

TSC Alliance

Privacy Policy

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The TSC Alliance (or “we,” “us,” “our”) respects your privacy. We protect your personal information and adhere to the highest standards in gathering, using, and safeguarding constituent information, including all personal donor and gift information. We want you to understand how we collect and use information from our website <https://www.tscalliance.org/> (the “Site”) and our related services, (together with the Site, the “Services”) so you can interact with us with confidence. By using the Services, you accept and agree to the practices this Privacy Policy describes.

We periodically update this Privacy Policy. When we so, we will also revise the “last updated” date at the beginning of the Privacy Policy. We encourage you to review this Privacy Policy periodically.

1. INFORMATION WE COLLECT

When you visit the Services, we may collect and use personally identifiable information about you, as well as other usage information. We collect information in the following ways:

- *Information You Give Us Directly* by filling in forms on our Site. This may include name, postal address, email address, telephone number, or similar information that can be used to identify you and is defined as personal or personally identifiable information under applicable law.
- *Information Provided to Us When You Communicate with Us* for any reason, including information you provide in emails you send us, responses to surveys, search queries, and details of any donation.
- *Payment Information.* We may collect and process payment information from you when you donate online, including credit card numbers and billing information, using third-party PCI-compliant service providers. Except for this, we do not collect any financial information from you.
- *Information We Get from Your Visit to the Site* and the resources that you access—including, but not limited to, traffic data, location data, weblogs and other communication data, including your IP address, browser type, the date and time you accessed or left the Websites, and which pages you viewed. Some parts of our Site use cookies, tags and scripts, or other technologies to collect this information about your general internet usage. See the section below called “Use of Tracking Technologies” to learn more.

2. HOW WE USE THE INFORMATION WE COLLECT

We use the information we collect from you primarily to enable us to provide our services in the best possible manner. We only use this information in compliance with this Privacy Policy. We will never sell your personal information.

2.1 Use of Personal Information

Information you provide – such as name, physical address, phone number or email address – will be used only to deliver such services and to keep you informed and up to date on TSC Alliance activities, including programs, services, special events, funding needs, opportunities to volunteer or legislative alerts. In addition, we may use your personal information to:

- respond to any requests you may have;
- send you communications and updates relating to TSC Alliance;
- notify you about changes to the Services;
- improve your browsing experience by personalizing the Site;
- perform analytics to learn about the behavior of our Site users;
- better understand certain diseases or health challenges and treatments;
- provide you with information, products, or services that you request from us or which we think may be of interest to you; or
- evaluate or conduct a merger, divestiture, restructuring, reorganization, dissolution, or other sale or transfer of some or all of our assets, whether as a going concern or as part of bankruptcy, liquidation, or similar proceeding, in which personal information held by us about our Site visitors is among the assets transferred.

We may also use your personal information for any other purpose with your consent.

2.2 Use of Tracking Technologies

We may use various technologies to collect and store information when you visit the Websites or use the Software.

Cookies

A cookie is a small file placed on your computer or device when you visit a website. We use cookies for various functions, including to understand whether a visitor has previously visited a particular website or to make the log-in experience easier. Cookies are uniquely assigned to you and may store user preferences and other information. You may refuse to accept cookies by activating the appropriate setting on your browser. However, if you select this setting you may then be unable to access certain parts of the Site. Please note that cookie-based opt outs must be performed on each device and browser that you wish to have opted out

Tags and Scripts

Certain pages of the Site and our emails may contain small electronic files known as web beacons (also referred to as clear gifs, pixel tags, and single-pixel gifs) that permit us, for example, to count users who have visited these pages or opened the email and provide other related website statistics (for example, recording the popularity of certain website content and verifying system and server integrity). This assists in informing us which systems are operating effectively and helps us understand how well our Site is performing for visitors.

2.3 Use of Credit Card Information

When you make a payment on our Site, we use a third-party service provider to manage credit card processing. This service provider is not permitted to store, retain, or use information you provide except for the sole purpose of credit card processing on our behalf.

3. INFORMATION WE SHARE

The TSC Alliance does not rent, sell or trade our mailing lists or other personal information. Except as described below, your name or other information will not be shared with third parties unless you have specifically requested or agreed for us to do so, such as when you choose to participate in our TSC Connect, Step Forward to Cure TSC recognition programs, donor match programs or research programs, when disclosure may be required by law.

We utilize other trusted companies and people to assist in the maintenance or administration of the organization's records and to otherwise provide support. In all cases where we share your information with such service providers, we require that they take appropriate security measures to ensure the confidentiality of any personal information they handle.

We may also disclose your personal information, if we have a good faith belief that disclosure is necessary to:

- comply with any court order, law, or legal process, including to respond to any government or regulatory requirement; or
- protect the rights, property, or safety of TSC Alliance, our customers, or others. This includes exchanges of information with other companies and organizations for the purposes of fraud protection and credit risk reduction.

4. CHOICE

Our goal is to be clear about what information we collect, so that you can make meaningful choices about how it is used. Therefore, upon request, we will provide you with information about whether we hold any of your personal information. If you provide us with your personal information, you may:

- review the information that you have supplied to us;
- request that we correct any errors, outdated information, or omissions in user information that you have supplied to us;
- request that your information not be used to contact you;
- request that your information be removed from any solicitation list that we use; or
- request that your information be deleted from our records.

To exercise any of these rights, please contact us at info@tsalliance.org. We will respond to your request to change, correct, or delete your information within a reasonable time and notify you of the action we have taken.

If your information has been shared with a third party, as described elsewhere in this Privacy Policy, then that third party has received its own copy of your data. If you have been contacted by one of these third parties and wish to correct or delete your information, please contact them directly.

If at any time you wish to receive less information via mail or online, wish to be removed from any or all of our communications, or have any concerns with respect to this policy or any information provided or obtained by the TSC Alliance, simply contact us by phone at 800-225-6872 or via email at info@tscalliance.org. We will gladly accommodate your request.

5. INFORMATION SECURITY

We have implemented a variety of measures designed to secure your personal information from accidental loss and from unauthorized access, use, alteration, and disclosure.

Unfortunately, the transmission of information via the internet is not completely secure. Although we do our best to protect your personal information, we cannot guarantee the security of your personal information transmitted to us. Any transmission of personal information is at your own risk. We are not responsible for any circumvention of any privacy settings or security measures contained on the Site.

6. THIRD-PARTY CONTENT

Some of the content or applications on the Site are served by third parties, including content providers and application providers. We are not responsible for the privacy practices used by other websites that may be accessible or linked to by our Site. By accessing other third-party websites or applications through the Site, you are consenting to the terms and privacy policies of those websites. It is possible that other parties may collect personally identifiable information or use cookies to collect information about your online activities over time and across different websites.

Our Services may include social media features, such as Facebook “Likes.” These social media features may require cookies to be set to function properly. These features may also collect Personal Information such as your IP address. These features are governed by the privacy policy of the social media platform. Please review the privacy policy of the social media platforms to learn how they protect your information.

7. INFORMATION ABOUT CHILDREN

The Websites are not intended for or targeted at children under thirteen (13), and we do not knowingly or intentionally collect information about children under thirteen. If you believe that we have collected information about a child under thirteen, please contact us at jmartucci@tscalliance.org, so we may delete the information.

8. GENERAL DATA PROTECTION REGULATION

For our customers residing in the European Economic Area (EEA), Switzerland, and the United Kingdom, the General Data Protection Regulation (“GDPR”) may be applicable. The GDPR provides a framework for organizations to ensure protection of the personal information of European citizens and gives European citizens certain rights.

Legal Basis for Processing

If you are an individual located in the EEA, United Kingdom, or Switzerland, our legal basis for processing your personal information will depend on the personal information concerned and the specific context in which it is collected. However, we will normally collect or process personal information from you only where:

- We have your consent to do so; or
- We need the personal information to perform a contract with you (e.g. to deliver services).

In some cases, we may also have a legal obligation to process Personal Information from you or may need the Personal Information to protect your vital interest or those of another person. If we rely on your consent to process the Personal Information, you have the right to withdraw or decline your consent at any time in writing or as otherwise permitted. Please note that this does not affect the lawfulness of the processing based on consent before withdrawal, nor will it affect the processing of your Personal Information conducted in reliance on lawful processing grounds other than consent.

Retention

We will retain your personal information for as long as is needed to fulfill the purposes we collected it for, including for the purposes of satisfying any legal, accounting, or reporting requirements, unless a longer retention period is required or permitted by law.

Rights to Access and Control Your Personal Data

Individuals residing in the European Economic Area, United Kingdom, and Switzerland have certain rights to access and control their personal data. These rights include:

- the right to be informed;
- the right of access;
- the right to rectification;
- the right to erasure;
- the right to restrict processing;
- the right to data portability;
- the right to object; and
- rights in relation to automated decision making and profiling.

9. CLINICAL RESEARCH

The Site may offer you the option to participate in one or more clinical research studies. If you choose to participate, the use and disclosure of information provided as part of the study will be governed by the informed consent and privacy terms related to that study.

10. CONTACT US

If you have any questions or comments about this Privacy Policy, please email us at dklein@tsalliance.org