SANFORD RESEARCH

CoRDS

KBG SYNDROME ASSOCIATION

STEPS TO THE KBG 4 SYNDROME REGISTRY

4. Share!

#1 Registries can improve patient care

#2 Registries amplify your voice

#3 Registries can improve chances of drug development

3. Sign up and start answering questions!

There are only a few steps to enroll:

- Complete the CoRDS Activation Form and review the informed consent section.
- Complete the questionnaire with information about your specific disease symptoms.

2. Visit the website:

https://cords.sanfordresearch.org/account/login

1. Gather your information

To make everything easier we recommend collecting the following before starting:

- Genetic Reports/Testing
- Birth Information
- Current Height, Weight, Head Circumference
- Past measurements
- IQ records if applicable

Registry Highlights:

- Each participant is assigned a Global Unique Identifier that enables de-identification of the data when shared with approved researchers to protect the patient's privacy. This means that your name and other identifying information will not be passed on.
- The de-identified data will be shared only with researchers approved by Sanford's Scientific Advisory Board (SAB).
- The registry is compliant with the European Union General Data Protection Regulation (GDPR).
- Importantly, the participant owns his/her personal data and can withdraw the data from the registry at any time.
- There is no cost to the participants.
- Providing your consent to the KBG Syndrome Association to have access to the data you provide will allow us to better understand KBG Syndrome, help us understand where to drive our research initiatives, and let us know how patients need more support.

www.kbgsyndrome.org