

## **Privacy Notice**

Updated 3/20/2025

### **Who We Are**

The KCNT1 Epilepsy Foundation is committed to protecting and respecting your privacy. This privacy notice explains how we collect, use, and protect personal data collected through our census initiative.

### **What Information We Collect**

We collect personal information that you provide directly to us through our survey and registration forms. This may include, but is not limited to, your name, contact details, medical diagnosis, and any other information relevant to the KCNT1 variants census.

### **How We Use Your Information**

Your personal data is used to:

- Facilitate your participation in our census and studies related to KCNT1 variants.
- Update our global patient count and research databases.
- Communicate with you about events, research findings, new initiatives, and ways you can get involved further with our community.

### **Legal Basis for Processing**

We process your personal data based on your explicit consent, which you provide by opting in when you complete our survey or registration form.

### **Who We Share Your Data With**

Your personal data is strictly used for the purposes outlined above and will not be shared with any third-party organizations without your explicit consent, except to comply with legal obligations or to protect our rights.

No mobile or messaging consent information will be shared with third parties/affiliates for marketing or promotional purposes. All the above categories exclude text messaging originator opt-in data and consent; this information will not be shared with any third parties.

### **How We Protect Your Data**

We employ robust technical and organizational measures to ensure the security of your personal data. Access to your personal data is limited to authorized personnel only.

### **Your Rights**

Under GDPR, you have several rights concerning your personal data, including:

- The right to access the personal data we hold about you.
- The right to request correction of any incorrect data.
- The right to request deletion of your data, under certain conditions.
- The right to object to processing or to request restriction of processing, under certain conditions.
- The right to data portability.
- The right to withdraw consent at any time, without affecting the lawfulness of processing based on consent before its withdrawal.

To exercise any of these rights, please contact us at [manager@kcnt1epilepsy.org](mailto:manager@kcnt1epilepsy.org).

### **How to Contact Us**

If you have any questions about how we use your personal data or wish to exercise your rights, you can contact our data protection officer at [manager@kcnt1epilepsy.org](mailto:manager@kcnt1epilepsy.org)

### **Changes to Our Privacy Notice**

We may update this privacy notice from time to time by posting a new version on our website. We will provide you with notice of significant changes where required by law.

By submitting your personal data through our forms, you agree to this privacy notice.