



# TURNER SYNDROME ANXIETY PROJECT



Newsletter, Vol 1, March 2024

## A STUDY UPDATE

Dear friends,

Welcome to our first newsletter! Our team is excited to connect with our supporters and past participants to share progress on the project, resources for families, and ways to stay involved. The Turner Syndrome Anxiety Project began in May 2022 with a request from the community to help people with TS experiencing anxiety. We received funding from the Colorado Clinical & Translational Sciences Institute for the first phase of the project where families participated in online surveys and in-depth interviews. An advisory board made up of women with TS, parents, and clinicians reviewed all of the data and developed some important resources based on our findings (see our one-pagers below!). Your participation helped us understand some of the unique ways anxiety presents in TS (see Alexa's presentation at WMRC below). When we wrapped up that study in April 2023, it was clear that our work was not yet finished. We have received additional funding to develop a new anxiety screener for TS (see the RATE study below) and have plans for much more- such as improving anxiety screening procedures in TS clinics and developing an intervention to treat anxiety in people with TS. We have big plans for the project and hope you will continue to be involved with this important work! See below for ways to participate and please reach out with any questions. Together, we can reduce symptoms of anxiety and improve quality of life so people with TS and their families can thrive!

**+ Join me on March 27th 6pm MT (via Zoom)  
at the Research Insights meeting hosted by TSGA**

Thank you,

Dr. Talia Thompson  
eXtraOrdinary Kids Clinic and Research Team  
Childrens Hospital Colorado



I will be presenting recent research on Anxiety in TS!

Stay after with a cup of tea or glass of wine to connect with others from the TS community.

[CLICK TO REGISTER](#)



## INCREASING AWARENESS

The TS Anxiety Project aims to raise awareness about anxiety in the TS community.

We are excited to share three new informational TS Anxiety Project "one-pagers"!

These resources are meant to be shared with individuals with TS, parents, and teachers. We hope you find them useful. Please share with anyone you think would benefit from learning more about anxiety in TS.

[INDIVIDUAL WITH TS ONE-PAGER](#)

[PARENT ONE-PAGER](#)

[TEACHER ONE-PAGER](#)

Click to download and share!



# PAST RESEARCH



## Engaging community to address barriers and facilitators to diagnosis and care

In January, Alexa Carl, MPH traveled to Carmel, California to present findings from our first study at the 2024 Western Medical Research Conference (WMRC). The WMRC is an annual event attended by students, residents, physicians and researchers in pediatrics, psychology, family medicine, and more. **Alexa received an Outstanding Abstract Award for this work!**



## Here's what we learned

### Anxiety is common in Turner syndrome

Caregivers and individuals with TS expressed that anxiety regularly impacts daily life. Anxiety in TS is often felt at school or the doctors office and expressed at home.



### Families carry the burden of managing anxiety symptoms in the home

Separation anxiety can make daily life events like going to the grocery store or winding down for bed a source of stress for girls and their families.

### Like the seasons, anxiety is always changing

As kids grow, meet other kids, start new schools, and get involved in activities, their interests and worries will evolve. Symptoms and triggers of anxiety can change over time.



### The key to anxiety management is early identification

Parents reported that when they received their child's TS diagnosis, anxiety was not discussed as a possible concern. These conversations are important to have early in life, so anxiety symptoms can be properly diagnosed and treated.

# CURRENT RESEARCH

# RATE

## Recognizing Anxiety In Turner syndrome Early

Our current research is funded by the Ludeman Family Center for Women's Health Research. Study aims:

**Abstract currently under review**



Participants take brief online surveys about anxiety. We are at 37% of our enrollment goal.

Participants interested in RATE must be enrolled in the InsignTS Registry: **ENROLL TODAY**



Email Turnersyndromeanxietyproject@cuanschutz.edu for more information

<b>AIM 1:</b> Develop a TS-specific anxiety screener/questionnaire	<b>Complete</b>
<b>AIM 2:</b> Validate the TS-specific anxiety screener	<b>In progress: currently enrolling</b> 8–18-year-old girls with TS and/or their parents
<b>AIM 3:</b> Test out the TS-specific anxiety screener in clinic	<b>In progress:</b> we are giving the screener to patients at the monthly TS Multi-Disciplinary Clinic at the Children's Hospital Colorado

**STAY CONNECTED**

Turner Syndrome Anxiety Project Website

Thank you to TS Colorado and our funders for supporting this project

