

Privacy Policy for KCNT1 Epilepsy Foundation and its Members

Introduction

The KCNT1 Epilepsy Foundation is committed to protecting the privacy of our members and their families. This privacy policy outlines how we collect, use, and safeguard personal information.

Information We Collect

We collect the following types of information:

Family contact names and contact information: This is collected to facilitate communication and support within the community.

Basic demographics: We collect basic demographic information for census data to track the numbers of new patients across the world.

Use of Information

The information collected is solely used for internal purposes, including:

- Facilitating communication and support within the community.
- Tracking census data to understand the prevalence and distribution of the rare disease.
- Improving our services and outreach efforts.

Data Sharing

We never share or sell any personal information collected with third parties. Access to this information is restricted to authorized personnel only.

Data Security

We take appropriate measures to ensure the security of the information collected, including:

- Storing data in secure online folders with restricted access.
- Implementing encryption and access controls to safeguard data.

Member Rights

Members have the right to:

- Access their personal information upon request.
- Request corrections to inaccurate or incomplete data.
- Request deletion of their personal information from our records.

Consent

By joining [Rare Disease Group Name], members consent to the collection and use of their personal information as outlined in this privacy policy.

Changes to Privacy Policy

We may update this privacy policy from time to time. Any changes will be communicated to members via email or through our website.

Contact Information

For inquiries or concerns regarding our privacy practices, please contact us at Manager@KCNT1Epilepsy.org

Additional Information

This privacy policy applies to all members of the KCNT1 Epilepsy Foundation and governs the collection, use, and disclosure of personal information.