Q&A: Online Information Evening for KBG Families for the BEOND Study

How do I take part in BEOND?

You can complete the survey online by going to redcap.link/beond. You can also find the link to take part in the survey online by going to our website www.cerebranetwork.com/beond-kbg and clicking 'take part online'.

KEY RESOURCES	
KBG Foundation	www.kbgfoundation.com
Cerebra Network	www.cerebranetwork.com
Unique KBG leaflet	https://rarechromo.org/disorder-guides/
FIND website	www.findresources.co.uk
Education resource	www.findteacherresources.co.uk

If you would like a postal pack, you can request one on our website.

Can we fill out the survey in multiple sittings, or does it need to be completed all at once?

Once you've completed the consent questions, you can return to the survey in multiple sittings to complete it, you do not need to complete the survey all at once. In total, the survey takes around an hour to complete.

Do people need to upload or share records like genetic tests to prove their child has KBG?

Uploading records or a letter from a clinician to confirm the KBG diagnosis is an optional question in the survey, but it would be very helpful to us if you choose to do so. We take data security very seriously. All data from this survey will be stored on secure servers housed at the University of Birmingham, using a system called REDCap which is often used in the UK in hospitals, universities, and other research facilities for clinical research.

When do you want to have all the questionnaires submitted? What's the closing date?

The survey will be open for some time, but we would hope to have most responses within the first two months of launching the BEOND survey with a syndrome group. For KBG families, we would therefore hope that most families will complete the survey by the end of May 2023.

How long does it take to analyse the survey results and provide the feedback report to the family? Can we use some of these reports as evidence in another country?

We hope to analyse the data around 6 months after launching the survey, and then will be working on producing the individualised reports. We are very much committed to making sure we do this in the timeliest way possible for families. The reports are research reports rather than clinical reports, but they will be yours to keep and use however you would like, and use validated measures often used in clinical settings. We've heard from families who have found it useful to have these reports to take to schools and educational meetings, for example.

We struggle with educational and healthcare professionals recognising and understanding KBG. Do you have any advice or resources that would help?

Unique have a leaflet which provides a summary and introduction to KBG syndrome, including information on medical concerns, development, and management recommendations. This can be useful for families to use and bring to appointments, interviews, and meetings with professionals. The leaflet can be found here. The KBG Foundation also has a range of informational resources on their website here.

The free resource at www.findteacherresources.co.uk is a broader resource but was developed to raise awareness and understanding of the complex needs of children with genetic syndromes, and to support educational practitioners and teachers who are working with these children.

Our child has been recently diagnosed with KBG syndrome. We would like to connect with other families, where can we find out more?

The KBG Foundation has created a document with a few tips and a list of potential specialists you may need to get to know. Patients and caregivers can join their private **KBG SYNDROME FAMILIES FACEBOOK GROUP.**