Step by Step Guide

Welcome to the Turner Syndrome Research Registry (TSRR). The Turner Syndrome Research Registry (TSRR) is dedicated to advancing the understanding of Turner syndrome (TS). It is the only online collection of TS patient information securely stored for use by TS research teams. You have the ability to enter information about yourself and allow research teams to access your answers, with or without your personal contact information. You control all the information you enter, such as how long it is available for researchers to use it, who, if anyone can view it and you may delete your entire record at any time. Don’t worry, although it may sound complicated, most people find it self-explanatory when they register.

You may participate in the registry if you have TS, are the parent of a daughter with TS, or have authority to register on behalf of someone with TS (or deceased). The current questionnaire is set up for girls with TS who have been born alive. We are working on questions about pregnancy and a prenatal diagnosis of TS. All TSRR participants register, create health profiles, take a questionnaire about living with Turner Syndrome, and choose their own privacy settings.

If you have TS, you will answer questions for yourself. A parent can input information for a daughter, and it is highly encouraged to allow her to enter her own information if she is 18 or older (or 21 in Colorado.) Respecting an adult’s wishes to participate or not and understanding the purpose of the registry is important if she is physically or mentally unable to participate for herself.

When you create an account you may either:
• Create a health profile for yourself. Questionnaires/surveys within TSRR will be presented to you in the first person.
• Or create a profile for your daughter, for whom you will act as a proxy. Questionnaires/surveys will be presented to you in the third person so that you can enter information about your daughter.

This document will provide you with instructions on creating a health profile, for navigating within TSRR and from sharing health information to managing your account and associated health profile.

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A detailed walk-through for each portion of the process follows. Please feel free to use the table of contents above to skip to relevant sections!

Set Up Your Account
To get started, go to tssus.org, and it will look like or similar to the visual below.

Figure 1 Double click on Turner Syndrome Research Registry box anywhere. You should see the visual below.
Figure 2  You may watch the short introductory video; Click on “Read FAQ’s” and when you are ready, click the button “Register Now.”

Figure 3
The system requires that you enter an email address. If you do not have an email account, you may go to gmail.com and set up a free account. You will receive an email confirmation and link from TSRR so that you will need access to your email account. Go ahead and access your email in a second tab or a second window of your browser. If you are not on your own computer, you will need to bring along your password.

Create a new account on the Sign Up Screen (Figure 3) by entering your email address in the space under ‘First time user?’ and checking the box to indicate that you are over 18. You will receive an alert if your email address has already been used to create an account. Once you
have activated your account, you can stop at any time and return to where you left off. Then, you would sign in under ‘Returning user?’.

If you are younger than 18 (or 21 in Colorado), your parent or guardian must fill this out. Click on Sign-up after you have filled in your email address.

Figure 4

Choose a user name and a unique password (Figure 4). Read the checked box on the bottom of the page. Click on continue when you’re finished.

Figure 5
After selecting your username and password, choose three security questions (Figure 5). These are just like the security questions used in online banking: they help to protect your account from unlawful activity. Select three easy-to-remember questions, type in the answers, and click **Continue** to proceed. Be sure to write down these questions and answers in case you forget them – you’ll need these to log in to your account in the future.

**Figure 6**

On this screen (Figure 6) pick your site key by clicking on an image (i.e. kitten) and entering an image caption. Your image caption should be very simple. When you log in to your account, this image and caption should always appear! Be sure to write down this information for your records. This site key provides an additional layer of protection to help you verify your identity. Press Continue when you are finished.

**Figure 7**

After choosing your challenge questions and site key, view (Figure 8) and accept the **End---User License Agreement (EULA)**. (Figure 7)
To read the EULA click on the link in Figure 7 to open a pop-up window containing the text of the agreement (Figure 8). Additional information about Private Access’ privacy policy is also available here. If you would like, use the links in the menu to the right to view the Private Access Privacy Policy, Privacy Statement, and Terms of Service.

When you’re finished, exit out of the pop-up window by clicking on the X in the upper right-hand corner and click on Accept EULA in Figure 7. This is the last step in creating your account. From here on, you can stop at any time and return to where you left off in the set-up process.

TSRR will send you an email confirming your registration (Figure 9). Check your email for a link that you must click on to activate your account (Figure 10). Click to activate your account.
Figure 10

The link will take you to a screen (Figure 11) displaying the site key you chose earlier in the account set-up process. Before entering your password, make sure that the image and caption are the ones that you chose!
Welcome to the registry! Click Let’s Get Started to add your information.

On this screen, you will be able to provide your contact information. This should be your information as the account holder (meaning that even if you are taking this survey for your daughter, you should still put your information here). Your contact information will be available to different organizations and researchers... but only if you decide to share it. You decide who can access your contact information a little later on in the registry experience. (Figure 13)

Please note: if you are filling this out for your daughter, you will be able to enter her information on another form, when you make your first health profile. You will need to scroll down to get to the entire page.

Once you are finished, click on Continue.
Create your Health Profile

Check the appropriate option in Figure 14, either: myself or my child, and press Continue. The majority of the TS Community who fill this out will check Myself or My Child.

If you are filling it out for your daughter, skip the next two slides.

Click on Who will have access to this information? (Figure 16)
After reading figure 16, fill out this information and click slides.

If you are filling this out for your daughter, check the My Child box. Click on Continue.

Figure 18
Fill in your profile information. Don’t forget to switch from “he” to “she”!

Click on “Who will have access to this information?” to learn more about how your information may be shared. Once again, it’s up to you to decide which researchers and organizations will or will not have access.

Figure 19

Read **Who will have access to this information?** Fill out this information and click Save Profile. Don’t forget to check the “She” box.

**TS Basic Questionnaire**
Figure 20 Click on Start, after **TS Basic Questionnaire** (Figure 20).

Figure 21 the rest of the questionnaire should take 10 minutes. Click on Continue.

Figure 22

If you are the parent, fill out the following forms regarding health information about your daughter. They will be worded a bit differently than forms Figure 25 through Figure 55, but the questions are all asking for basic health information. If you are an adult with Turner syndrome, fill out the following forms starting with Figure 22. Examples of all are as follows. If there is no copy below the figure, fill out the page and click on Save and Continue.
Pick the correct weight from the scroll down and click on Save and Continue. You will have the option to click on Skip on most of the following questions. Please remember the more information you provide will help the researchers learn about TS. Every time you click on a response, you will be able to see the breakdown of how others responded. (Figure 24)
Choose the height from the scroll down and click on Save and Continue. Please note, if you choose under 5’ and Click Save and Continue, you will be able to choose your height in Figure 26.
Figure 27 Figure 27 through Figure 53 is a quick look at those slides. Check off the answers that apply and click on Save and Continue at the bottom.

Figure 28
Figure 35

Figure 36

Figure 37
This platform is used for other disease conditions which is why you are asked about your gender. Click on your response and click Save and Continue.
Click on a box and click Save and Continue. Don’t forget to update your health profile as things change!
Figure 49
Click on all of the boxes that apply and click Save and Continue.

Figure 50

Figure 51
Please help the TS Community by sharing a link to this registry with others in the TS Community and suggest they take the survey. Click on Complete Survey. This is your record. You may come back and review your answers at any time. We will send you information on new questionnaires, and new chances to update your information, as your permissions allow.

**Data Sharing, Privacy and Access Settings**

Click on Blue arrow at the far end of the main screen after Get Started.
Figure 5

Click on the Start button after manage data sharing, privacy and access preferences.

The final step in the registry experience is to choose your sharing, privacy and access settings (Figure 56). This process is the same whether you are creating a profile for yourself, or for your daughter. These settings control who will be able to access this profile’s health information for research purposes, and potentially contact you for future studies or inquiries. You will be able to decide not only who to share with, but how much you’d like to share with them.

Figure 56

To start, click on View TSRR’s default privacy settings. You will be able to decide whether to keep these settings or customize them.
Please review the default privacy settings. The default settings chosen by TSRR allow only TSSUS or the researchers vetted by TSSUS/TRN to access participant’s information for research (either by searching for you in the registry database – that’s the “Find/Analyze” setting – or by exporting your information from the registry database – that’s the “Export/Link” setting) and contact you (the “Get Contact” setting). Any researcher chosen will have gone through a thorough vetting process. Other groups and researchers reaching out to Genetic Alliance’s PEER registry will not have access to your contact information but can search for your non-identified information. Click on the ‘I’ button to the left of each row to read more about the different organizations and researchers with whom you can share data, and on the “click for details” link under each column to read more about the different types of data sharing. If you have any questions, please contact TSSUS at 1-800-365-9944.

If you choose the default settings, click on Keep Default Privacy Settings and skip to the end of the document – you’re all done! If you choose to customize, click on Customize your Privacy Settings.
Settings. Here, you may either choose to customize the settings on your own, or choose to do so with the assistance of a “community guide.” Each guide provides their examples of privacy settings, together with a video.

Privacy Settings

![Image of Privacy Settings]

Figure 59 Choose a guide or choose your own privacy settings. Selecting a guide will assist you in the process of choosing these settings. These guides are members of the TSRR community who provide several sets of recommended sharing settings that you can choose from and customize depending on whether you have low, medium or high concerns about privacy. Before choosing a guide, you can see the guides’ pictures, where they have rated themselves on a spectrum from complete access (“it is ok for researchers to use my data without my consent at all”) to complete privacy (“I would not want researchers to contact me or use my data under any circumstances”), and read the short guide biographies. Hit the gray Choose a guide buttons to select a guide (Figure 59), and then, to view and customize his or her recommended sharing settings (Figure 60). Alternatively, choose to set your own sharing settings by selecting Create Preferences Manually.

When viewing the privacy setting examples, the higher the concern level you select, the more it will limit researchers from using your information.
Each guide provides a table of his or her recommended settings. Cindy has low concerns about privacy, in general, but you can also view her recommendations for individuals with moderate and high concerns about privacy.

Barb has moderate concerns about privacy, but you can also view her recommendations for individuals with low or high concerns about privacy.

View the guide’s recommended settings. In Figure 62, Cindy’s recommended Settings are set to her default, **low concerns about privacy** (since Cindy is a little more to the left on the spectrum of complete access to complete privacy) – but she also has recommendations for individuals with higher concerns about privacy. In Figure 63, Barb’s recommended settings are set to her default, **moderate concerns about privacy** (since Barb is a little more to the right on the spectrum of complete access to complete privacy) but she also has recommendations for individuals with lower or higher concerns about privacy. Choose which guide you’d like to start with, and then choose which set or privacy settings you’d like to view based on your own feelings about privacy.
When you’re ready, decide whether to use the recommended sharing settings provided by your guide as is, or whether to customize them. To use the settings as is, click on **Accept and continue**. To customize the settings, click on **Customize**. If you choose to customize the settings, you will see the following customization screen (Figure 64). Edit the settings using the dropdown menus.

![Customize To preferred privacy settings](image)

**Figure 62**

You can choose Allow or Deny for the Find/Analyze setting, and Allow, Deny or Ask me for the Export/Link and Get Contact settings. Ask me means a researcher can send you a notification through the system asking whether it’s ok to use your information for their study. There’s no ask me option for the Find/Analyze setting because that’s what determines whether someone
can search for you in the registry database in the first place. Someone can’t ask to find you if they don’t know you exist!

Figure 64