

WEB SITE PRIVACY POLICY

BY USING THE WEB SITE, YOU ACCEPT AND AGREE TO THE PRIVACY POLICY SET FORTH BELOW. If you do not agree to this policy, you may not access or otherwise use this web site, including any sub domains thereof (the “Web Site”). We may change this policy from time to time, at any time without notice to you, by posting such changes on the Web Site, and your use after such change signifies your acceptance of the changed terms. Please check this policy periodically for changes.

This policy is intended to help you understand how Turner Syndrome Society of the United States (“TSSUS” or “we” or “us”) collects, uses and safeguards the information you provide on our Web Site. This Privacy Policy does not apply to the use or disclosure of information that is collected or obtained by us through means other than this Web Site.

PERSONAL DATA

If you browse the Web Site, you may generally do so anonymously without providing any personal information. However, there are cases where we may ask you for personal data, including in connection with registration for an account. When personally identifiable information is collected, you will know because you will have to fill out a form. For example, when you register for an account with the Web Site we collect personal information in your profile. In addition, we request personal information when you make a donation, register to receive additional information regarding us or our products and services or send us a question. If you choose not to give information we request, you can still visit most of the Web Site, but you may be unable to access certain options, offers, and services.

In case you change your mind or wish to update or delete personal information (such as your zip code), we will endeavor to correct, update or remove the personal data you give us. You can do this by contacting us at the contact points specified below.

ORDERS AND DONATIONS

When you make a donation or place an order for a product, we need to know your name, e-mail address, mailing address, credit card number and expiration date. This information is required so that we can process your donation or fulfill your order. All payment transactions with TSSUS are performed via PayPal® and subject to PayPal’s terms of use and privacy policies.

TSSUS COMMUNICATIONS

When you make donations, purchase products online from us, request product information or otherwise provide us with personal information, we automatically place you on our list to receive [e-mail/direct mailings] regarding TSSUS and its mission and activities, special offers and updates. If you do not wish to receive these communications, you can simply follow the opt-out procedure in the received communication or contact us via the contact points below to tell us that you do not want to receive any future communications.

USE OF PERSONAL DATA

Personal information provided by users who are 13 years of age or over will be used for TSSUS business only, including its marketing and promotional purposes. If you agree to allow your

personal information to be offered by TSSUS staff to other TSSUS members or make inquiries for support purposes then your information will be used solely for such reasons. TSSUS does not offer our database lists to third parties. We may provide your personal information to third party agents we have hired to help us provide a good or service you have requested. For example, in connection with a product you ordered, we would need to provide your credit card number to a payment authorization service and your address to a shipping company to deliver your package.

While we use all reasonable efforts to safeguard the confidentiality of your information, TSSUS will have no liability for disclosure of any information obtained due to errors in transmission or the unauthorized acts of third parties.

We may share statistical or aggregated non-personal information about our users with advertisers, business partners, sponsors and other third parties. This data is used to customize Web Site content and provide usage information to help us deliver a better experience to our users.

COOKIES, WEB ANALYTICS AND IP TRACKING

We gather certain web usage information to help us manage and administer our Web Site. We use web traffic data and analytics for traffic monitoring and capacity purposes and to see how visitors use our site. To do this, we utilize cookies and may also detect and use your internet protocol (IP) address or domain name. No personal information is obtained; rather just the patterns of usage of our various users may be tracked to provide you with improved service and content based on aggregate or statistical reviews of user site traffic patterns. If for any reason you wish to not take advantage of cookies, you may have your browser not accept them, although this may disable or render unusable some of the features of the Web Site.

WEB BEACONS

Web pages on this Web Site or e-mail messages you receive from us may contain a small graphic image called a web beacon (sometimes called a web bug or clear gif). Web beacons are typically very small (generally 1-by-1 pixel) and invisible to the user, however any electronic image viewed as part of a web page or e-mail message, including an advertisement or HTML content, can act as a web beacon. Web beacons are designed to allow us or a third party to collect certain information and monitor user activity on our Web Site. Collected information can include the IP address of the computer that the web beacon is sent to, the URL of the page the web user comes from, and the time the web beacon is activated (such as when you view the web page, advertisement, or e-mail that contains the web beacon). We may permit third parties to place web beacons on our sites or in e-mails sent on our behalf for purposes of collecting these same types of information. No personal information is obtained from this tracking; rather just the patterns of usage of our various users may be tracked to provide you with improved service and content based on aggregate or statistical reviews of user site traffic patterns.

SPECIAL CASES

TSSUS reserves the right to disclose personal information in special cases, when we have reason to believe that disclosing this information is necessary to identify, contact or bring legal action

against someone who may be causing injury to or interference with (either intentionally or unintentionally) our rights or property, other Web Site users, or anyone else that could be harmed by such activities. We may disclose personal information without notice to you in response to a subpoena or when we believe in good faith that the law permits it or to respond to an emergency situation.

In the event TSSUS or its assets are sold, merged or otherwise involved in a corporate transaction, your personal information will likely be transferred as part of that transaction. We reserve the right to transfer your information without your consent in such a situation; provided that we will make reasonable efforts to see that your privacy preferences are honored by the transferee.

Specific areas or pages of this Web Site may include additional or different provisions relating to collection and disclosure of personal information. In the event of a conflict between such provisions and this Privacy Policy, such specific terms shall control.

POLICIES FOR CHILDREN

TSSUS does not knowingly collect or use any personal information from users under 13 years of age. No information should be submitted to the Web Site by guests less than 13 years of age and guests less than 13 years old are not allowed to register for accounts, newsletters, contests or activities.

LINKED SITES

Please be advised that our Web Site contains links to third-party Web Sites. The linked sites are not under the control of TSSUS, and we are not responsible for the contents or privacy practices of any linked site or any link on a linked site.

CONTACT INFORMATION:

Turner Syndrome Society of the United States
11250 West Rd., Suite G
Houston, TX 77065
Phone: 800-365-9944
Fax: 832-912-6446
Email: tssus@turnersyndrome.org

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