

**PRIVACY POLICY  
OF  
TAY-SACHS AWARENESS AND PREVENTION ORGANIZATION**

**What information do we collect?**

We collect information from you when you subscribe to our newsletter, submit a story, respond to a survey, or fill out a form for one of our prevention programs or initiatives.

When submitting a survey or form on or from our site, you may be asked to enter your: name, e-mail address, mailing address, phone number, date of birth, household information, health and health insurance information, employment and education information, or genealogical information. You may, however, visit our site anonymously without submitting any information.

**What do we use your information for?**

Any of the information we collect from you may be used in the following ways:

To conduct our prevention programs and initiatives as described on our website and in our surveys and forms associated with the submission of your information;

To increase awareness of genetic conditions and as described on our website and in our forms;

To personalize your experience (your information helps us to better respond to your individual needs);

To improve our website (we continually strive to improve our website offerings based on the information and feedback we receive from you);

To improve customer service (your information helps us to more effectively respond to your customer service requests and support needs);

To process transactions;

To administer a survey, contest, promotion, or other site feature; and

To send periodic emails.

If you provide an email address, e.g., for our surveys or forms or programs or initiatives, the email address may be used to send you information and updates pertaining to these surveys or forms or programs or initiatives, in addition to receiving occasional organizational news, updates, related product or service information, etc.

Note: If at any time you would like to unsubscribe from receiving future emails, we include unsubscribe instructions at the bottom of each email.

Your information, whether public or private, will not be sold, exchanged, transferred, or given to any other company for any reason whatsoever, without your consent or except as described herein, on our website, in our surveys, or in our application forms, other than for the express purpose of the survey, form, program, or initiative for which it was collected.

### **How do we protect your personal and health information?**

We implement a variety of security measures to maintain the safety of your personal and health information when you enter, submit, or access your personal information.

We offer the use of a secure server for donations through our partner, Paypal. Your private payment information is not stored on our website's servers.

We maintain all electronic personal and health information on a password-protected server hosted by Google.

We limit the use and disclosure of your health information to the minimum necessary to accomplish our mission. We also protect your health information and ensure it is not used or disclosed improperly.

### **Do we use cookies?**

We do not use cookies. Our website is hosted by Weebly. Please see Weebly's privacy policy regarding their use of cookies at [www.weebly.com](http://www.weebly.com).

### **Do we disclose any information to outside parties?**

We do not sell, trade, or otherwise transfer to outside parties your personally identifiable information. This does not include trusted third parties who assist us in operating our website, conducting our nonprofit programs, or servicing you, so long as those parties agree to keep this information confidential. We may also release your information when we believe release is appropriate to comply with the law, enforce our site policies, or protect ours or others rights, property, or safety. However, non-personally identifiable visitor information may be provided to other parties for marketing, advertising, or other uses. If you have any concerns about the use of your personal or health information, please contact us at [info@tsapo.org](mailto:info@tsapo.org).

### **Third party links**

Occasionally, at our discretion, we may include or offer third party websites, products, or services on our website. These third party sites have separate and independent privacy policies. We therefore have no responsibility or liability for the content and activities of

these linked sites. Nonetheless, we seek to protect the integrity of our site and welcome any feedback about these sites.

### **California Online Privacy Protection Act Compliance**

Because we value your privacy we have taken the necessary precautions to be in compliance with the California Online Privacy Protection Act. We therefore will not distribute your personal information to outside parties without your consent.

### **Childrens Online Privacy Protection Act Compliance**

Our website and services are all directed to people who are at least 13 years old or older.

### **Your Consent**

By using our site, you consent to our privacy policy.

### **Changes to our Privacy Policy**

If we decide to change our privacy policy, we will post those changes on this page.

This policy was last modified on November 18, 2013.

### **Contacting Us**

If there are any questions regarding this privacy policy you may contact us using the information below.

Tay-Sachs Awareness and Prevention Organization  
3033 Wilson Blvd. Suite E (Box 212)  
Arlington, Virginia 22201-3843

[info@tsapo.org](mailto:info@tsapo.org)