

# Rett Syndrome Research Trust (RSRT) Privacy Policy

## 1. Purpose of Data Collection

Individuals may register with RSRT and RSRT may periodically conduct surveys, polls, or questionnaires (“Surveys”) for the purpose of advancing research into Rett syndrome. Registration and participation in Surveys is voluntary. Any personal or health-related information collected is used solely to support research, data analysis, or community understanding related to Rett syndrome.

Some Surveys may be conducted outside of formal Institutional Review Board (IRB) oversight and are intended for exploratory or community research purposes. Surveys requiring IRB approval will include separate consent language, as applicable.

Surveys may be administered using third-party platforms or service providers (e.g., secure survey or data-hosting platforms). Once RSRT receives survey responses, RSRT is responsible for the use, storage, and protection of that data under this Privacy Policy. Data collected through third-party platforms is also subject to the privacy policies of those platforms.

## 2. What Information We May Collect

Registration and Surveys may request personal information, including:

- Name
- Contact information (email address and/or phone number)
- Location (city or state)
- Birthdate (or age)
- Sex
- Rett-specific clinical information such as MECP2 mutation

For Surveys involving minors or individuals unable to provide consent, participation requires consent from a parent, legal guardian, or legally authorized representative acting on the individual's behalf.

## 3. HIPAA-Aligned Practices

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a U.S. federal law that establishes national standards for the protection of individuals’ medical information. The HIPAA Privacy Rule governs how protected health information (PHI) may be collected, used, and disclosed by “covered entities” such as healthcare providers, insurers, and their business associates.

Although RSRT is not a HIPAA-covered entity, RSRT follows practices consistent with the HIPAA Privacy Rule, including:

- Collecting only the minimum necessary information to support research purposes
- Restricting access to identifiable data to authorized personnel
- Applying de-identification practices consistent with HIPAA standards where feasible for external use or publication, unless explicit consent is provided

## 4. Use of Information

Information collected is used exclusively by RSRT and authorized staff or research collaborators for Rett syndrome-related research purposes.

RSRT does not sell, rent, trade, license, or otherwise share personally identifiable information (PII) or personal health information (PHI) with third parties for unrelated purposes, including marketing, advertising, or fundraising.

RSRT may use contracted service providers to support research operations (such as secure data storage or survey administration). These providers are permitted to access information only to perform services on RSRT’s behalf and are required to protect the confidentiality of that information.

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Any externally shared information will be de-identified. De-identified information may be aggregated (grouped with other responses) for use in summaries, analyses, or publications. Individuals will not be identified in any resulting analyses, publications, or presentations.

RSRT does not use survey or registration data for automated decision-making, profiling, or determinations affecting individual rights, eligibility, or access to services.

### **5. Voluntary Participation and Consent**

Registration and Survey participation is voluntary. For Surveys collecting identifiable or potentially sensitive information, or those involving minors or individuals unable to provide consent, participation requires consent from a parent, legal guardian, or legally authorized representative acting on the individual's behalf before any data collection begins.

Participants may withdraw consent at any time. Withdrawal will apply to future uses of identifiable information; data that have already been analyzed, aggregated, or de-identified may not be retractable.

### **6. Data Security and Confidentiality**

RSRT uses reasonable administrative, technical, and physical safeguards to protect data. Survey information collected will be associated with a coded link (unique identification number). Access to identifiable information is restricted to staff or collaborators who require it for approved research purposes. When feasible, personal identifiers are stored separately from research data.

Survey and registration data are stored on secure servers located in the United States. Access may be provided to authorized RSRT personnel or collaborators located in the United States or other jurisdictions, subject to confidentiality and data-protection obligations.

### **7. Data Retention and Deletion**

Identifiable information, if collected, is retained only as long as necessary to support research purposes. Participants may request access to their information, request corrections, or request deletion or anonymization by contacting RSRT, subject to legal and scientific limitations described above.

Depending on jurisdiction, participants may have additional rights regarding personal information. RSRT will honor such rights as required by applicable law.

### **8. Disclosure Exceptions**

RSRT will not share identifiable information except as described above, unless required by law. In the event of a data breach involving identifiable information, RSRT will provide notification consistent with applicable federal and state laws.

### **9. Contact**

For questions or requests regarding this Privacy Policy, please contact: **[info@rsrt.org](mailto:info@rsrt.org)**

### **10. Policy Updates**

RSRT may update this Privacy Policy periodically. Material updates will be posted on our website. If changes to this policy materially affect information previously collected by RSRT, affected individuals will be notified when feasible.