



## Patient Privacy Policy

**Effective Date:** January 30, 2023

**1. Introduction** TED Community Organization (referred to as "we," "us," or "our") is a nonprofit organization dedicated to supporting individuals affected by thyroid eye disease (TED). Protecting the privacy and confidentiality of our community members is of utmost importance to us. This Privacy Policy explains how we collect, use, store, and protect personal information.

**2. Information We Collect** We may collect the following types of information:

- **Personal Identifiable Information (PII):** This includes your name, contact information (such as email address, phone number, and mailing address), and other identifiers that you may provide when you interact with us.
- **Health Information:** Health-related information shared by patients, including information about TED diagnosis, treatment history, and other details shared during programs, surveys, events, or conferences.
- **Non-Identifiable Data:** Aggregated or anonymized data collected to improve our services and track overall program effectiveness. This information does not identify individual users.

**3. How We Use Your Information** We use your information to:

- Facilitate participation in programs, support groups, and events.
- Develop resources, surveys, and educational materials to benefit the TED patient community.
- Communicate updates, program offerings, and relevant news.
- Conduct research and analysis to improve services and programs. Aggregated data may be shared for research purposes without identifying any individual.

**4. Disclosure of Information** Your information will not be shared, sold, or rented to third parties except in the following circumstances:

- **Service Providers:** We may engage third-party vendors to assist in delivering services, such as event registration, surveys, or communications. These providers are required to maintain confidentiality and are restricted from using your information for any purpose other than assisting us.

- **Legal Requirements:** We may disclose personal information if required to comply with legal obligations or to protect the rights, property, or safety of our community, stakeholders, or the public.
- **Anonymized Data Sharing:** Anonymized and aggregated data may be shared with research institutions or partners for the purpose of advancing understanding of TED.

**5. Security of Your Information** We take reasonable measures to protect personal information from unauthorized access, use, or disclosure. These measures include data encryption, access control, and regular security assessments.

**6. Your Rights and Choices** Depending on your location, you may have the following rights regarding your personal information:

- **Access and Correction:** You may request access to or correction of your personal information.
- **Opt-Out:** You may opt out of receiving communications by following the unsubscribe instructions in emails or contacting us directly.
- **Data Deletion:** You may request the deletion of your personal information, subject to any legal or contractual obligations we may have.

**7. Children's Privacy** We do not knowingly collect or solicit personal information from individuals under the age of 13. If we discover we have inadvertently collected information from a child under 13, we will delete it as soon as possible.

**8. Changes to This Privacy Policy** We may update this Privacy Policy to reflect changes in our practices, legal requirements, or other reasons. We will provide notice of any significant changes through our website or direct communications.

**9. Contact Us** For questions or concerns regarding this Privacy Policy or the handling of your personal information, please contact us:

**TED Community Organization**

[hello@tedcommunity.org](mailto:hello@tedcommunity.org)

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