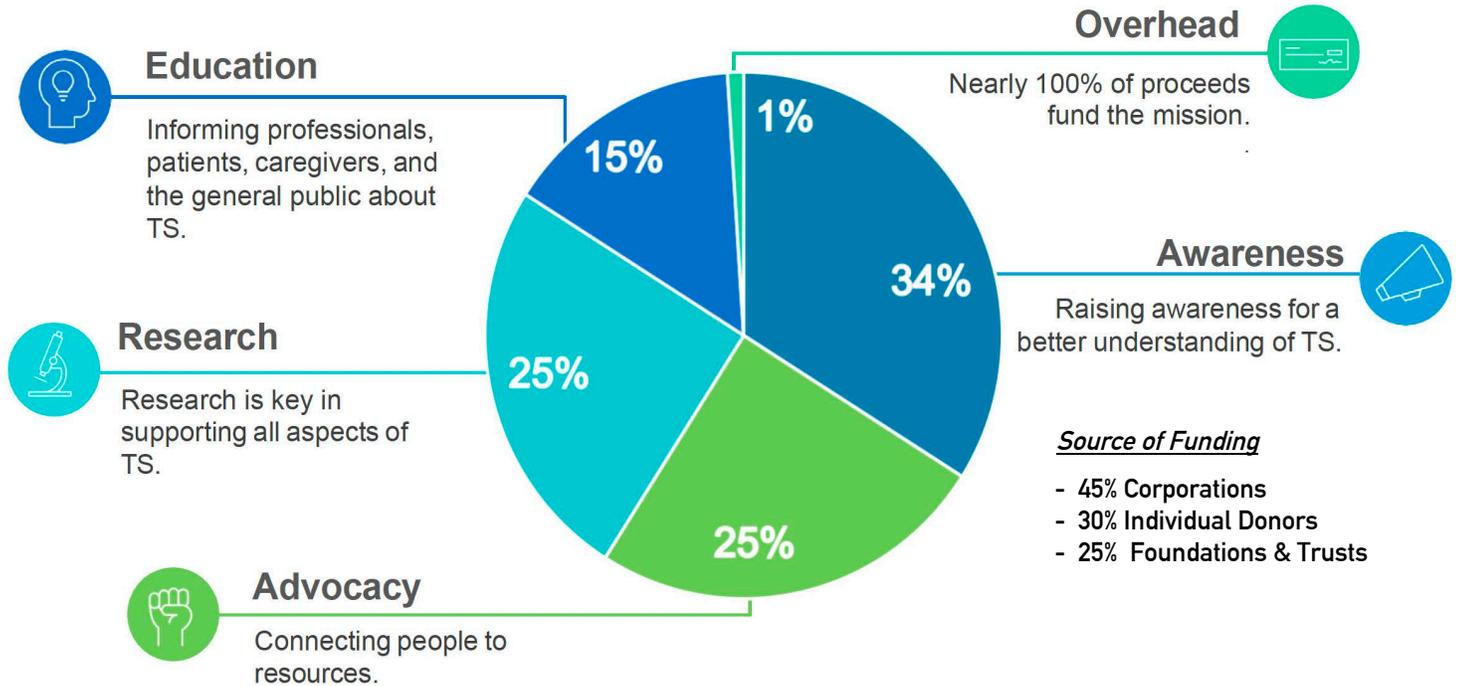
VOLUNTEER WITH TSF!

Get your friends and family involved in our mission by creating an online fundraising page. Community giving has a profound effect. Individuals with all backgrounds work with TSF, offering their skills and talents to move our mission forward. Individuals, groups, and corporations are the heart of this mission!

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MAKE A DIFFERENCE

WHERE YOUR MONEY GOES



STAFF MEMBERS



My goals for my work here include expanding legislative and public awareness of Turner Syndrome and advocating for legislation that will increase necessary aid, awareness, and accommodations for members of the TS community. ~ Catherine Melman-Kenny



It is my pleasure to be the Blog Coordinator for TSF. Having been diagnosed with TS myself some 34 years ago, I know the importance of having reliable resources and support through childhood, adolescence, and adulthood. ~ Susan Herman



Thank you to our generous donors and volunteers!



Together we will be #TurnerSyndromeStrong in 2023!



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**Turner Syndrome
by the Numbers**

From the Turner Syndrome Foundation



**1 in 2,000 live female
births affected**

Endocrine Web

**1 TS baby is born
every 8 hours**



T. Hakim, verified by A. Gratton



**1 in 200
conceptions affected**

A. Dorfman, Children's Hospital of Pennsylvania

**Patients can spend
\$20,000 a year or
more in medical care**



Text "SUBSCRIBE" to 72572



*Philanthropic support increases the capacity for the Turner Syndrome Foundation to freely deliver support for critical **LIFELONG CARE** and **SCIENTIFIC ADVANCEMENTS** that help to improve the health and emotional and social outcomes for precious babies, their caregivers, and the women they become. Since 2009, Individual and corporate supporters have placed their trust in the **MISSION OF THE TURNER SYNDROME FOUNDATION.***

