

## What is the purpose of the registry?

Researchers will be able to compare your answers with those of others. The researchers will then be able to detect patterns, identify common symptoms and gain insights into effective and ineffective treatments. Your answers will provide a better overall understanding of KBG Syndrome and how the disease develops/progresses over the course of a lifetime.

Our goal is to collect and provide valuable information and to speed up research studies of KBG Syndrome and help start clinical trials for treatments.

The information you provide to this registry can help to:

- Drive research towards better treatments and possibly a cure
- Allow healthcare professionals and researchers to learn more about the disease
- Create a strong patient and research community
- Enhance treatment guidelines for patients to improve quality and management of care

## Can data be collected worldwide?

Yes, the registry can be accessed all over the world with the link provided on our website. International participation is highly encouraged.

## How is my personal information used and protected?

The information you provide will be provided to researchers studying KBG Syndrome. CoRDS has put many safeguards into place to ensure that this information will be kept safe and confidential. The registry is compliant with the European Union General Data Protection Regulation (GDPR).

### How will my data be used by The KBG Syndrome Association?

If you choose to share your data with the KBG Syndrome Association, we will analyze the data and may get back to you if any responses are missing or need further clarification. This would be done in order to assure that data is as complete and accurate as possible, which is critical in order for it to be useful to researchers. We will summarize the findings for patients and researchers without identification. We may also contact you occasionally to share additional research opportunities or online surveys that you can choose to participate in.

If you have any questions or concerns about sharing your data, we encourage you to reach out to us at [kbg syndrome@gmail.com](mailto:kbg syndrome@gmail.com).

## Will results of my participation in the registry be shared with me?

Yes, all data that is shared with **The KBG Syndrome Association** will be analyzed and results shared with the community in a timely manner.

## Who will decide which researchers can access the data?

The de-identified data will be shared only with researchers approved by Sanford's Scientific Advisory Board (SAB) together with representatives from The KBG Syndrome Association. No personal identifying information (such as patient's or caregiver's name, emails, addresses) will be shared

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