



**Turner
Syndrome
Foundation**

2021

ANNUAL REPORT

Letter from the Executive Director

This mission means the world to me, both personally and professionally. My heart sings with gladness for every victory and weeps with every loss, for it is in faith that we attend to an overwhelming uncertainty, and it is in unity where we find our greatest strength. In times such as these it is easy to become unraveled, even divided; unless, we find gratitude and strength in one another - for we are not alone.

The Turner Syndrome Foundation attends to everyday challenges through the stories and needs of the people we serve. Over the past decade, or so, it has been an upward climb

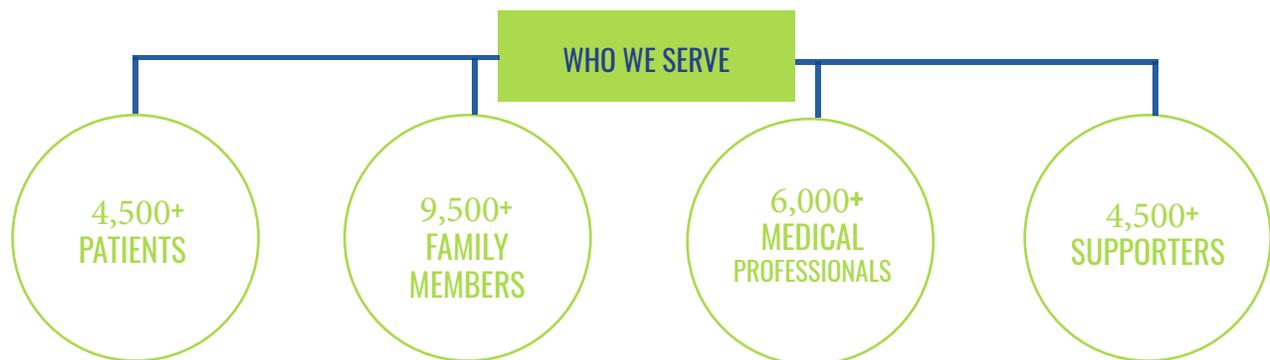
on a new frontier establishing a mission to improve and save lives. At this very moment someone is being told they, or their child, have Turner Syndrome, a condition that is not widely recognized. They will turn to TSF to find compassionate support that includes information, education and enriching initiatives. With the ongoing support of our many donors and volunteers we are here for them today and will be on 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 are stewards of this mission by giving money and providing service to a cause that truly impacts lives of baby girls and the women they 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



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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

Dr. Mary Gwyn Roper has been an active contributor on several initiatives, and now assumes a leading role.



Dr. Roper is a pediatric endocrinologist who was diagnosed with Turner Syndrome at the age of 2.

Dr. Roper has taken-on several initiatives in partnership with TSF to advance patient care through advocacy and physician outreach.



In my interactions with other physicians, I have come to realize how very little knowledge there is about TS in the medical community. There needs to be greater education about TS among the pediatricians, as they are on the front lines and are often the first to be able to make an early diagnosis of TS. The earlier a girl with TS is diagnosed, the more she will be able to benefit from necessary treatments of any associated medical issues.

Gratitude

To the many experts who dedicate their life's work to the improvement of the health and well-being of the Turner Syndrome patient, thank you!

We shall change the future of Turner Syndrome once we bond and work together.

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PIVOTAL PROGRAMS IN 2021

You spoke, we listened. 2021 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 child with unique needs.

“

My name is Lori Kobular and this is my 33 year old daughter with TS, Julie. Julie is diagnosed as Multiple Handicapped 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 program 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 supports available to them and how to navigate insurance challenges.

Star Sisters

Star Sisters is an online support group for all individuals with Turner Syndrome.

In 2020 we introduced virtual meetups, which provides a unique opportunity to form deeper connections.

Signups to join Star Sisters more than doubled in 2021!

WE Learn Webinars

Our webinar program has taken off in 2021, becoming 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 2021. All webinar recordings are available to view on-demand 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, and continuing to work with, you and 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 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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PROFESSIONAL INITIATIVES

Strategies for Improving the Cardiovascular Care

The Council on Cardiology 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 life
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 patient with Turner Syndrome

Research

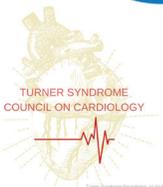
TSRX

The TSRx pin, in collaboration with Invitae, collects data from individuals diagnosed with Turner Syndrome to make accessible to researchers worldwide.

COVID IMPACT STUDY

COVID-19 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 2022

Always looking to the future, the Foundation has several top priorities for patient-centered programs in 2022...

- **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 establish goals that can be achieved through federal policy.
- Strengthening activism through coordinated volunteer recruitment and engagement.
- "Advocacy is the key to change for the Turner Syndrome community."

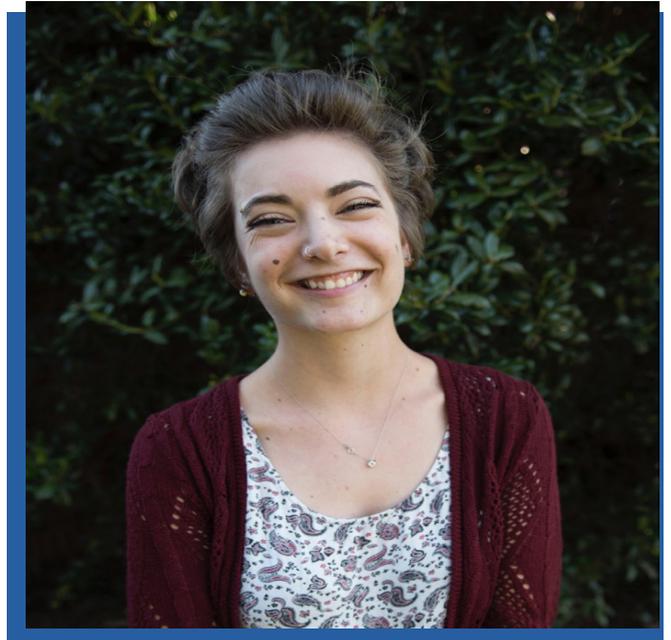
- **PHYSICIAN OUTREACH**

- In an effort to address the challenges and opportunities of applying new knowledge from evidence-based research into practice, the Turner Syndrome Foundation will provide resources to professionals.
- Educating physicians about TS to decrease the age of diagnosis.
- Developing a guide for pediatricians.
- Professional membership is offered to specialized care providers.

TURNER SYNDROME IMPACT

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As a TS patient, I've been longing for a community and resources to access the information and community I've been craving. TSF has given that to me 10-fold as I began joining their online forums, volunteer on their Awareness Committee and see the wonderful resources they are connecting their followers to. ~ Sara, woman with TS



#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 Turner girls. ~ Susan, parent of a woman with TS

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MAKE A DIFFERENCE

SUPPORT

There are many ways to support TSF as we embark on a new year.

BECOME A MONTHLY SUPPORTER

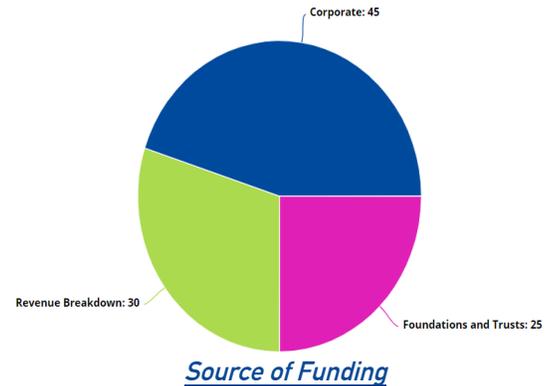
To multiply your impact, consider designating a monthly donation to benefit TSF. Giving at every level makes a difference!

BECOME A CORPORATE SPONSOR

Many corporations are philanthropic and will support this mission.

LEGACY & PLANNED GIVING

Turner Syndrome Foundation EIN# 27-1409942



- 45% Corporations
- 30% Individual Donors
- 25% Foundations & Trusts

FUNDRAISE

Get your friends and family involved in our mission by creating an online fundraising page. Community giving has a profound effect.

“Turner Syndrome may be a part of who I am, but it does not define me. One of my greatest joys in life is being able to help spread awareness about Turner Syndrome. Your donations contribute to ongoing research and advocacy that brightens the future for many girls and women ~ Sarah



VOLUNTEER

Individuals with all backgrounds volunteer with TSF, offering their skills and talents to move our mission forward.

“It is my pleasure to be a volunteer blog post editor for TSF. Having been diagnosed with TS myself some 33 years ago, I know the importance of having reliable resources and support through childhood, adolescence, and adulthood. ~ Susan blog writer/editor



Thank you to our generous donors and volunteers!

Together we will be #TurnerSyndromeStrong in 2022!



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Turner Syndrome by the Numbers

From the Turner Syndrome Foundation



1 in 2000
females 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



Sign-up for text updates. 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, 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.**

