

FREQUENTLY ASKED QUESTIONS

What is a patient registry?

A registry is a program for collection, storage, retrieval, and dissemination of clearly defined information for a specific purpose. Data collected in this registry includes diagnosis and treatment, management of care, quality of life and longitudinal information for KBG Syndrome

Why a KBG Syndrome registry?

In one word, PROGRESS. Having a registry specifically for individuals with KBG Syndrome allows approved researchers to have easy access to useful medical data on many individuals with KBG Syndrome. Since we will have already collected this data and obtained your consent to share it, researchers can begin to develop better studies much more quickly, and more easily find participants for these studies.

Who should participate?

Everyone with KBG Syndrome! Participating in the Registry at CoRDS is a great way for participants to take part in helping to identify the specific causes, symptoms, and treatments of KBG Syndrome.

Is personal information safe?

Internet polls, questionnaires, and surveys are often used to collect information quickly and easily from respondents. **However, to publish their results, researchers must only use information obtained in a specific way.** The patient data they use must have written approval from patients to use their data this way and must adhere to strict privacy regulations.

The registry is compliant with the European Union General Data Protection Regulation (GDPR). CoRDS has worked hard to ensure that researchers can use the information you provide. CoRDS submits every questionnaire to their Institutional Review Board approval. The IRB is group that reviews the ethics of medical research studies. Informed consent also safeguards participant data. When registering to participate in CoRDS, participants (or their representatives) are given a chance to read the consent documentation before filling out the questionnaire. For any questions, participants can call CoRDS at + 1 877 658 9192 or send an email cords@sanfordhealth.org.

If researchers receive approval to look at the registry or questionnaire responses, they will be given only the anonymous data without the identifiable information. The KBG Syndrome Association can only access your identifiable information if you choose to share it with us when you complete your registry questionnaire.

Your privacy is also protected even if you indicate that you are willing to be contacted for additional research. For example, a researcher might contact CoRDS to ask for additional information from all participants who have a specific symptom, such as loss of hearing. CoRDS would then contact every participant in the registry who said that they had loss of hearing and that they would like to participate in additional studies. CoRDS would then provide these people with the researcher's contact information, and it would be up to the individual participants to contact the researcher to participate in additional research. CoRDS will never provide your contact information to anyone.

When should I update registry information?

Updates can be done any time and should only take 10-15 minutes. But updates should be done at least every year, after any significant change in the participant's health, and immediately after their 18th birthday. If the participant was enrolled in the registry as a minor, their data becomes inaccessible 30 days after their 18th birthday unless and until they are re-enrolled.