**“The Turner Syndrome Research Registry is an essential tool**

 **for TS research.”**

**- 2016 TS professional symposium attendees**

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​***What is the Turner Syndrome Research Registry (TSRR)?***

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The TSRR collects and stores information about individuals diagnosed with Turner syndrome. People with TS or their guardians voluntarily join the registry by providing contact information as well as health information. Participant contact information is stored at TSSUS, and information obtained through questionnaires and research studies is held at the University of Texas Health Center under the direction of Siddharth Prakash, MD.

The Turner Syndrome Society of the United States Scientific Advisory Board meets regularly to ensure the registry advances TS research. They ensure the information collected is secure, useful, and accessible to TS researchers. The Scientific Advisory Board works personally with prospective researchers to ensure quality studies that support advancing TS research.

The TSRR is patient powered because participant information is shared with TS researchers based on the consent given upon registration. A participant may choose to stop sharing information or participating at any time. Researchers are required to share the information they gather. For instance, if one researcher obtains the karyotype of a participant, then the participant's record is updated in the TSRR with the new information and available for future TSRR researchers. The TS community values responsible data sharing. The TS community directs research efforts by providing information about research topic needs.

​​***How do I know if I'm already a participant in the TSRR?***

You would have filled out a registration form, asking for your permission for the registry to utilize your health information. You would then fill out a health survey with basic information. You may receive emails from time to time asking for you to participate in certain studies. If you are unsure if you are registered in the TS Research Registry, you can email tssus@turnersyndrome.org and we can let you know.

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​***What can a participant of the TSRR expect?***

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* Join the registry by filling out an informational questionnaire about health and experiences related to TS. The information will help identify if someone is a candidate for a study and eliminates the burden of you answering the same questions for multiple studies.
* You will be invited by email to participate in certain studies. We anticipate 2-3 studies a year will be approved by the Scientific Advisory Board. Not all participants will be invited to participate in all studies, for example, if you don't have diabetes, you may not be invited to a study on TS and diabetes.
* You are encouraged to reach out to us at info@turnersyndrome.org or 800-365-9944 or 832-912-6006 if you have trouble joining, are not sure of how to answer a question, or have other needs related to the registry or a study.

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***Why is the TS Research Registry needed (TSRR)?***

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The TSRR provides health care professionals and researchers with first-hand information about people with TS, both individually and as a group, and over time, increases our understanding of TS. The general TS survey asks very basic questions about health history that would help determine whether someone is possibly eligible to join a research study. The data collected through research studies supports researchers with clinical health information that creates a virtual cycle of targeted TS data.

Thank you for partnering to save lives and bring hope to those with conditions like aortic dissection, premature hearing loss, and cognitive deficits affecting people’s daily lives.