Privacy Policy for Cure RTD

Effective Date: March 1, 2018
Last Updated: August 4, 2026
At the **Cure RTD Foundation** ("Cure RTD," "we," "us," or "our"), we deeply value the trust of the Riboflavin Transporter Deficiency (RTD) community. Because we put patients and families at the heart of everything we do, protecting your personal privacy and the sensitive medical identity of patients and their families is our highest priority.
This Privacy Policy outlines how we collect, use, protect, and handle personal and health-related information when you visit our website (**www.curertd.org**), participate in our community programs, share patient stories, or support our research initiatives.

1. Information We Collect

We collect information to connect families, provide support, raise awareness, and advance research. This information generally falls into two categories:

- **Personal and Contact Information:** Names, email addresses, phone numbers, postal addresses, and relation to an individual with RTD (e.g., parent, patient, clinician, researcher), provided voluntarily when you sign up for newsletters, make a donation, register for events, or contact us.
- **Medical and Family Stories (Collected with Explicit Consent):** Information regarding an individual's RTD diagnosis, symptoms, treatment journeys, photos, videos, and personal narratives. **We never publish or share medical details or identifiable patient stories without explicit, written consent from the patient, parent, or legal guardian.**

2. How We Use Your Information

We use the information you provide exclusively to fulfill our mission of finding a cure for RTD. This includes:

- Connecting newly diagnosed families with peer support and vital medical resources.
- Sharing patient journeys, updates, and awareness campaigns (only with clear, prior authorization).
- Processing donations and issuing tax receipts.
- Communicating about research breakthroughs, clinical trial opportunities, and foundation updates.
- Facilitating connections between researchers, clinicians, and the patient community *strictly* under compliant data-sharing agreements and participant consent.

3. Strict Protection of Patient and Family Identity

We recognize that RTD is a rare genetic disorder, and protecting the identity of patients and minors is paramount.

- **Anonymization & Pseudonymization:** When sharing data, case studies, or communicating with medical researchers/partners, we prioritize stripping direct identifiers (such as full names, exact birthdates, and specific locations) unless explicit consent is given to disclose them.
- **Minimization:** We only collect and share the minimum amount of personal data

necessary to achieve a specific, family-approved purpose (e.g., connecting a family to a specific clinical trial).
- **No Commercial Use or Selling of Data:** Cure RTD **never** sells, rents, trades, or commercializes personal data, medical histories, or contact lists under any circumstances.

4. Sharing of Information

We do not share your personal information with third parties except in the following limited circumstances:
- **With Your Explicit Consent:** For instance, if you ask to be connected with a specific medical expert, researcher, or another RTD family.
- **Service Providers:** Trusted third-party vendors who assist us in running our website, processing donations securely, or managing emails, all of whom are strictly bound by confidentiality obligations.
- **Legal Requirements:** If required by law, court order, or governmental regulation to protect the safety, rights, or property of Cure RTD or our community.

5. Data Security Measures

We implement robust administrative, technical, and physical security measures designed to protect your personal and medical information from unauthorized access, loss, misuse, or alteration. While we strive to use commercially acceptable means to protect your data, no method of transmission over the internet is 100% secure, and we cannot guarantee absolute security.

6. Your Rights and Choices

You have complete control over your family's data. At any time, you may:
- **Access or Update:** Request to view or update the personal information we hold about you or your family.
- **Opt-Out:** Unsubscribe from our newsletters or marketing communications by clicking the "unsubscribe" link at the bottom of our emails.
- **Request Deletion:** Ask us to delete your personal information, remove a patient story, or take down media/photos from our platforms.

To exercise any of these rights, please contact us directly at **info@cureRTD.org**.

7. Children's Privacy

Because RTD frequently affects infants and children, we treat minor data with extraordinary care. We do not knowingly collect personal information directly from children under 13 online without parental or guardian consent. If you are a parent or guardian and believe your child’s information was submitted improperly, please contact us immediately.

8. External Links

Our website may contain links to external sites (such as scientific journals, research institutions, or partner non-profits). Cure RTD is not responsible for the privacy practices or content of those external websites. We encourage you to review their respective privacy policies.

9. Changes to This Privacy Policy

We may update this Privacy Policy from time to time to reflect organizational changes, technological updates, or legal requirements. Any modifications will be posted directly on this page with a revised "Last Updated" date.

10. Contact Us

If you have any questions, concerns, or requests regarding this Privacy Policy or how your family's information is handled, please reach out to us:

- **Email:** info@cureRTD.org
- **Mailing Address:**
  Cure RTD Foundation
  P.O. Box 1228
  Red Oak, TX 75154
  USA
- **Website:** www.curertd.org