Frequently Asked Questions about the Registry

The Turner Syndrome Research Registry (TSRR) is an online system for collecting health care information from individuals with TS. The system, called PEER “Platform for Engaging Everyone Responsibly”, is used by many patient advocacy organizations because it is privacy-assured and enables individuals to set their own sharing, privacy and data access preferences. No other registry system is patient centered like PEER.

**What is the purpose of the TS Research Registry?** To collect health information from individuals with Turner syndrome and share the information with TS researchers. The registry encourages collaboration of research efforts as collected information from individuals and studies will be available for future researchers.

**Who can input information into the TS Research Registry?** A woman with TS, a parent or guardian of a child, someone with permission to act on behalf of someone living or deceased can register. Information about an individual can only be submitted by one person.

**Why should I be a part of the TS Research Registry?** To improve the understanding of the effects of TS. Every registered person offers unique and valuable answers. Personally, we hope that your participation will save you time, so that you won’t need to fill out the same information for future TS research studies. You may also print a copy of the questions and answers you provide to support your personal record keeping.

**How do I give my health information to the registry?** You can input the information using a computer. Go to www.turnersyndrome.org to access the registry or directly to http://tinyurl.com/z7oppplb. You may call 1-800-365-9944 if you have questions. It only takes 15 minutes to register & complete the general information survey.

**Can I decide who can use the information I enter?** Yes! That’s what makes our registry unique. We realize everyone has a different comfort level with sharing health information. The default settings of the registry allow researchers approved by the Scientific Advisory Board to access your information, contact you, or request your participation, based on your preferences. If you would like to change the default settings, you are encouraged to do so during registration.

**Who maintains the registry with my information?** Genetic Alliance is contracted by the Turner Syndrome Society of the U.S. to provide the PEER software, security, training, maintenance and support services.

**When will researchers begin using information from the registry?** When the Scientific Advisory Board determines the data offers a sound representation of the TS community, approximately 500-1000 records.

**How will researchers be approved to access the TS Research Registry data?** Researchers that focus on Turner syndrome may request to utilize the TS Research Registry by filling out a request form found on the TSSUS website. The request will be reviewed by the Turner Resource Network (TRN) Scientific Advisory Board. The Scientific Advisory Board members include TS researchers, TS clinicians and at least one TS patient advocate.

**Should I encourage others in the TS community to participate?** Yes! Please let others know they can search “Turner Syndrome Research Registry” and easily sign up. You may also request printed information to share with TS providers, friends or those in your area. Thank you for sharing the opportunity.

Disclaimer. The Turner Syndrome Research Registry is a service provided by the Turner Syndrome Society of the United States (TSSUS). Modifications to the services of the PEER Registry may be out of the control of TSSUS. The Turner Syndrome Society of the US shall not be liable to you or any third party for any modification, suspension, fees for usage to third parties or discontinuance of the registry service.

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