



**YEARS TOGETHER**

# Letter from the President

*Looking Toward the Next Ten Years and Beyond*



Your support in 2018 proved that we are stronger together. With your support, we introduced novel new programs, such as the Star Sisters webinar series and the Tina Talks Turner's children's book, which you can read more about on page five. With your generous contributions, we attended the 2019 Pediatric Endocrinology Nursing Society (PENS) Conference, where we educated the professionals who stand at the front lines of diagnosing Turner Syndrome. We are pleased to share that a TSF Professional Member spoke at the conference on *Specific Care Considerations for Patients with Turner Syndrome*. Thanks to you, we made great strides to fulfill our mission in 2019.

But our work didn't begin there and it is not where it will end. This mission began a decade ago, when the message of Turner Syndrome lacked hope. The status quo saw Turner Syndrome as a lifetime of doctor's visits and medical expenses for those lucky enough to survive – and receive a timely diagnosis. Fortunately, through greater awareness and education, we're happy to report a movement toward acceptance, understanding, and positivity.

Over the past ten years, we've seen an increase in TS research and professional interest. Yet, there is still so much that remains to be accomplished. Too many girls are diagnosed in adolescence or later, too late for important medical interventions. Too many lives are lost to cardiac complications associated with Turner Syndrome due to a lack of professional knowledge. Too many girls and women spend their lives feeling alone without the chance to meet another like them.

The good news is that these problems can be solved. If we continue working together for the next ten years and beyond, we can be sure to see real change. Together we can build a community of support, education, and awareness. Join us in supporting this mission today – every life touched by Turner Syndrome is counting on you.

Your partner in change,

Laura Fasciano  
Director & Founding President

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# TSF Timeline

## *A Decade of Service*



# Board of Directors

Laura Fasciano, *President*

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Director of Patient Care

Suzanne Bousquet, PsyD, *Secretary*

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Danielle Moore, PhD, Research

Dawn Petr, M.Eng., Technology

## *Welcome New Board Members!*



Lori Kobular is a veteran volunteer of the Turner Syndrome Foundation. She has taken her experience leading charity events and love for crafting and turned them into something impactful – organizing multiple successful fundraising events. Lori is proud to volunteer in honor of her daughter, Julie, who was diagnosed with TS at birth. Lori is interested in contributing to research initiatives and advocacy efforts to improve care standards throughout the lifespan.

Janis Elwell has been a Turner Syndrome Foundation volunteer since January. Her degree in Computer Science and experience in Executive Administrative roles have contributed greatly to data management in 2019. As a longtime volunteer in her community, Janis brings the perspective of our invaluable volunteers to the TSF Board. Janis aims to raise awareness of Turner Syndrome throughout her community and beyond.

# Medical Advisory Board

Henry Anhalt, DO, FAAP, FACOP, FACE

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Martin Weinstein, D.M.D., M.S.

Sunil Wimalawansa, MD, PhD, MBA, FACE,

FACP, FRCP, DSc

# Serving the TS Community

## Program Updates in 2019

### Turner Syndrome Council on Cardiology (COC)

The COC was established to improve cardiac care outcomes to save lives. The goals of this initiative are to promote early diagnosis to improve treatment of congenital cardiovascular disease, raise clinical awareness of cardiac care guidelines, emphasize preventative care, and develop a crisis plan for emergency cardiac care. The Council has made great strides in developing a professional education module to fulfill these goals, which TSF aims to release to physicians in 2020.

Thank you to Dr. Darlene Field, TSF Medical Director, and Dr. Sheetal Patel, COC Chairperson, for leading this life saving initiative, and to the members of the COC for their hard work and dedication:

Dr. Allan J. Fischer, MD, FACOG, FACMG  
Dr. Khoa N. Nhuyen, MD  
Dr. Karen Rubin, MD

Dr. Helen Binns, MD, MPH  
Dr. Luciana T. Young  
Dr. Pankaj Madan

**“Congenital or acquired cardiovascular diseases cause increased mortality and morbidity in Turner Syndrome patients. Improving their cardiovascular health through collaboration, research, awareness and advocacy can improve their overall outcomes.”**

### Autumn Retreat

Imagine being diagnosed with a condition that your family, friends, even your doctors are not familiar with. Unfortunately, this is the reality for many in the TS community. The Autumn Retreat provides peer support – an important, and often neglected, aspect of care – by bringing women and girls together. The result is connections and friendships that last long after the camp weekend ends.

**“It was an incredible weekend. Presentations and activities were phenomenal. It was great to also have down time to bond and share experiences.”**



### Star Sisters Webinar Series

Education is the cornerstone of TSF’s mission. With knowledge, patients can advocate for themselves and receive proper care. Patient education began with workshops at local libraries, expanded to medical centers, and has now grown to online webinars. This new platform allows TSF to reach individuals nationwide on their own schedule. To date, physicians representing various specialties have spoke on fertility, lifelong care milestones, research, and more.



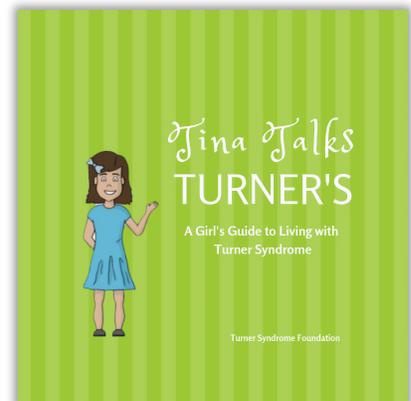
## Research Initiatives

Research is a team effort, recruiting patients, researchers, students, and more to accomplish a common goal. In 2019, we are proud to partner with Coriell Institute for Medical Research, Rutgers School of Public Health, and Emory University Department of Anthropology on various studies focused on Turner Syndrome. In addition, TSF's own research registry, the Turner Syndrome Research eXchange (TSRX) has doubled in number of participants. TSRX is a patient-centered registry that connects the global research community to improve treatments and understanding of TS.

**“Turner Syndrome Foundation helps improve lives every day with their commitment to research initiatives. The Turner Syndrome Research eXchange is to their credit...The objective, give everyone a chance to attain good health and educational outcomes.”**

## Tina Talks Turner's

TSF has developed a series of videos that highlight the stories of women and girls of all ages, bringing awareness to many aspects of living with TS. Most notably, the “Importance of Early Diagnosis” video has been played in doctor's offices across the U.S., reaching more than 8 million viewers. In 2016, TSF added “Tina Talks Turner's” to the repertoire. Studies show that sharing a diagnosis with a child leads to improved health outcomes. “Tina Talks Turner's” provides parents the tools to share a diagnosis. In 2019, the video was developed into a companion book that features journal pages to facilitate discussion and help a young girl cope with her diagnosis.



## Professional Membership

The TSF Professional Membership is a network of providers dedicated to providing the best care to the TS community through a collaborative approach, development opportunities, and a transfer of knowledge. The goal of the Professional Membership is to highlight and connect the providers specializing in the treatment of TS. TSF invited Dr. B. Michelle Schweiger, pediatric endocrinologist at Cedars-Sinai Medical Center and TSF Professional Member, to speak at the 2019 PENS Conference in Long Beach, CA on *Specific Care Considerations for Patients with Turner Syndrome*.

**“I was so impressed, as a nurse, that TSF offers education, at no charge, for patients, parents, educators, and health care providers. There is so much information available on the web site to support the families.”**

# TSF By the Numbers

## *Charting Our Impact*

The goal of the Turner Syndrome Foundation (TSF) is to support research initiatives and facilitate educational programs to increase professional awareness and enhance medical care of those affected by Turner Syndrome. Early diagnosis and comprehensive treatments over the lifespan may lead to a brighter and healthier future for all young girls and women with Turner Syndrome.

### **Who We Serve**

TS Women & Girls	<b>3,000+</b>
Family Members	<b>8,100+</b>
Medical Professionals	<b>5,900+</b>
Donors & Volunteers	<b>2,900+</b>

### **Program Results**

One-on-One Support to Women & Caregivers	<b>2,000+</b>
TSRX Participants	<b>100+</b>
Awareness Month Petition Signatures	<b>250+</b>
Tina Talks Turner's Viewers	<b>800+</b>
Webinar & Workshop Participants	<b>200+</b>
Monthly Website Visitors	<b>10,000+</b>

**What do these numbers mean? That thousands of women, girls, caregivers, family members, and physicians are better equipped to manage their Turner Syndrome journey.**

# What People Are Saying

## Client Testimonies

A couple years ago I was looking to get more involved with the TS community, and I couldn't be happier or more grateful that I came across the Turner Syndrome Foundation. From the start I have felt apart of such a loving, caring community, **I am in awe of all the hard work everyone involved with the Foundation contributes in terms of advocacy, raising awareness, research initiatives**, and making sure that every girl and woman affected by TS has the best quality of life possible. The Foundation does so much to improve the lives of every girl, and woman affected by TS and I couldn't be more honored to be a small part of it all. I am looking forward to getting even more involved in the near future.



*Sarah S.*

**I must admit out of any other educational site on TS, the Foundation I find to be personally the best.** There is always a person on the other end trying to help you in anyway they can, and it's very much appreciated. I'd definitely recommend the Foundation if you need any form of help. *Jean M.*



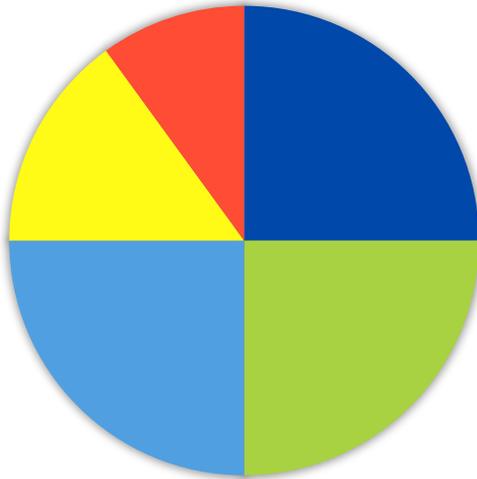
*Samantha O.*

I was diagnosed with TS at age 8. I never had any support system and was never around others with TS until recently. I am now 30. It has made for some trying times, but I have overcome those trying times and am now so ecstatic to be a part of such an amazing organization. I have made some amazing TS friends, and hope to continue with new adventures and continue to make new relationships with other women with Turners. **[TSF] events truly inspire me, they help me realize and know I am not alone in this fight.** That is exactly what TS is everyday, a fight. In this fight though we have each other, and together we are always Turner strong. This helps me make it each day in this life.

I have been involved with TSF and been a donor for several years. It is amazing what we can do with great volunteers and hard earned funding. TSF has great ideas to help women and families dealing with TS. Unfortunately, we have to choose which ones we can fund! **I wish TSF could attract the type of funding and attention that the big charities get. Imagine the things we could do.** *Dawn P.*

# Financials

## Budget

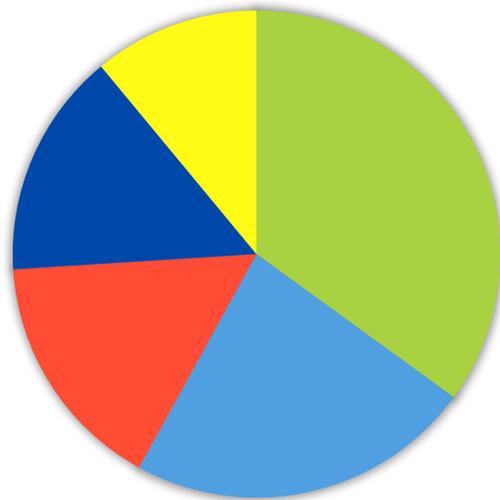


Only 10% of TSF's budget is used for administrative expenses.

- Awareness (25%)
- Advocacy (25%)
- Education (25%)
- Research (15%)
- Administrative (10%)

## Revenue

- Individual Contributions (35%)
- Fees for Service (23%)
- Foundation & Trust Grants (16%)
- Corporate & Business Grants (15%)
- Other (11%)



Full financial information available on [GuideStar.org](http://GuideStar.org).

## Top Corporate Sponsors



# Make a Difference

*An Opportunity for Everyone*

No matter your experience or your connection to this cause, there is an opportunity for you here. From canvassing in your neighborhood to hosting a team building fundraiser in your office, we will work with you to develop a volunteer opportunity that's right for you – and help you along the way. Get started today by contacting [volunteer@tsfusa.org](mailto:volunteer@tsfusa.org).



Individual



Group



Professional

## *Multiply Your Impact*

One of the most valuable ways to support TSF today is to give an outright donation. When you give, you're helping TSF advocate, deliver physician and patient education, and support new research initiatives.

To multiply the impact of your donation, consider becoming a monthly donor, designating TSF in your will or estate, or obtaining a matching gift from your employer. At TSF, we offer all of our programs and resources free of charge to the TS community. With your support, we can keep it that for the next decade and beyond. To learn how you can give today, visit [www.TurnerSyndromeFoundation.org](http://www.TurnerSyndromeFoundation.org) or contact [philanthropy@tsfusa.org](mailto:philanthropy@tsfusa.org).



# Thank you to our generous donors & volunteers!

## Special thank you to our Professional Members:

*Patricia Fechner, MD  
Seattle Children's Hospital*

*Jan Foote, DNP, ARNP, CPNP, FAANP  
Blank Children's Endocrinology Clinic*

*Sara Kahn, RN, BSN  
Michigan Medicine Pediatric Endocrinology*

*Josephine Kasa-Vubu, MD  
Michigan Medicine Pediatric Endocrinology*

*Leslie S. Lam, MD  
Children's Hospital at Montefiore*

*Siddharth Prakash, MD, PhD  
University of Texas Health Science Center at Houston*

*Paul Saenger, MD  
Winthrop Endocrinology Diabetes & Metabolism*

*B. Michelle Schweiger, DO, MPH  
Cedars-Sinai Medical Center*

*Roopi Kanakatti Shankar  
Children's National Medical Center*

## Connect With Us



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