

# NEWLY DIAGNOSED

## Guide for Families

DIAGNOSIS IS JUST THE BEGINNING



### LOOK—WE KNOW IT CAN BE HARD TO HEAR THAT YOU OR YOUR CHILD HAS KBG SYNDROME

You probably feel overwhelmed and confused. You're asking yourself, "What now?"

Well, the good news is that you now have a community of families to support you. You don't have to maneuver this alone. You have the support of others who have felt this same shock and perhaps a range of new emotions.

**Your diagnosis is simply the first step.** Dig in. Take action. And know that we have everything you need to help your child live their best life surrounded by people who know exactly what you're going through.

### GETTING STARTED WITH KBG SYNDROME

It is so hard to know where to start when you are facing a rare syndrome. Here are a few of the recommendations given when newly diagnosed.

- Echocardiogram
- Palatal Assessment
- Hearing Screens
- Dental Assessment
- Screening for developmental delays, Autism and behavioral anomalies
- EEG if concerns for seizures
- Assessment for feeding difficulties or failure to thrive

Additional assessments or screenings will depend on individual presentation and symptoms.

### SPECIALISTS YOUR CHILD MAY SEE

It is important to remember that individuals with KBG Syndrome will NOT experience every condition. The presentation is variable and best managed by a symptom based approach.

- Neurologist
- Neuro-surgeon
- ENT
- Cardiologist
- GI
- Pulmonologist
- Nephrologist
- Hematologist
- Immunologist
- General Surgeon
- Neuro-Developmental Physician
- Psychologist/Psychiatrist
- Endocrinologist
- Urologist
- Dentist/Orthodontist
- Craniofacial specialist
- Sleep Specialist
- Ophthalmologist



## COPING WITH KBG SYNDROME



“**always**

REACH OUT FOR HELP, DON'T BE AFRAID TO ASK QUESTIONS OR FOR SUPPORT.

### 1. Give Yourself Time to Absorb the News

Anger, denial, fear, and anxiety are all normal reactions to hard news. Allow yourself the chance to work through the emotions.

### 2. Create a Support System

The first instinct for many people, especially parents who are used to taking care of everyone else, may be to hide the news. This can leave you feeling isolated. Reach out to friends, family, and neighbors. When they know, they will be in a better position to help you

### 3. Educate Yourself

Search reputable sources to learn as much as you can. Check out [www.kbgsyndrome.org](http://www.kbgsyndrome.org), National Organization for Rare Disorders and the Orphanet Journal of Rare Diseases

### 4. Take a Deep Breath and Look Ahead

Your child is so much more than a diagnosis on a piece of paper. It cannot define them and their worth.

## FINDING OTHER PARENTS AND GUARDIANS OF CHILDREN WITH KBG SYNDROME

No one will understand the impact of a new diagnosis like someone who has already been there. Finding people who already know what the day-to-day management of KBG Syndrome looks like may help you as you learn to navigate this new reality. It may also provide you with an understanding and compassionate shoulder to lean on.

“**It's OK to cry**

And it's OK to be angry and think why my child? Take each day as it comes, learn as much as you can when you can. Most importantly look after yourself too... Be patient with yourself as well as with your child.



### GET SUPPORT:

- **Email a KBGSA friend:** [kbgsyndrome@gmail.com](mailto:kbgsyndrome@gmail.com)
- Connect with other patients or guardians by joining: <https://www.facebook.com/groups/kidwithkbg>
- Follow us on Facebook for information on KBG and future patient/family gatherings at: <https://www.facebook.com/KBGSyndrome>

