



## **The Turner Syndrome Society of the United States Member and Donor Privacy Policy**

### **Member and Donor Privacy Policy**

Updated 07/24/2023

Your right to privacy is very important to the Turner Syndrome Society of the United States (TSSUS). We recognize that providing us with personal information is an act of trust. Therefore, we have created a privacy policy to protect your personal information. Your name and address and other information you provide will be used to keep you informed and up to date on the activities of TSSUS, including programs, services, funding needs, special events, advocacy, volunteer opportunities, membership opportunities, and opportunities to give.

We will not sell, rent, share, or trade our mailing lists, including: donors', member's, or participant's names, addresses, email addresses, phone numbers, or any other personal information with any other entity, nor send mailings to our members or donors on behalf of other organizations. This policy applies to all information received by TSSUS, both online and offline, on any Platform ("Platform" includes the TSSUS website, social media, event registrations, and mobile-friendly applications), as well as any electronic, written, or oral communications.

Any and communications for TSSUS events and programs will come directly and only from the TSSUS national office, including communications for local group activities and events, online/virtual events, national events, and newsletters.

### **Our Commitment to Members and Donors**

Our organization is committed to protecting the privacy of the personal information of its members, employees, board members, donors, clients, and stakeholders. We value the trust of those we deal with, and of the public, and recognize that maintaining this trust requires that we be transparent and accountable in how we treat the information you chose to share with us.

During the course of our various projects, special events, and activities, we gather and use personal information. When donating to TSSUS, online or offline, information will be collected that must remain private.

TSSUS is the sole owner of all information collected in the donation process. TSSUS will not, under any circumstances, sell, rent, share, or trade your information in ways other than what we describe in this statement.

## **Privacy Practices**

Personal information gathered by our organization is kept in confidence, under lock and key. Industry standard safeguards are in place to ensure that the information is not disclosed or shared more widely than is necessary to achieve the purpose for which it was gathered. We take additional measures to ensure the integrity of this information is maintained and to prevent it being lost or destroyed.

## **Opt-Out Policy**

Members and donors, be they online or offline, may opt out of receiving mailings, emails, or phone calls from TSSUS at any time by contacting us as described below.

## **How to Contact Us**

If you have questions about this Donor Privacy Policy, please contact the Turner Syndrome Society of the United States via:

- email at [becky@turnersyndrome.org](mailto:becky@turnersyndrome.org) with “Member and Donor Privacy Policy” or “Opt-Out” in the subject line; or
- postal mail to: Becky Brown, National Director of Development & Communications, Turner Syndrome Society of the United States, 11250 West Road, Suite G, Houston, TX 77065.
- By phone at 832.912.6446 or 800.365.9944